Practical Treatment Options for Chronic Pain in Children and Adolescents

An Interdisciplinary Therapy Manual

Michael Dobe
Boris Zernikow
Editors

Second Edition

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Michael Dobe
German Paediatric Pain Centre
Children's and Adolescents' Hospital
Witten/Herdecke University
Datteln
Germany

Boris Zernikow
German Paediatric Pain Centre
Children's and Adolescents' Hospital
Witten/Herdecke University
Datteln
Germany

Department of Children's Pain Therapy and Paediatric Palliative Care
Faculty of Health, School of Medicine
Witten/Herdecke University
Witten
Germany

ISBN 978-3-030-19200-6 ISBN 978-3-030-19201-3 (eBook)
https://doi.org/10.1007/978-3-030-19201-3

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Foreword to the First Edition

There are a number of textbooks in print on pediatric pain, but very few of them warrant inclusion of the word "Practical" in the title. Michael Dobe's and Boris Zernikow's *Practical Treatment Options for Chronic Pain in Children and Adolescents* provides an approach that is above all practical and useful for clinicians caring for children with chronic pain.

The presentation follows a logical progression, through epidemiology, mechanisms, assessment and measurement, therapeutic approaches, and development of a roadmap for clinical decisions about which patients require more routine versus more intensive treatment settings. The authors support many of their recommendations with a superb blend of case discussions, theoretical considerations, and outcome data. The tone throughout is child and family centered. The authors emphasize wellness and fostering a child's capacity to heal himself or herself.

Those of us who specialize in treatment of chronic pain in children are a relatively small club. There are stylistic differences among our treatment centers that reflect differences in theoretical models, in local expertise and training, in the cultural backgrounds of our patients and families, and in the type of healthcare system and larger society that surrounds us. Sometimes, a manual or textbook written in one language may translate poorly into another for linguistic reasons or for cultural reasons. As an English-speaking physician in the USA, I find that Dobe and Zernikow's book translates very well linguistically, and it also translates well culturally. Among the predominantly English-speaking countries, there are widely divergent healthcare delivery models and very different cultures, and these local factors may lead to modifications of some specific recommendations. Nevertheless, the core themes of the approach outlined in this book are immensely applicable across cultures and languages. I think that clinicians in a wide range of Anglophone countries, including the USA, Canada, the UK, Australia, and New Zealand, will find the English edition of this book to be among the best "roadmaps" available for guiding treatment of chronic pain in children. In my opinion, this book will be extremely useful for a broad audience, including primary pediatricians, pediatric subspecialists, pediatric psychologists, physical and occupational therapists, child life specialists, nurses, and many others worldwide. I salute Dr. Dobe and Prof. Zernikow for their superb and truly practical book.

Boston, MA, USA Charles Berde, MD, PhD

Foreword to the First Edition

This manual is a masterful, compelling, and satisfying read for all professionals in children's pain management. Going beyond the biomedical model, it provides a comprehensive appreciation of the physiology, psychology, pharmacology, and familial/social aspects of common pediatric chronic pain syndromes. It emphasizes the broad impact of pain on the lives of children and teens, as well as the complicated process of recovery. Drs. Dobe and Zernikow achieve this by bringing us into the functioning of their inpatient treatment unit in Germany for children and teens with chronic pain. They share their intake procedures, assessment process and instruments, their well-developed decision-making processes, the nuances of their therapeutic program, interdisciplinary team's functioning, and their research outcome—a tour de force!

What makes this chronic pain treatment program stand apart is the tight integration of clinical practice with their research program, based firmly within a biopsychosocial framework in the child-family systems context. In fact, they are consistently systems-oriented. A continuous flow-through of research findings informs the clinic's intake and treatment parameters, which in turn feeds their ongoing research. They give considerable attention to the patient's social, emotional, familial, and physical systems. You'll note the well-integrated system of trained professionals—nurses, psychotherapists, physicians, psychologists, and physiotherapists—and the different forms of psychobiological treatment regimens to address and relieve pain that the children receive, either as outpatients or inpatients for 6 weeks in their "Lighthouse" treatment unit.

With a 10-year history of treating some of the most distressed and pain-compromised children and teens in Germany (their patients aged 7–17 years have suffered chronic pain for an average of 3.5 years before starting treatment), the authors discuss their philosophy of care and treatment regimen in considerable detail. Their philosophy is based on principles that we've come to appreciate as critical for the effective treatment of children and teens. This includes principles of transparency, collaboration, requiring the child's commitment to treatment, incorporation of parents at pivotal decision and treatment points, challenging the patient's self-limiting behaviors, providing a well-organized treatment program that requires intensive work on the part of the child, and supporting the child's follow-through with engaging therapeutic relationships and active support to complete the program.

There is clinical brilliance and ingenuity in this intensive treatment program, particularly in the lively, sometimes challenging, and strategic nature of their psychotherapy interventions, such as the “Three Letters” in Chap. 6. There are aspects that some North American practitioners may find usual. The authors carefully explain their rationale and care in implementing these practices, their experience, and research outcomes. One of these is that a child who does not take on all aspects of the program can be asked to leave. Under certain circumstances, they can be invited to reapply when they deem themselves ready. As part of that application, they are required to write a convincing letter about what has changed and how they are now ready to fully engage with the 3-week treatment program.

Other novel practices are the “Stress day,” an individually tailored challenge day, and “Pain provocation,” an established cognitive behavioral strategy which ultimately provides the child with a greater sense of control over his or her pain. All of these techniques are described in sufficient detail for a clear appreciation of their therapeutic benefit. These are not boot camp techniques. They are implemented within empathic relationships and supportive and negotiable contexts and consistently reflect their treatment approach of encouraging self-management.

Providing psycho-education on pain and ensuring that the children and teens understand it well enough to write about how pain is processed is emphasized throughout this manual. With humor and transparency, Drs. Dobe and Zernikow convey the idea that the doctor “isn’t in charge of your body,” and from the outset they change the relationship dynamic by asserting that it is the child who defines what is “the correct” pain perception, not the parents, psychotherapist, nor physician. A further declaration made early to the child and family is that sustained pain reduction cannot be achieved unless the child engages in learning and using active pain coping strategies. The authors provide detailed case examples of their multimodal intake and treatment procedures, which makes their treatment system come to life. The child and family are required to make a commitment to this system, and it is evident that this is more than matched by a commitment by skilled personnel at every step along the trajectory toward pain relief.

Contrary to common practices, their treatment process is one that relies heavily and successfully on humor and playfulness as a therapeutic attitude for treating chronic pain. This is summed up by one of the teens in Chap. 4 who asks, “Why did you become a therapist, when you like to laugh so much?” This positive hope-giving attitude is supported by a therapeutic focus on enhancing the child’s resources and problem-solving capacity—irrespective of the severity of the pain or symptoms of anxiety, depression, or trauma.

Families of children with chronic pain suffer themselves. How to work with these families can sometimes present a particular challenge to the chronic pain team. Drs. Dobe and Zernikow address this from the very start and provide practical recommendations, case examples with dialogue, and strategies that help lay the groundwork for successful family teamwork. The parents, too, are part of the treatment process—and their learning and change provide for a better long-term outcome, once the child is discharged.

The hard truth of treating children and teens with chronic and complex pain is that there is no quick fix. I was heartened to read this statement by Dr. Boris Zernikow: "In a time of limited human resources and a shift to technical medicine the inpatient pain therapy program of the German Paediatric Pain Centre with its personnel-intensive multimodal approach focusing on the child and his/her family may seem to be a relic from the past. However, it is exactly that human approach that makes the program so successful."

Key, catchy phrases remind families and children of essential concepts in understanding pain, and these are reiterated throughout the treatment process. For example, Drs. Dobe, Kriszio, and Zernikow discuss in Chap. 4 the "Three Thought Traps": (1) "Everything is of pure psychological origin"; (2) "Everything is of pure physical origin"; and (3) "The pain must vanish at all costs." Debunking these commonly held myths as part of the initial psycho-education builds a solid foundation for the wide range of interventions that are explicated in this groundbreaking manual.

Chapter 6–13 is the heart of this manual on the treatment of pediatric chronic pain. This chapter alone is worth the price of the book. You'll be glued, as I was, to the discussion of how to assess and treat children who present with concomitant depression or trauma concurrent with their chronic pain. This is a unique contribution. In the pediatric pain literature to date, there is little research and discussion on children who have experienced trauma and present with chronic pain. We know clinically that their pain will not be successfully resolved without the skillful and sensitive concurrent treatment of the trauma and/or depression. Dr. Michael Dobe is masterful in his systematic exposition on how to engage the traumatized child. He discusses what images and therapeutic strategies are conducive to building psychological flexibility, adaptive cognitions, and trust, while not re-traumatizing the child. Imaginative techniques, such as "The Safe Place," used to provide emotional stability and training in how to self-assess tension levels and use relaxation techniques, are but a few of the cognitive behavioral strategies that are well-described in this chapter.

Drs. Dobe and Zernikow have included in this manual contributions from their team members Drs. Wager, Kriszio, and Hechler explaining in Chap. 3 the necessity of a comprehensive assessment and the use of standardized multimodal instruments in determining the full scope of the emotional, cognitive, physical, social, and familial impact/burden of chronic pain. Drs. Hechler, Dobe, and Zernikow conclude the book with a well-written response to the question "Is it all worthwhile?—Effectiveness of intensive interdisciplinary pain treatment" by providing convincing evidence for the effectiveness of intensive interdisciplinary pain programs.

The authors generously provide a list of their questions and materials and in the Appendix supply 19 worksheets to explore patients' resources and their stress factors. These worksheets are very useful and include descriptions with standardized instructions regarding the most important therapeutic interventions. They invite us to take these materials and worksheets with their detailed information and apply them in our own settings, whether in an outpatient or inpatient pain program. We should do so, as there is enough rich material, research, clinical cases, and depth of understanding, whatever one's profession, for this substantial manual to remain a primary resource for pain practitioners for many years to come. It provides an excellent standard of care in the complex treatment of pediatric chronic pain in the second decade of the twenty-first century.

I congratulate Michael and Boris and their team on this superb contribution to the field of pediatric pain and applaud their generosity in sharing their research, considerable clinical and teaching experience, and their assessment and treatment materials, which all add to the progress in treating chronic pain—one of the most exasperating of all pains.

Vancoucer, BC, Canada Leora Kuttner, PhD, Reg. Psych.

Acknowledgment

Special thanks to Erik Michel, Walter Magerl, and Leora Kuttner who made many helpful suggestions for the first edition of the manual. We are additionally grateful to all colleagues who contributed to this second edition (Julia Wager, Lorin Stahlschmidt, Michael Frosch, and Holger Kriszio). Special thanks also to Monique Ribeiro from Boston, who provided an important international perspective in Chap. 12. We would like to thank the medical, therapeutic, and nursing team of the German Paediatric Pain Centre, who provided the authors with the necessary time to work on the manual by taking on some of their appointments and clinical commitments.

Finally, we would like to thank Lorin Stahlschmidt for translating the manuscript and our Australian colleague, Donnamay Brown, for her fantastic work in English language editing.

Many, many thanks to my wife, Stefanie, for her constant emotional support and to our children, Jan, Marlon, and Noah. I'm so grateful for your presence!

On behalf of the editors, Michael Dobe

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List of Editors and Contributors

List of Editors

Michael Dobe German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Boris Zernikow German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Department of Children's Pain Therapy and Paediatric Palliative Care, Faculty of Health, School of Medicine, Witten/Herdecke University, Witten, Germany

List of Contributors

Michael Dobe German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Michael Frosch German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Holger Kriszio German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Monique Ribeiro Department of Psychiatry, Department of Anesthesiology, Perioperative and Pain Medicine – Harvard Medical School, Boston Children's Hospital, Boston, MA, USA

Lorin Stahlschmidt German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Julia Wager German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Boris Zernikow German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany

Abbreviations

ACC	Anterior cingulate cortex
ACR	American College of Rheumatology
APPT	Adolescent pediatric pain tool
ARCS	Adult responses to children's symptoms
AT	Autogenic training
ATP	Adenosine triphosphate
AWMF	Association of the Scientific Medical Societies in Germany
CASI	Childhood anxiety sensitivity index
CDI	Children's depression inventory
CGRP	Calcitonin gene-related peptide
CNS	Central nervous system
COMT	Catechol-O-methyltransferase
COX	Cyclooxygenase
CPG	Chronic pain grading
CPSS	Child PTSD symptom scale
CR	Conditioned reaction
CROPS	Child report of posttraumatic symptoms
CRPS	Complex regional pain syndrome
CS	Conditioned stimulus
CSD	Cortical spreading depression
CSES	Child self-efficacy scale
DNA	Deoxyribonucleic acid
DSM	Diagnostic and statistical manual of mental disorders
ECG	Electrocardiogram
EEG	Electroencephalography
EMA	European Medicines Agency
EMDR	Eye movement desensitization reprocessing
FDA	U.S. Food and Drug Administration
FDI	Functional disability inventory
FOPQ-C	Fear of pain questionnaire for children
FPS-R	Faces pain scale revised
GABA	Gamma-aminobutyric acid
GI	Gastrointestinal
GPPC	German Paediatric Pain Centre

IASP	International Association for the Study of Pain
ICD	International Classification of Diseases
ICHD	International Classification of Headache Disorders
IEG	Immediate early gene
IHS	International Headache Society
IQ	Intelligence quotient
IRRT	Imagery rescripting and reprocessing therapy
JFMS	Juvenile fibromyalgia syndrome
JIA	Juvenile idiopathic arthritis
KiGGS	German Health Interview and Examination Survey for Children and Adolescents
LOX	Lipoxygenase
LTD	Long-term depression
LTP	Long-term potentiation
MAO	Monoamine oxidase
MOH	Medication-overuse headache
MRI	Magnetic resonance imaging
MTT	Medical training therapy
NET	Nursing and educational team
NMR	Nuclear magnetic resonance
NRS	Numerical rating scale
NSAID	Nonsteroidal anti-inflammatory drug
PACAP38	Pituitary adenylate cyclase-activating polypeptide-38
PBQ	Pain beliefs questionnaire
PCQ	Pain coping questionnaire
PCS-C	Pain catastrophizing scale for children
PCS-P	Pain catastrophizing scale for parents
PedsQL	Pediatric quality of life inventory
PMR	Progressive muscle relaxation according to Jacobson
PPCI	Pediatric pain coping inventory
PPCI-R	Paediatric pain coping inventory-revised
P-PDI	Paediatric pain disability index
PPQ	Pediatric pain questionnaire
PPT	Pain provocation technique
PQCA	Pain questionnaire for children and adolescents
PRI	Pain response inventory
PTSD	Posttraumatic stress disorder
QST	Quantitative sensory testing
RAP	Recurrent abdominal pain
RCADS	Revised children's anxiety and depression scale
RCT	Randomized controlled trial
SNP	Single nucleotide polymorphism
SNRI	Selective serotonin and norepinephrine reuptake inhibitor
SSRI	Selective serotonin reuptake inhibitor
TCA	Tricyclic antidepressants

TENS	Transcutaneous electrical nerve stimulation
TRPV1	Transient receptor potential vanilloid subtype 1
TTH	Tension-type headache
VAS	Visual analogue scale
WDR Neuron	Wide dynamic-range neuron

Introduction (For the First Edition)

Anouk, a 13-year-old girl, presents at our paediatric outpatient pain clinic accompanied by her mother after having undergone an extensive diagnostic investigation of her abdominal pain which yielded no pathological findings. Anouk has been suffering from chronic abdominal pain for about 4 years; the pain has been constant over the last 2.5 years. She has undergone various outpatient and inpatient diagnostic procedures, including esophagogastroduodenoscopy with biopsy, laparoscopy, appendectomy, and NMR with angiography, all yielding no clinically relevant findings, histology of the appendix included. During a laparoscopy 1 year ago, adhesions were successfully removed from her lower right abdomen, but she experienced only minimal improvement for a short while; during the last 6 months, the pain has been increasing again. For the last 3 months, Anouk has been unable to attend school due to abdominal pain; 2 months ago, Anouk stayed 4 days at a paediatric clinic for further diagnostic medical investigations. Since then, the intensity of the constant pain has actually increased, now scoring 7–9 on a numeric rating pain scale from 0 to 10 (0 = no pain, 10 = worst pain). Most of the time, Anouk slacks off and doesn't participate in any family activities, causing her parents to worry. Anouk told us that she was burdened and exhausted and was not able to concentrate anymore. According to her mother, the family burden due to these pain episodes was extraordinary, even impacting close relatives. Consequently, Anouk has feelings of guilt.

Anouk's case illustrates the fact that pain may be so strong and extensive that it severely affects the patient's and his/her family's lives. Pain is a universal experience. Mostly, pain is a sign of muscular tension or of minor injury (e.g., contusion) and will vanish quickly. This is typical of acute pain. But, if pain is present for a longer period of time (6 months in adults, 3 months in children) for at least 15 days/month, it is called chronic pain. Three to five percent of all children and adolescents report severe chronic pain, also affecting different aspects of their lives (Huguet and Miro 2008).

Some of the children and adolescents (referred to as "children" from now on) will get sufficient help in primary care. But a substantial number of severely affected children remain who are strongly impaired in their daily lives. Most of these children might be effectively treated in an outpatient setting. Unfortunately, suitable paediatric outpatient clinics for children with chronic pain or equivalent treatment options are rare. Thus, it often proves impossible to arrange the indicated measures for children with chronic pain in an outpatient setting. Reasons for the paucity of outpatient treatment centres might be that only recently has attention been brought to the problem of diagnosing and treating chronic pain and recognizing it as an independent disease. It is only during the last few years that various medical and psychological university faculties and therapeutic medical schools/institutions have specialised in chronic pain and pain disorders in adults and children. As a consequence, a physician unaware of the pain disorder won't offer adequate treatment.

The lack of knowledge of many physicians, paediatricians, and therapists is also reflected in the fact that many children with chronic pain have a wrong diagnosis and receive insufficient treatment. We would like to emphasize that "simple" chronic pain is already of substantial negative impact for the patient's mental and psychosocial development. These children tend to miss school because of their pain. They attend fewer social activities than their healthy peers, and they more frequently show signs of depression (Palermo et al. 2009; Eccleston et al. 2004). Each month of insufficient treatment makes it more probable that the symptom of pain will become independent of physical input and lead to a chronic pain disorder. As seen in the case of Anouk, many patients and their families report a medical odyssey but have never been educated about chronic pain.

As mentioned before, untreated chronic pain frequently leads to pain-related absenteeism from school combined with a high emotional burden for the child and his/her family. Children like Anouk suffer pain disorders, diseases where pain has become an independent disease in such a way that it has a strong impact on thoughts, feelings, behaviours, family life, or social activities. If the pain is not too severe, outpatient pain (psycho)therapy may be sufficient. But if the child is severely affected in his/her everyday activities and at school, outpatient pain treatment will in most cases not be effective, and participation in a multimodal inpatient pain therapy programme is indicated (Hechler et al. 2009).

How should children with a chronic pain disorder be treated? Only since the end of the 1980s has the medical community engaged in the understanding and treatment of chronic pain disorders. Thus, it is not surprising that a treatment manual or even instruction for clinical practice for the treatment of paediatric chronic pain disorders is not yet available. Another point is the paucity of scientific data on paediatric inpatient pain therapy. So far, the inpatient pain therapy programme of the German Paediatric Pain Centre (GPPC) is one of the few scientifically evaluated inpatient treatment programmes for children with chronic pain, irrespective of pain location, underlying cause, or duration of the pain disorder.

With this manual, we intend to integrate the latest scientific knowledge with our long-standing clinical experience in the treatment of children with chronic pain disorders and their families. Along with the explanation and detailed description of our clinical experience, we have included its theoretical background. Following our detailed manual, an experienced psychotherapist should be able to successfully treat children with a chronic pain disorder.

This manual should guide the psychotherapist or the medical doctor through the therapeutic process of treating children with chronic pain. The expert knowledge and therapeutic attitude imparted focus on clinical application and are suitable also in an outpatient setting, as are most of the methods illustrated in Chaps. 4, 6, and 7. Moreover, this manual should allow other inpatient institutions to offer effective inpatient pain therapy to children with a chronic pain disorder. Described in detail are the setting, inpatient routines, daily routines as well as therapeutic work, interventions of the nursing and educational team (NET), and the therapeutic approach of including other professions based on the patient's needs. This will also allow minor modifications according to preexisting institutional or therapeutic concepts. We feel that the comprehensive description of the latest scientific knowledge, therapeutic attitude, education, treatment methods preferred by our team, and the institutional structure of the GPPC will help other institutions to successfully establish their own inpatient concept for the treatment of chronic pain in children.

Chapter 1 gives an overview of the latest epidemiological data. Chapter 2 summarizes the scientific state of the art with respect to the background and understanding of paediatric chronic pain. Chapter 3 describes the instruments useful in exploring chronic pain, while in Chap. 4 the necessary basic therapeutic knowledge is outlined in detail. Chapter 5 discusses the criteria for allocating patients to either the outpatient or the inpatient therapeutic setting. Chapter 6 delivers a comprehensive description of the inpatient paediatric pain management concept at the GPPC, not only listing the different tasks of the various professions but also giving practical hints for therapeutic interventions, illustrated by the presentation of sample clinical cases. An extra focus is set on imparting knowledge on working with the patient's family and the implementation of treatment approaches for children with chronic pain disorders concomitantly suffering, for example, psychotrauma or depression. Chapter 7 covers more general aspects of the therapeutic work with children suffering comorbid mental, psychosocial, or physical symptoms. Chapter 8 summarises results from the latest effectiveness studies especially on inpatient pain treatment.

Chapter 9 includes some material for the clinical work. You will find various worksheets which help to explore patients' resources and psychological stress factors and some sheets just for getting acquainted with the patient. We also include descriptions of the most important therapeutic interventions, with standardised instructions.

We hope that the manual will reflect our enthusiasm for working with children with chronic pain and their families, and we wish the reader success in implementing the therapeutic programme.

Datteln, Germany

Michael Dobe
Boris Zernikow

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Introduction (For the Second Edition)

In the last 7 years since the publication of this manual, many important improvements have been achieved for the treatment of children and adolescents with chronic pain. Still, many affected children and adolescents ("children" hereafter) can successfully be treated in primary care. For children like Anouk, who suffered severely from her chronic pain and was restricted in her everyday life, there are more and more points of contact, because a growing number of special outpatient services for children with chronic pain are now available. For many of these affected children, outpatient therapeutic interventions are sufficient.

Medical and psychological experts now agree that chronic pain is an independent illness and its diagnostics and treatment is now more and more included in the curriculum of medical and psychological faculties of universities and therapy training institutes. Therefore, we find it difficult to understand why, still, so many children with chronic pain and pain disorders who present at our institution have received insufficient or no education on chronic pain, have been treated with a purely unimodal approach (usually physical therapy or pharmacological treatment), and have undergone many and frequently senseless diagnostic investigations. Often, months or even years pass by—time that is lost for the affected children and that contributes to chronification. Since the publication of the manual, we have met many children like Anouk, whose story is representative of approximately 5% of all children.

Despite the progress in research and the understanding of chronic pain, and despite improvements in the training of physicians and psychotherapists, still too many children report that they have met experts during their odyssey that have explained to them and their family: "You have pain, because of …—please insert any of the following—… a crossbite; an imbalance of energies; associated heterophoria; blockade of the vertebra; pelvic obliquity; unequal leg length; an intolerance of lactose, fructose, histamine, glutamate or gluten; small fibre neuropathy; a lack of oxygen in the brain; tensions in the neck like a 70-year-old woman; …." This list could be extended indefinitely and represents a fundamental fallacy in the diagnostics and treatment of chronic pain. Generally, chronic pain cannot be successfully treated with a passive unicausal treatment approach; all research agrees on this (see Chap. 2). Unfortunately, in many cases, the patient's hope for treatment success leads to a short-term improvement (placebo effect), which is mistakenly interpreted as an indicator of the effectiveness of the intervention.

If the child is severely impaired in everyday life due to pain, an inpatient/day-hospital interdisciplinary pain treatment is indicated (see Chap. 5), as outpatient pain therapeutic interventions are likely to fail and there is an urgent need for action in light of the severe impairment in life and school. Unlike 7 years ago, the current state of research regarding the effectiveness of an inpatient interdisciplinary pain treatment for children has improved considerably. Still, the treatment programme of the German Paediatric Pain Centre is the only programme for paediatric pain disorders (irrespective of location, cause, and duration of the pain) that has been evaluated with prospective studies and a randomised controlled trial. However, in the meantime, a large number of (randomised) studies were able to confirm the long-term effectiveness of whole inpatient programmes as well as the efficacy of single treatment components (see Chap. 16).

Important updates have been made in this edition. Chapters 6–14 have been comprehensively revised to better support psychotherapists and physicians in the treatment of affected children and families in outpatient and inpatient settings. Particularly, therapeutic interventions are explained in more detail. In Chaps. 2 and 3, we have added the most important advances in research and diagnostics on paediatric chronic pain.

We hope that this manual will reflect our enthusiasm for working with children with chronic pain and their families and will assist in bridging the gap between theory and practice for the diagnosis and treatment of children with chronic pain.

Datteln, Germany

Michael Dobe
Boris Zernikow

Part I

The Basics of Paediatric Pain Treatment

1 Epidemiology of Chronic Pain in Children and Adolescents

Lorin Stahlschmidt

And I thought I was alone.
—Jessica (15 years), chronic pain disorder with abdominal pain

Contents

Abstract

Chronic pain is common and affects approximately one-quarter to one-third of all children and adolescents. Older age, female sex and stress could be identified as risk factors. Overall, 5% of all children and adolescents suffer severely from chronic pain and are in need of an interdisciplinary pain treatment.

Children with chronic pain are often surprised to learn that there are other children who also suffer chronic pain. Most patients feel alone with their pain in school or in their social environment. They feel misunderstood and excluded due to their pain (Forgeron et al. 2011). On their first day on the pain ward, it is usually a great relief for the affected children to meet other children with chronic pain who are well able to understand their symptoms.

Chronic pain in children and adolescents is quite common. In epidemiological studies, chronic pain is most frequently defined as pain that is recurrent or constant for at least 3 months. When this definition is applied, prevalence estimates from studies with representative samples range from 6% in Canada (Van Dijk et al. 2006) to 46% in Germany (Roth-Isigkeit et al. 2004). Worldwide, most studies report that

L. Stahlschmidt (✉)
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: l.stahlschmidt@deutsches-kinderschmerzzentrum.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_1

recurrent or constant pain for at least 3 months is found in one-quarter to one-third of all children and adolescents (Caes et al. 2015; Du et al. 2011; Haraldstad et al. 2011; Huguet and Miro 2008; Noel et al. 2016; Perquin et al. 2000; Petersen et al. 2009; Siu et al. 2012). Overall, the prevalence of headache and musculoskeletal pain has increased over the last decades (Anttila et al. 2006; Bandell-Hoekstra et al. 2001; Hakala et al. 2002; Laurell et al. 2004; Luntamo et al. 2012).

Most children have headache, followed by musculoskeletal pain and abdominal pain in varying order depending on the study (Gobina et al. 2015; King et al. 2011; Krause et al. 2017; Van Tilburg et al. 2011). A systematic review that summarized the results of 41 international studies reported that with increasing age the prevalence of headache and musculoskeletal pain increases (King et al. 2011) while the prevalence of abdominal pain decreases (King et al. 2011; Chitkara et al. 2005). In general, the prevalence of chronic pain increases with age (King et al. 2011). Apart from age, sex also has an impact on the prevalence of chronic pain. Consistently, a higher prevalence of chronic headache, musculoskeletal and abdominal pain is reported for girls (King et al. 2011).

In addition, studies have demonstrated that stress is a risk factor for chronic pain in children and adolescents. Both daily hassles and critical life events are important. Chronic stress, lack of leisure time and high academic demands were shown to increase the risk for chronic pain in children and adolescents (Albers et al. 2013; Diepenmaat et al. 2006; Gaßmann et al. 2009; Milde-Busch et al. 2011). Critical life events that are associated with stress and chronic pain are the separation of the parents (Diepenmaat et al. 2006; Juang et al. 2004; Petersen et al. 2009), frequent changes of residence (Bakoula et al. 2006; Boey and Goh 2001) and bullying (Boey and Goh 2001; Due et al. 2005). For bullying, a dose–response relationship could be demonstrated: the risk of chronic pain increases with increasing exposure to bullying (Due et al. 2005). However, to date longitudinal studies on risk factors are rare. Most findings originate from representative cross-sectional studies that do not allow conclusions regarding the direction of the effect.

Although chronic pain prevalence is rather high among children and adolescents and pain is generally experienced as unpleasant, most affected children and adolescents have little or no impairments due to their pain. Only approximately half of all children and adolescents with chronic pain visit a physician due to their pain and approximately 40% take pain medication (Ellert et al. 2007). A doctor's visit is primarily determined by the amount of pain-related disability in everyday life (Hirschfeld et al. 2015).

This chapter aims to describe the treatment of children with a pain disorder. Therefore, the question is for how many children and adolescents a specialised pain treatment is indicated, because they are severely impaired in everyday life due to pain. One option to assess pain severity is the Chronic Pain Grading (CPG; Wager et al. 2013), which integrates measures of pain intensity and pain-related disability in everyday life. Children and adolescents are assigned to one of five grades (grade 0–4) according to their pain severity. The majority of children and adolescents who receive an inpatient pain treatment at the German Paediatric Pain Centre report pain with severe impairments in everyday life and school corresponding to grades 3 or 4, the highest grades of the CPG (Stahlschmidt et al. 2017). In a Spanish study with 561 school children, approximately 5% of these children were assigned to grade 3 or 4 (Huguet and Miro 2008).

Overall, approximately 5% of all children and adolescents suffer such severe pain that it has a negative impact on school attendance, leisure time activities, contact with peers and family (Konijnenberg et al. 2005*; Logan et al.* 2008*; Palermo* 2000*; Roth-Isigkeit et al.* 2005*).*

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Pain Disorder: A Biopsychosocial Disease

2

Boris Zernikow, Holger Kriszio, Michael Frosch,
Michael Dobe, and Julia Wager

Contents

Abstract

Pain is an individual and purely subjective experience. Pain processing depends on both somatosensory and emotional brain areas (e.g. the limbic system). Therefore, pain is never a purely sensory perception, but always includes emotional determinants. Finally, the family and other social contexts of the child are important determinants of pain perception. Hence, in order to better understand the origin and maintenance of pain disorders, biological and psychological factors as well as the social environment have to be taken into account. In this chapter, we describe biological, emotional, cognitive and social factors that play a role in the origin, perpetuation and amplification of pain disorders.

B. Zernikow (✉) · H. Kriszio · M. Frosch · M. Dobe · J. Wager
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: B.Zernikow@kinderklinik-datteln.de; H.Kriszio@kinderklinik-datteln.de; M.Frosch@kinderklinik-datteln.de; M.Dobe@kinderklinik-datteln.de; j.wager@deutsches-kinderschmerzzentrum.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_2

Pain is an individual and exclusively personal experience (Coghill et al. 2003; Turk and Okifuji 1999). Numerous areas of the central nervous system (CNS) take part in pain processing, e.g. somatosensory areas as well as emotional areas (e.g. the limbic system) (Melzack 2005). The International Association for the Study of Pain (IASP) also highlights the different dimensions in their definition of pain (IASP 2011) as "***an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage***". Individual perception of pain with all its sensory and affective components makes a comprehensive assessment of the multidimensional pain experience indispensable (Schroeder et al. 2010). Pain experience is mostly operationalised by the description of individual pain perception (Schroeder et al. 2010).

The assessment of pain perception has a scientific basis, particularly in adults. Typically, the components of pain intensity and pain quality (pain perception in a closer definition) are assessed separately (Wager et al. 2010). Sensory pain quality is for example characterised by the rhythm of the perceived pain or by its thermic characteristics. The affective component of pain is described in terms such as "tiring" or "horrible", delivering hints as to the weight of the individual psychological burden and the concurrent suffering (Wager et al. 2010).

Finally, the patient's social environment is an important determinant of pain perception (McCracken et al. 2007; Eccleston et al. 2004). Compared to adults, in children the social context is thought to have a much larger impact (Wager and Zernikow 2018). While the social context (e.g. parents) has an impact on the child's pain chronification, the child's disorder also has an impact on his/her environment (e.g. burden on his/her parents).

The following sections will describe in detail the biological factors involved in the origin and maintenance of pain disorders. Later sections provide an overview of emotional, cognitive and behaviour-related processes contributing to the origin, perpetuation or even amplification of pain disorders in children. For didactic purposes, it is not until Chap. 8 that we give an in-depth presentation of the important psychological or social determinants of pain disorders and a description of possible therapeutic interventions aiming to change those determinants.

2.1 Biological Determinants of Acute or Chronic Pain

2.1.1 Nociception

Nociception is purely biochemical/biophysical, and results from neuronal changes as a response to actual or potentially damaging stimuli. Those changes and the processing of pain clearly show interindividual variability (Binder et al. 2011). Nociception comprises the subprocesses of transduction, transmission, modulation and perception.

Transduction in Nociceptors

Transduction is the transfer of a biochemical/biophysical response caused by tissue damage into a neuronal answer. Tissue damage due to injury or inflammation induces local cellular release of various substances like K^+ ions, H^+ ions, ATP, autacoids like histamine, serotonin or bradykinin. Local substances (H^+ or K^+ ions) are able to directly activate the nociceptive neurons, while prostaglandins or leukotrienes indirectly sensitise the nervous system to physical as well as chemical stimuli. These mediators of the arachidonic acid cascade are generated by enzymes called cyclooxygenases (COX) or lipoxygenase (LOX). The activity of the cyclooxygenases may be inhibited by substances like acetylsalicylic acid, indometacin or ibuprofen.

In addition, nociceptors have a secretory efferent function releasing vasoactive neuropeptides like substance P and calcitonin gene-related peptide (CGRP), which contribute to the local inflammatory response (neurogenic inflammation) and are important mediators in the neuro-immune interaction mediating chemotaxis, arteriolar smooth muscle relaxation, capillary vasodilation and increased venolar permeability (leakage). Several new treatment options like the topical application of high concentration capsaicin for chronic neuropathic pain in adults are based on this pain pathophysiology.

Transmission

Injury or inflammation activates several types of peripheral nerve fibres that process the nociceptive signal and transmit it to the CNS, where it is eventually transformed into the conscious experience of pain. These nerve fibres are named nociceptors, and they make up the vast majority of afferents (up to 90%) in almost all tissue. Some tissue, e.g. cornea, tympanic membrane or dental pulp is almost exclusively innervated by nociceptors. There are two types of nociceptors, **C-fibres** and **Aδ-fibres** with two subgroups each, appearing anatomically as free endings of nerve fibres. **C-fibres** are non-myelinated nerve fibres that may be activated by mechanical, thermal (heat and/or cold) and a variety of chemical stimuli. They have conduction velocities of around 1 m/s. **Aδ-fibres** are thinly myelinated, allowing for much higher conduction velocities (10–25 times that of C-fibres), and they are also activated by mechanical, thermal or chemical stimuli. Beyond this crude classification, nociceptors are a very complex system of afferents subdivided into many highly differentiated groups of sensors with diverse functions ranging from simple to polymodal sensors.

There are many C- as well as Aδ-fibres in skin, muscles and joints. In contrast, visceral structures exhibit many C-fibres, but just a few Aδ-fibres. Aδ-fibres are generally more sensitive in almost any sensory modality than C-fibres, making them prime candidates for detection of noxious events. Thresholds of Aδ-fibres are significantly lower than those of C-fibres. Their faster signal conduction enables the organism to withdraw quickly from a damaging stimulus, limiting stimulus impact at higher intensities in order to avoid permanent or at least further damage. Thus, for instance after thermal injury, permanent tissue impairment (burning) may be limited or even avoided. The main feature of C-fibres is their ability to continue with signal transmission for a long time after acute tissue injury in order to signal to the organism that it should rest the respective body part, or make it undergo treatment. Hence, healing is supported.

Modulation

Incoming nociceptive information is modulated in the CNS. Afferent neurons of both the spinal nerves and the cranial nerves with their cell bodies in the dorsal roots ganglia or cranial nerve counterparts (e.g. the Gasserian ganglion of the trigeminal nerve) transmit nociceptive or sensory stimuli to the spinal dorsal horn. For a long time, it was believed that this level is a “hub”, switching the incoming signal to the second neuron of the pain tract, but nowadays we know that the processes in the dorsal horn are more complex. Even at that level of signal transmission, various synaptic or biochemical interactions result in summation effects, or selection. Neuronal signals coming from primary afferents converge in the dorsal horn. There, by means of local inhibitory interneurons, they may be inhibited by segmental or descending control even before reaching a higher spinal level or the cerebrum.

According to *Gate Control Theory* published in “Science” by Melzack and Wall in 1965, both non-nociceptive stimuli are conducted to the dorsal horn (via large myelinated fibres) and nociceptive stimuli (via Aδ- and C-fibres) (Melzack and Wall 1965). Since several peripheral neurons converge to one spinal neuron, this type of convergent neuron was named wide dynamic-range neuron (WDR neuron). The fact that different types of fibres converge to one neuron may be one of several reasons why counterirritation, i.e. rubbing of the affected area after injury, sometimes alleviates the pain (other mechanisms are the activation of long-term depression (Treede 2008)).

The human organism inherited a very effective and highly preserved evolutionary endogenous pain-inhibiting system, the principal layout of which is found in even very primitive organisms, like snails or insects. According to requirements, this endogenous pain control is more or less active, depending on emotions. Based on that model, Melzack and Wall succeeded in explaining how after even the most severe injuries (i.e. accident) or under extreme emotional stress, some people—at least transiently—will not perceive pain from their injuries, even including a total lack of pain perception. Mediated by the **monoaminergic neurotransmitters noradrenaline or serotonin**, descending tracts of the brainstem are able to reduce the excitability of spinal nociceptive neurons directly or indirectly by stimulating inhibitory interneurons within the spinal grey substance. Some of these **inhibitory neurons** may release endogenous opioid peptides (i.e. endorphins) that stimulate opioid receptors, which may inhibit signal transduction to the WDR neuron.

Perception

After having undergone modulation by interneurons, the second neuron of the nociceptive projection pathway is intraspinal. Its dendrites cross the midline of the spinal cord into the contralateral anterolateral funiculus (see Fig. 2.1).

The ascending nociceptive spinal tracts comprise several different parallel projecting tracts, namely the spinothalamic, spinomesencephalic, spinoreticular and spinoparabrachial tracts. The **spinothalamic tracts** can be further subdivided into the more **lateral** part (**neo-spinothalamic tract**) and a more **medial** part (**paleo-spinothalamic tract**). Pain signal conduction from neck or head areas follows a similar anatomic and physiologic assignment via the trigeminal nerve.

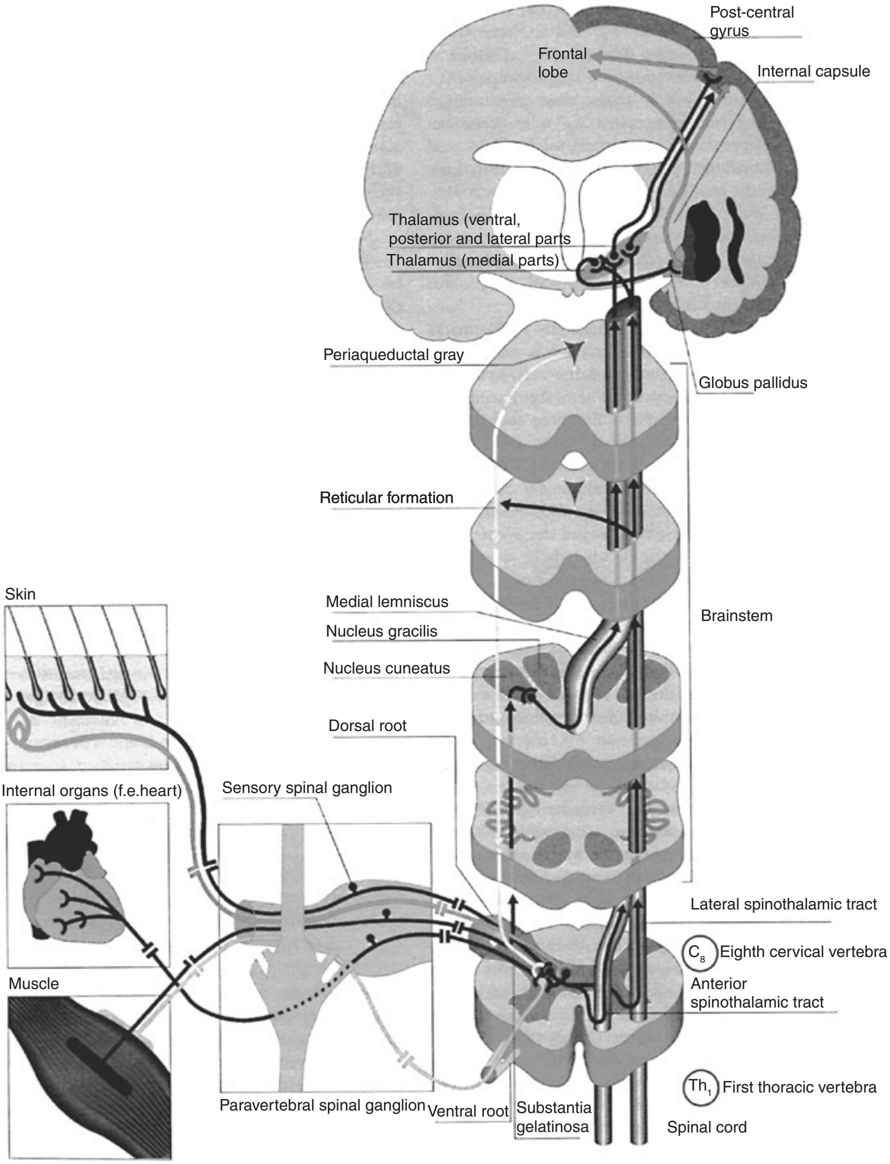

Fig. 2.1 The nociceptive system: nociceptors, ascending and descending spinal pathways, thalamic relay nuclei, subcortical and cortical projection areas (according to Brune et al. 2001, modified)

The lateral **<u>neo-spinothalamic tract</u>** consists of large myelinated fibres that lead centrally and are switched to the third neuron of the pain tract in the ventral, posterior and lateral parts of the thalamus. The third neuron projects parallel to the **primary and secondary somatosensory cortices**, and nociceptive parts of the insula and operculum which are all **somatotopically organised** (**localisation of the pain**).

The medial **paleo-spinothalamic tract** is composed of both short and long fibres and is less myelinated than the neo-spinothalamic tract. Many synapses help to transmit the signal into deeper brain structures like periaqueductal grey, cingulate cortex, hypothalamus, or the medial thalamic parts. From there the signal pathway is **more diffuse**—and less somatotopically organised—into the **limbic system** and the **frontal cortex (emotional dimension of the pain**).

Anatomical organisation of both systems with their different numbers of synapses and their different grade of myelinisation suggests that the **neo-spinothalamic tract** (exhibiting fewer synapses and faster signal conduction into the somatosensory cortex) is responsible for the signalling of **acute pain**. Its localisation, and the scoring of its severity, allows the organism to quickly protect itself from the acutely damaging stimulus, or to stay away from the painful stimulus. The **paleo-spinothalamic tract** with its slower responses and its connections to, for example, the limbic system is thought to be primarily responsible for **emotion and memory**. This makes the paleo-spinothalamic tract the ideal candidate to be responsible for an arousal reaction, or for reactions aimed at avoidance of further injury, i.e. behavioural changes, like avoidance behaviour.

Obviously, conscious experience of pain goes far beyond the transmission of a signal from the peripheral nervous system to the CNS, which we term nociceptive processing. Pain is a multidimensional process including former experiences, emotions, cultural imprinting, familial and social relationships.

It is well-known that the hypothalamus, the limbic system and the medial parts of the thalamus are involved in motivational or emotional experiences, and that they are connected to the paleo-spinothalamic tract. These systems are connected to other cerebral structures as well, i.e. the frontal cortex. Under pain, those phylogenetically old cortical areas, like the anterior cingulate cortex (ACC), are known to trigger autonomic reflexes like an increase in blood pressure, heart rate or respiratory frequency (collectively termed pseudo-affective reflexes). The motivational and emotional state is of crucial influence in the spinal modulation of pain processing via descending tracts. Here, interdisciplinary pain treatment has its biological basis of pain modulation.

2.1.2 Peripheral and Central Pain Sensitisation and Inhibition

Peripheral Sensitisation

In **Aβ-fibres** that transmit sensory information from **non-noxious stimulus** modalities (touch, proprioception), continuous or repeated stimuli lead to exhaustion, expressed as an **increased threshold** to the stimuli. This is totally different in the transmission of nociceptive signals. In this respect, nociceptors are a unique type of sensor responding to repeated stimuli with increased sensitivity, **lowered threshold**, and a longer lasting response beyond the actual stimulus impact (after discharge). In case of repeated or very severe painful stimuli, this characteristic of **C- and Aδ-fibres** may contribute to the **peripheral sensitisation**.

Peripheral sensitisation is triggered by the release of locally acting substances from surrounding tissue and associated intracellular responses (e.g. increase of Ca^{2+}

concentration in the peripheral nociceptor terminal) conjointly leading to a decrease of nociceptor threshold and an increase in suprathreshold stimuli. Additionally, insensitive (silent) terminals or branches may become sensitised, leading to an increase of receptive field size.

Central Sensitisation

Central sensitisation contributes to an amplification of the noxious input (**hyperalgesia**) and the onset of pain from normally innocuous stimuli (**allodynia**). There are similarities between the processes at the cellular level resulting in use-dependent spinal "pain traces" and the hippocampal cellular processes that are regarded as the cellular basis of cognitive learning and memory. "Pain traces" in the nervous system often are called "pain memory", however, they represent a non-conscious mechanism of use-dependent implicit learning and memory. In parallel to motor learning, where repeated stimuli (exercise) lead to specific and often highly automated sequences of motions (e.g. playing tennis, skiing, climbing), repeated pain experiences may "train" the brain with the result of a lower pain threshold and/or the feeling of pain even in the absence of a pain trigger (e.g. chronic daily headache). Triggered by long-lasting or repeated painful stimuli, the CNS, especially the dorsal horn, responds with functional and structural changes (corresponding to histomorphologic changes). These neuroplastic changes are part of nociceptive central sensitisation. Hyperalgesia, allodynia or spontaneous pain with a concomitant increase in the painful body area are characteristic of central sensitisation.

One may intervene in the path of signal transduction in order to reverse sensitisation by using measures of counterirritation, therapeutically exciting sensible nerve fibres. This can be accomplished using transcutaneous electrical nerve stimulation (TENS), or physical modes of pain control, i.e. the application of heat or cold. Some counter irritative measures are able to inhibit pain for some hours, or even days, the effect lasting longer than the nerve stimulation itself.

Recent in vivo and in vitro studies showed that the synaptic transmission between Aδ- or C-fibres and the spinal neurons is permanently inhibited provided the parameters of stimulation are correctly chosen (synaptic long-term inhibition). Even the long-term potentiation of spinal synaptic transmission may be reversed.

In order to do so, it is necessary to excite the Aδ-type nerve fibres. Unfortunately, the necessary stimuli intensities are often perceived as a bit painful. Hence the stimulus is mostly applied with only low frequency (1–3 Hz), presumably activating paths of spinal neural transmission that at least partially reverse sensitisation. If the intensity of the stimulus is such that only low-threshold Aβ-fibres are excited, sensed by the patient as non-painful paraesthesia, there will be no lasting effect. Exciting all afferent nerve fibres, including the high-threshold C-fibres, would not only be very painful to the patient, but moreover, it may also be unnecessary for maximum effect or even be detrimental, overruling the specific ameliorating pain-depressing effect of Aδ-nociceptor stimulation. This is in accordance with the clinical observation that long-term analgesia using TENS or acupuncture can be reached only if a painful stimulus is used.

With (functional) MRI, structural and functional changes in the CNS can be measured both when chronic pain develops and when chronic pain is successfully treated with an interdisciplinary multimodal approach. After successful treatment, a reduction of the pathological hyper-connectivity in the pain matrix, as well as an increase in the pre-treatment pathological reduced grey matter volume in some brain areas, can be observed (Becerra et al. 2014; Erpelding et al. 2016). Some pathological brain alterations may persist even after successful pain treatment rendering the child vulnerable to a relapse of the pain disorder (Linnman et al. 2013).

2.1.3 Pain Disorders

Migraine

Etymologically, migraine originally describes a typical hemicranial severe headache (Greek—hēmíkraira = half the head). Women suffer from migraine about three times as often as men. A similar gender distribution is found in adolescents but not in younger children.

In the last 10–15 years the prevalence of migraine in Western developed countries increased to about 10% in children and adolescents (Larsson and Fichtel 2014). Migraine is a complex disorder of the brain. The phenotype of migraine is extremely varied. One aspect of the migraine disorder is recurrent headache attacks. A migraine attack may arise without any forewarning. But often a migraine headache is preceded by a prodromal phase which may consist of fatigue, euphoric or depressive mood, irritability, ravenousness generally, or for special food like chocolate, neck stiffness, reduced peristaltic movement or constipation, attacks of yawning, and an increased sensitivity to light, noise and smells (Burstein et al. 2015).

Unfortunately, the term “migraine” has developed in common language into a term for any type of severe headache. On closer examination, a headache that may be described as a “migraine” often does not comply with the criteria of the International Headache Society (IHS).

According to the IHS, migraine is defined as a sudden periodic headache, usually with a throbbing quality. This may be accompanied by symptoms such as nausea, vomiting, or increased sensitivity to light (photophobia) or auditory stimuli (phonophobia). Very often symptoms increase in severity with physical activity and thus the patient withdraws, avoiding physical activity.

Especially in younger children, who are not able to verbally describe their photophobia or phonophobia due to their developmental age, their behaviour provides important diagnostic clues. There are two different forms of migraine: migraine without aura and migraine with aura. The migraine aura is defined as focal neurological symptoms arising before, during or after the migraine attack. The migraine aura is produced by a cortical spreading depression (CSD) that moves with a velocity of 2–6 μm over the cortex. CSD causes positive focal neurological signs and symptoms like glimmering jagged lines spreading from the centre to the periphery of the visual field or tingling sensation (gain-of-function). The CSD is followed by a 15- to 30-min-long lasting period where the cortical activity is diminished leading to negative symptoms like visual scotoma, numbness sensation of the skin or even muscle weakness or paralysis of the extremities (loss-of-function). The most common type of migraine is without aura, which has a higher attack frequency than migraine with aura. The diagnosis of migraine as a primary headache should not be given unless other neurological diseases can be excluded. The IHS defines the following diagnostic criteria for migraine (https://www.ichd-3.org/):

Diagnostic Criteria

A. At least five attacks[1] fulfilling criteria B–D
B. Headache attacks lasting 4–72 h (untreated or unsuccessfully treated)[2,3]
C. Headache has at least two of the following four characteristics:
   1. Unilateral location
   2. Pulsating quality
   3. Moderate or severe pain intensity
   4. Aggravation by or causing avoidance of routine physical activity (e.g. walking or climbing stairs)
D. During headache at least one of the following:
   1. Nausea and/or vomiting
   2. Photophobia and phonophobia
E. Not better accounted for by another ICHD-3 diagnosis

Sometimes it is quite difficult to differentiate between migraine without aura and episodic tension-type headache (see below). In order to help children, parents and professionals to differentiate tension-type headache from migraine in childhood, Table 2.1 lists the typical symptoms pinpointing the differences.

There is a strong genetic basis of migraine development. Social and environmental factors also play a role in the development of the clinically relevant migraine disorder.

It remains unclear where exactly in the brain the origin of the migraine is located or which pathophysiological imbalance causes the migraine attack. Some researchers think that the “migraine generator” is located in the brain stem, others argue that hyperexcitability of the cortex is responsible for migraine. What remains indisputable is that a migraine attack goes along with a strong activation of the trigeminus nerve and that a neurogenic inflammation can be observed that is mediated by neuropeptides like serotonin, substance P, calcitonine-gene-related peptide and pituitary adenylate cyclase-activating polypeptide-38 (PACAP38) (Amin et al.

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[1] One or a few migraine attacks may be difficult to distinguish from symptomatic migraine-like attacks. Furthermore, the nature of a single or a few attacks may be difficult to understand. Therefore, at least five attacks are required. Individuals who otherwise meet criteria for migraine without aura but have had fewer than five attacks should be coded “Probable migraine without aura”.

[2] When the patient falls asleep during migraine and wakes up without it, duration of the attack is reckoned until the time of awakening.

[3] In children and adolescents (aged under 18 years), attacks may last 2–72 h (the evidence for untreated durations of less than 2 h in children has not been substantiated).

Table 2.1 Typical symptoms of tension-type headache and migraine in childhood

	Tension-type headache	Migraine
Frequent symptoms and typical course	• Duration of headache 30 min to 7 days • Mild to moderate intensity • Bilateral location • Pressing or tightening quality • **Physical activity does not aggravate pain** (most important criterion) • Nausea or vomiting missing; sometimes lack of appetite • Mild photophobia or phonophobia	• Duration of headache 1–72 h • Moderate to severe intensity • Frequently unilateral location • Frequently pulsating quality • **Physical activity does aggravate pain** (most important criterion) • Nausea or vomiting • Photophobia and phonophobia
Less frequent (but possible) symptoms	• Neck pain • Teeth grinding • Dizziness	• Aura (visual acuity impaired; flashes; restricted area of focused sight; paralysis; etc.) • Frequent yawning, ravenous appetite, extreme fatigue before the attack • Bilateral location • Pressing or drilling quality • Very short pain attacks • Smell disturbances • Abdominal pain • Neck pain • Cutaneous hyperalgesia • Dizziness • Paleness

2014). This neurogenic inflammation may lead to a temporary change in the diameter of intra- and extracranial blood vessels before, during or even after a migraine attack. However, these vasodilatations or vasoconstrictions do not always occur during a migraine attack and they play no role in pathophysiology (Amin et al. 2013). Once the trigeminal nerve is activated by the “migraine generator”, pain thresholds are further lowered and the reaction of the nerve to various stimuli is increased (central sensitisation) (Burstein et al. 2015). This means that stimuli that are normally ignored by the brain, like normal light or sound, are now detected and other stimuli, like pressure or traction to the meninges, cause pain. During a migraine attack, vibration of the brain caused by normal body movements may lead to pain. This is the reason why children often want to go to bed during a migraine attack. The progress in the sensitisation process of the trigeminal nerve leads to a burning and painful scalp in some patients and others show an increased muscle tension (Burstein et al. 2015). This is the period of the migraine attack where children do not tolerate pressure on the scalp. They tend to avoid wearing hats, glasses or even headphones. Some children experience allodynia in the whole body accompanied by muscle tension and the inability to wear tight clothes or to tolerate a hug.

The headache is often “accompanied by a variety of autonomic symptoms (nausea, vomiting, nasal/sinus congestion, rhinorrhoea, lacrimation, ptosis, yawning, frequent urination, and diarrhoea), affective symptoms (depression and irritability), cognitive symptoms (attention deficit, difficulty finding words, transient amnesia, and reduced ability to navigate in familiar environments), and sensory symptoms (photophobia, phonophobia, osmophobia, muscle tension, and cutaneous allodynia)" (Burstein et al. 2015).

The migraine can be accompanied by other weird symptoms that are not primarily psychogenic, like: visual illusions (autokinesis (a stationary small point of light appears to move), corona phenomenon (several concentric rings around an object and a central bright area); cinematographic vision; double vision; metamorphopsia (a grid of straight lines appears wavy); visual splitting; dyschromatopsia), complex higher cortical dysfunctions (altered perception of body size or weight) or synaesthesia (stimulation of one sensory pathway leads to automatic, involuntary experiences in a second sensory pathway; numbers are perceived as inherently coloured; words cause a special taste) (Jürgens et al. 2014).

Often the headache phase is followed by a period with muscle weakness and concentration difficulties that lasts up to 3 days.

The treatment of migraine consists of migraine attack therapy (usually Ibuprofen and/or Triptans depending on the characteristics of the single attack) and psychosocial interventions. We know about the relationship between migraine pain and neurotransmission. Data being gathered since the implementation of Triptans into treatment are of special importance in clarifying these interrelationships. Triptans turned out to be very effective in the treatment of an acute migraine attack. In spite of the severity of migrainous pain, there is no underlying destructive cerebral process. The only risk with migraine is not to treat it the right way, i.e. using analgesics at the very beginning of an attack. Treated with delay (i.e. not taking the medication until the patient cannot stand the pain anymore), insufficiently (i.e. using a low drug dose) or in the wrong way (taking a nap instead of taking medication; using relaxation techniques *during* a migraine attack) makes children suffer severe headache more frequently. As time goes by, it becomes more probable that pain accompanied by fear of the upcoming pain attack is *learned*, establishing a *pain memory* and chronic headache.

In very rare cases there are defined migraine triggers. In most children some stressors trigger a migraine attack when the brain is already in the "migraine mode" and it does not make sense to generally avoid those triggers. Often patients think that, e.g. chocolate is causing their migraine attacks. But in fact, more often it is vice versa: the migraine attack alters the brain function in the way that the patient has a desire to eat chocolate. Chocolate is not the cause but the consequence of the migraine attack. There is no scientific evidence for special migraine diets or the avoidance of a huge amount of triggers in daily life (Hoffmann and Recober 2013). A better way is to adapt to unavoidable triggers like school stress.

Many international guidelines recommend a pharmacological treatment to reduce the frequency of migraine attacks. Our impression is that in children and adolescents, psychosocial interventions are much more powerful than pharmacological treatments in reducing the frequencies of migraine attacks. This view is supported by a meta-analysis and reviews (Fisher et al. 2018). Furthermore, prophylactic drugs have very small scientific evidence with many "negative" studies (e.g. Powers et al. 2017) and may cause severe side effects. Therefore, we recommend not to use drugs to try to reduce migraine attack frequency.

Tension-Type Headache (TTH)

Tension-type headache is said to be the most frequent primary headache. Although its aetiology and pathomechanisms are still unknown, the IHS defines this type of headache as a disease entity assigned to the primary headaches. It might well be that TTH comprises several different types of headache of still unknown origin. Meanwhile, many studies suggest that at least TTH with a severe course has a neurobiological origin.

It is helpful to distinguish between chronic TTH (headache ≥15 days/month on average for >3 months) and episodic TTH. Chronic TTH leads to an impaired quality of life and has the potential to severely affect daily routine. Episodic TTH comprises two subtypes: The sporadic subtype, exhibiting pain less than once per month, and the subtype with more frequent attacks. The impact of the sporadic subtype on the patient's life is mild, while the subtype with more frequent attacks may result in life impairment similar to chronic TTH, leading to frequent usage of analgesics and frequent contact with healthcare professionals, which may become a true financial burden to the family. Not only are medical doctors contacted due to persistent or recurrent headache; alternative practitioners and other health professionals are also visited. Some of them release spinal blockages; others blame the teeth or their position for the pain.

Infrequent Episodic Tension-Type Headache

Infrequent episodic TTH shows rare episodes of headache lasting minutes to days. The pain is double-sided and of pressing, tightening quality. It is mild to moderate and is *not* amplified by routine physical activity. There is no accompanying nausea, but there may well be photophobia or phonophobia.

Diagnostic Criteria for Infrequent Episodic TTH

A. At least ten episodes occurring on <1 day/month on average (<12 days/year) and fulfilling criteria B–D
B. Headache lasting from 30 min to 7 days
C. Headache has at least two of the following characteristics:
   1. Bilateral location
   2. Pressing/tightening (non-pulsating) quality
   3. Mild or moderate intensity
   4. Not aggravated by routine physical activity such as walking or climbing stairs
D. Both of the following:
   1. No nausea or vomiting (anorexia may occur)
   2. No more than one of photophobia or phonophobia
E. Not better accounted for by another ICHD-3 diagnosis

Frequent Episodic Tension-Type Headache

This diagnosis is characterised by frequent episodes of headache lasting minutes to days. The pain is typically bilateral, pressing or tightening in quality and of mild to moderate intensity. It does not worsen with routine physical activity. It is not accompanied by nausea, but photophobia or phonophobia may occur.

Diagnostic Criteria for Frequent Episodic TTH

A. At least ten episodes of headache occurring on 1–14 days/month on average for >3 months (≥12 and <180 days/year) and fulfilling criteria B–D
B. Headache lasting from 30 min to 7 days
C. Headache has at least two of the following four characteristics:
   1. Bilateral location
   2. Pressing or tightening (non-pulsating) quality
   3. Mild or moderate intensity
   4. Not aggravated by routine physical activity such as walking or climbing stairs
D. Both of the following:
   1. No nausea or vomiting (anorexia may occur)
   2. No more than one of photophobia or phonophobia
E. Not better accounted for by another ICHD-3 diagnosis

Patients suffering migraine without aura frequently also suffer episodic TTH. A headache diary (see Sect. 3.5.2) is the tool of choice to analyse the co-occurrence of TTH and migraine. Since treatment is essentially different in those two types of headache, it is very important to educate patients and parents in the differentiation of the two types of headache in order to enable them to choose the appropriate treatment. This will also prevent the development of medication overuse headache in the long run. We strongly advice against the use of drugs like Amitriptyline for TTH prevention. They work no better than placebo, sometimes diminish the motivation for appropriate psycho-social interventions and may cause long-term negative alterations of the developing brain.

Chronic Daily Headache

Many patients in our programme suffer chronic daily headache. According to our pain model we diagnose them as chronic pain disorder. The IHS offers several other diagnostic codes for those patients, of which many ignore the psycho-social dimension of chronic headache. Diagnostic categories suggested by the IHS are "chronic migraine", "chronic tension-type headache", "new daily persistent headache", "medication-overuse headache (MOH)" or "persistent headache attributed to mild traumatic injury to the head". In our clinical practice, the overuse of NSAIDs and Triptans is of huge relevance and often we have to withdraw these medications during the inpatient treatment.

Rheumatic Disease

The term "rheumatic disease" has its origin in the French doctor Guillaume de Baillou (1538–1616) who comprehensively described complaints of the musculoskeletal system. While the underlying theory of humoral pathology is long outdated, common language still uses the term, subsuming diseases of most different aetiologies into the rheumatic spectrum disorder. The more specific immunologically mediated rheumatoid diseases are as follows:

1. Juvenile idiopathic arthritis
2. Collagenoses
3. Psoriatic arthritis
4. Reactive arthritis
5. Rheumatoid arthritis (=chronic polyarthritis)
6. Ankylosing spondylitis (Bechterew's disease)
7. Vasculitis of different origin

Many readers will notice the diagnosis of Juvenile Fibromyalgia Syndrome (JFMS) is missing. The authors believe that FMS is not a helpful diagnostic label in children and adolescents. Traditionally, the so-called JFMS is defined according to the Yunus criteria. Other publications on JFMS use the definition of the American College of Rheumatology (ACR). Both the Yunus and the ACR criteria have substantial problems in their operationalisation. For a deeper discussion see Zernikow et al. (2012a). It may be better to code patients with the F45.1 (ICD10, German version) as "chronic pain disorder with somatic and psychological factors".

In paediatrics, the most frequent rheumatic diseases are reactive arthritis of different origin, frequently due to a recent infection, and juvenile idiopathic arthritis (JIA). The aetiology of the latter is still obscure. It may well be that JIA comprises different yet unknown diseases. It goes without saying that a causal treatment of JIA is not yet available.

An important prerequisite for successful treatment is the early diagnosis and transfer of the patient to physicians with experience in the treatment of JIA.

Only by doing so can early and effective treatment of both the inflammatory reaction and the pain be given. Effective control of any underlying disease and—if necessary—induction of remission, avoidance of joint contractures or destruction leading to persistent physical disabilities, as well as avoidance of impaired growth resulting in axial malposition, are the main goals of quality rheumatologic treatment. Concurrently with pharmacological treatment, it is of the utmost importance that the patient keeps moving and under no circumstances submits to passive pain control. Otherwise there is a high risk that the acute pain will become chronic, developing further into a chronic pain disorder with somatic and psychological factors (called "*pain amplification syndrome*" by rheumatologists; see also Sect. 3.1).

Successful treatment should allow children a somatic and psychological development free of major disturbances. On an 11-point scale, JIA patients rate their disease-related quality of life worse than their general quality of life (Feldman et al. 2000). Paediatric JIA patients score their quality of life lower than their healthy peers (Manschwetus 2003). Based on several JIA studies and the JIA national guidelines of the German scientific medical societies (AWMF), early diagnosis (within 1–2 months) and the assessment of disease activity are essential to rheumatologic therapy. To this end there are various validated scales (i.e. PED ACR) available. Pharmacological treatment should comply with the latest version of national or international guidelines.

Of special importance is physical and ergotherapy given by experienced and specifically trained therapists with the aims of maintenance or recovery of normal joint mobility, avoidance of contractures, stretching and activation of muscles, strengthening of muscles, facilitation of physiological movements in order to avoid the development of relieving postures or false posture. In the case of good disease control, participation in sports at school and other sporting activities is allowed and should be encouraged (!), as graded physical exposure has a positive effect on development and coping with the illness, and the risk of social isolation is minimised. As soon as acute inflammation has receded, training should be resumed, but only after the type of sports and training intensity are individually determined, since in inflamed joints sports that stress the joints may provoke an acceleration of destructive processes and lead to irreversible cartilaginous defects.

Complex Regional Pain Syndrome (CRPS) Type I and II

Blunt joint trauma and bruises primarily provoke an inflammation response similar to that seen in other types of arthritis. Both the vasoactive substances released by tissue damage and pain lead to locally increased blood flow and local oedema. An injured joint may accumulate an increased amount of fluid (effusion). Local cooling of the joint will depress pain, inflammatory response and oedema. Non-steroidal antirheumatics will also depress the inflammation. Skeletal or ligamental injuries need to be diagnosed as soon as possible to allow for targeted therapy. Any necessary immobilisation should be as short as possible. If impairment is observed under immobilisation, one should critically re-evaluate treatment. One should be aware of thrombosis as well as nerve compression. When the acute injury is healed, the aim is to mobilise the joint as soon as possible in order to avoid the development of relieving posture or inappropriate straining of a joint.

Case Report: Lotte (Age 14 Years), CRPS

> Lotte is the second child in her family, with an older sister. When getting up one morning, Lotte gets her index finger caught between the mattress and bed. She immediately feels severe pain in her whole hand. Clinical examination by a surgeon reveals a strain of the capsule of the metacarpal joint. Radiologically, a fracture can be excluded. Lotte gets a cast on her hand. A few days later, the pain is increasing and nearly unbearable; whole hand allodynia develops. The affected hand is swollen, the skin has changed to doughy and shiny, the finger joints are fixed in flexion and massively swollen. Ibuprofen, metamizole, tilidine and tramadol all are ineffective. A complex regional pain syndrome (CRPS) is diagnosed. Lotte gets pregabalin and inpatient interdisciplinary pain treatment. During the course of treatment, the trophical changes decrease. Lotte is able to move her hand again. After discharge, she is able to write using her hand and to participate in school as usual.

CRPS may develop after all types of trauma to the distal parts of the extremities. By definition, symptoms do not follow the course of peripheral nerves, or spinal roots. In extremely rare cases the symptoms may spread to other extremities. The diagnosis is made according to the clinical picture since there are no other suitable diagnostic methods available. The diagnosis is by exclusion. Nuclear magnetic resonance (NMR) tomography, Quantitative Sensory Testing (QST), or skeletal scintigraphy may be helpful. Complex regional pain syndrome develops with variable latency after injury of an extremity, i.e. trauma, or even diagnostic or therapeutic procedures, independent of type or grade of injury. Even a minor trauma may induce CRPS.

If the injury causes damage to a peripheral nerve and CRPS develops, the disease is named CPRS type II. If there is no nerve lesion present, it is CPRS type I. The International Association for the Study of Pain (IASP) defined sensitive and specific diagnostic criteria (Baron 2004; Harden et al. 2007).

Diagnostic Criteria IASP

1. The presence of an initiating noxious event, or cause of immobilisation.
2. Continuing pain, allodynia, or hyperalgesia with which the pain is disproportionate to any inciting event.
3. Evidence at some time of oedema, changes in skin blood flow, or abnormal sudomotor activity in the region of the pain.
4. This diagnosis is excluded by the existence of conditions that would otherwise account for the degree of pain and dysfunction.

Note: Criteria 2–4 must be satisfied.

Generally, any findings assessed by a doctor are more important than the subjective symptoms as described by the patient. A sentinel characteristic of CRPS is that symptoms are not confined to the area of the injured nerve, but tend to generalise distally sometimes also proximally, affecting the whole extremity.

The “Budapest” criteria of CRPS (Harden et al. 2007) are given below:

General Definition of the Syndrome

CRPS describes an array of painful conditions that are characterised by a continuing (spontaneous and/or evoked) regional pain that is seemingly disproportionate in time or degree to the usual course of any known trauma or other lesion. The pain is regional (not in a specific nerve territory or dermatome) and usually has a distal predominance of abnormal sensory, motor, sudomotor, vasomotor and/or trophic findings. The syndrome shows variable progression over time.

CRPS has been reported in children from the age of 2.5 years. A sentinel traumatic trigger is not always reported. The pain intensity at first admission is between 8 and 10 (NRS/VAS 0–10) for most patients. The affective expression is often incongruent to the high reported pain intensities; children report extreme pain intensities at times without signs of distress. The lower limb is more commonly involved in children than in adults. Cold and mechanical allodynia, burning pain, dysaesthesia and paraesthesia are the most common symptoms. Signs of autonomic dysfunction (oedema, cold skin, discoloration, changes in hair-growth and sweating), as well as movement problems such as dystonia and a limited range of motion are often present. Cognitive and emotional problems are common in children with CRPS. Many children report a feeling that the limb does not belong to the body (neglect of the affected extremity). This feeling may become so intense that the child wishes to "cut off" the affected limb. These signs and symptoms often do not conform to the classical symptoms in adult CRPS patients. Because of this it remains unclear whether or not CRPS in childhood and adolescence is the same disease as the CRPS in adults.

To Make the *Clinical* Diagnosis, the Following Criteria Must Be Met

1. Continuing pain, which is disproportionate to any inciting event.
2. Must report at least one symptom in *three of the four* following categories:
    - (a) **Sensory**: Reports of hyperaesthesia and/or allodynia.
    - (b) **Vasomotor**: Reports of temperature asymmetry and/or skin colour changes and/or skin colour asymmetry.
    - (c) **Sudomotor/Oedema**: Reports of oedema and/or sweating changes and/or sweating asymmetry.
    - (d) **Motor/Trophic**: Reports of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin).
3. Must display at least one sign **at time of evaluation** in *two or more* of the following categories:
    - (a) **Sensory**: Evidence of hyperalgesia (to pinprick) and/or allodynia (to light touch and/or temperature sensation and/or deep somatic pressure and/or joint movement).
    - (b) **Vasomotor**: Evidence of temperature asymmetry (>1 °C) and/or skin colour changes and/or asymmetry.
    - (c) **Sudomotor/Oedema**: Evidence of oedema and/or sweating changes and/or sweating asymmetry.
    - (d) **Motor/Trophic**: Evidence of decreased range of motion and/or motor dysfunction (weakness, tremor, dystonia) and/or trophic changes (hair, nail, skin).
4. There is no other diagnosis that better explains the signs and symptoms.

For *research* purposes, diagnosis should be applied when there is at least one symptom ***in all four*** symptom categories and at least one sign (observed at evaluation) in two or more sign categories.

Skin temperature is measured with suitable tools. All other symptoms are judged clinically. In order to answer point 4, the presence of diseases that can imitate CRPS must be excluded: rheumatic diseases, inflammation (i.e. infectious arthritis of any kind, post-surgical infections, polyneuritis or radiculitis), thrombotic affections, compartment syndrome or nerve compression syndrome. To this end, the patient should undergo biochemical investigations. It is *impossible* to diagnose CRPS exclusively by means of laboratory investigations like CRP or erythrocyte sedimentation rate.

Often it is difficult to discriminate CRPS from the results of a psychiatric disease. This is especially true with a dissociative disturbance with auto-aggressive components. Some of those diseases in fact are able to trigger CRPS, which complicates the situation. The course of the disease should be documented using methods common in pain treatment, i.e. subjective (NRS) and objective (QST) pain assessment, parameters of function (force/power, extent of mobility, circumference), and quantification of disturbances of the vegetative nervous system. For details on specific treatment in CRPS see also Chap. 12.

The treatment of CRPS in children and adolescents is based on a biopsychosocial pain model and should be multimodal and interdisciplinary. Invasive pain treatments like sympathetic blocks should be avoided.

Insufficiently Treated Acute Pain

Insufficiently treated severe pain may lead to permanent sensitisation of the CNS. It is thought that 20% of all children suffer persistent pain after operations (Rabbitts et al. 2017). Especially alterations at the spinal level are well investigated, and there is good reason to speculate that similar processes take place at the thalamus, and cerebral level as well. Long-lasting changes lead to an increased sensitivity of spinal and thalamic nociceptive neurons to noxious stimuli (Borsook et al. 2018). Clinically, this may manifest as pathologically increased algesia (hyperalgesia), even eliciting pain through non-nociceptive stimuli (i.e. by light touch or gentle cold stimuli, which manifest as dynamic mechanical or cold allodynia), or even as spontaneous pain. At the spinal level the arising synaptic long-term potentiation (LTP) may be suppressed by local anaesthetics and analgesics but not by general anaesthesia. The pain-inhibiting tracts descending from the cerebrum to the spinal level are similarly effective. In humans, it is still difficult to erase pain memory by drug treatment (see below). Counterirritation measures like transcutaneous electric nerve stimulation (TENS) may however have the potential under special circumstances to actively bring the increased sensitivity of the nociceptive system back to normal. Recent work in animals and humans suggests that TENS may at least in part activate the mechanism of synaptic long-term depression (LTD) counteracting long-term potentiation (LTP).

2.1.4 Pain and Gender

Numerous studies have investigated the gender-specific differences in pain prevalence. A good example is the German Children’s and Adolescents’ Survey (KiGGS) of the Robert-Koch-Institute. Overall, pain prevalence was the same in boys and girls in younger children. But, in the adolescent subgroup, the 11- to 17-year-old girls reported a significantly higher prevalence of recurrent headache, back pain and abdominal pain during the last 3 months than age-matched boys. These findings are in accordance with several similar studies. For example, large multinational epidemiological surveys including hundreds of thousands of adolescent participants report consistently that, in most countries, across most pain locations (but particularly headache and abdominal pain), adolescent girls have a higher prevalence of recurrent pain than boys (Gobina et al. 2019; Swain et al. 2014). These sex trends are consistent with findings from a detailed review conducted a few years earlier consisting of 41 smaller studies assessing paediatric pain prevalence (King et al. 2011).

Pain intensity is also higher in girls, reflecting the findings in chronic pain outpatient setting (Keogh and Eccleston 2006) and those of a study on inpatient children with pain (Hechler et al. 2010). LeResche et al. (2005) investigated the relationship between puberty development and pain sensitivity and found stage of puberty a better predictor for pain than age. It is still unclear if these findings reflect hormonal changes (as is speculated with the clustering of migraine in girls aged 12 years and up; see Sect. 2.1.2) or are better explained psychosocially in role finding or role expectation and their accompanying conflicts.

2.1.5 Genetic Determinants

There is good reason to assume that human pain sensitivity is partially genetically determined. The "fakir's gene" has long been known. This is a gene mutation first seen in a Pakistani family whose members are unable to sense pain. This gene coding for a sodium channel has the effect that affected people are unable to respond adequately to impairing environmental stimuli. Pain development and processing, however, are not monogenetically determined. Pain processing is determined by the cooperation of various genetic factors, more and more influenced by learning processes with increasing age. A single mutation does not necessarily grant increased, or blunted pain sensitivity, or various degrees of efficacy of analgesics in affected individuals.

Genetic contributions to resilience or vulnerability may be considered in a number of domains, like genes that moderate the noninflammatory stress response, genes that sensitise the nervous system to potentially develop chronic pain and genes that may alter the immune response (Borsook et al. 2018).

It has long been known that pain runs in families and an analysis of pain in individual subjects predicted pain sensitivity in their families (Birklein et al. 2008). Numerous methods are used to find candidate genes. Geneticists research large families to determine genomic markers that are present in affected family members but not in unaffected ones. If a marker is located near a relevant pain gene, it should be more frequently found in affected individuals than in healthy ones. Single Nucleotide Polymorphisms (SNPs) are particularly of interest. In SNPs, a single nucleotide of DNA is exchanged, resulting in a changed protein that can affect neural signal transmission.

More than 40 genes have been identified that play a role in perception of pressure, temperature and pain processing. Examples are the COMT gene, the OPRM1 gene and the TRPV1 gene. If the gene coding for the μ opioid receptor is affected, as it is for 11% of the population who are carriers of this polymorphism, pressure sensitivity is altered. A certain gene mutation coding for the capsaicin and heat-sensitive vanilloid receptor TRPV1, found in 37% of the population, results in a blunted pain response to cold, but only homozygous allele carriers showed a markedly blunted response. Activation of TRPV1-bearing C-nociceptors is essential for central sensitisation, and a snap of the TRPV1 receptor presumably resulting in a lack-of-function mutation of TRPV1 has recently been shown to prevent nociceptive sensitisation in patients with neuropathic pain (Binder et al. 2011).

Several genes have also been identified whose transcription and/or translation is triggered by pain, including genes from the IEG (immediate early genes) group; the gene products of these genes are detectable in dorsal horn neurons within minutes after a painful stimulus. So far, the significance of the post-pain changes in the phenotype of the nociceptive neurons has not been clarified. It may well be that they contribute to central sensitisation, too. Or they are a meaningful adaptation to increased neuronal activity. A pronounced increase in the concentration of calcium ions in neurons can trigger programmed cell death (apoptosis) or necrotic cell death. Obviously, inhibiting (antinociceptive) spinal dorsal horn neurons are particularly sensitive to triggered cell death, as following peripheral nerve lesions or trauma to peripheral tissue, the number of neurons using the inhibiting neurotransmitter GABA decreases. A loss of spinal GABA-ergic inhibition results in severe types of hyperalgesia, allodynia or spontaneous pain.

2.2 Psychological Determinants

Pain is an individual, subjective experience which comprises biological, psychological and social (context) components (Flor and Diers 2007). This is true with acute as well as chronic pain. The multidimensionality of pain becomes evident when the numerous components of central pain processing with the involvement of different areas of the CNS are considered. Apart from somatosensory areas, other areas determine the pain experience, e.g. those responsible for emotions, like the limbic system (Melzack 2005).

The significance of psychological and social factors can be illustrated by many examples. For instance, a child will typically not take notice of pain at first if hurt during play. The more pain becomes chronic, irrespective of the biological component, the more the significance of psychological and psychosocial factors increases. This is also reflected by the diagnostic criteria of pain disorders which will be presented in detail in Chap. 3.

A pain therapist needs to be well aware of the relationship between these different dimensions. A unidimensional treatment for children with a pain disorder is likely to fail (see Sect. 4.1).

In contrast, an interdisciplinary approach enables successful pain treatment.

Many studies have proven the effectiveness of the interdisciplinary concept presented in this manual (see Chap. 16).

2.2.1 Learning Pain

Learning theories assume that the development of chronic pain is facilitated by reinforcement. Reinforcement of pain-specific behaviour may arise from avoiding pain or from parental reactions to the child's pain. If a child lies down because of a headache, this may decrease his/her pain for various reasons. But whatever the cause, the child will display this behaviour more frequently in future due to the initial pain reduction. This is a classic example of operant conditioning. Apart from operant conditioning, less direct learning processes are included in the development of chronic pain as well. This is illustrated by the example of fear of pain. Children with recurrent pain often experience an increased fear of pain. In consequence, this fear may cause the child to continuously avoid any kind of potentially painful activities. A pronounced avoidance behaviour will further consolidate this fear of pain (Vlaeyen and Linton 2000; Asmundson et al. 2012).

A child's pain behaviour is also influenced by his/her parents' behaviour. According to learning theory, receiving more attention from the parents when experiencing (and reporting) pain will lead to a positive reinforcement of pain. Such behaviour is typical in parents of children with chronic pain and is triggered by worries, stress or negative cognitions, such as catastrophising thoughts (Lynch-Jordan et al. 2013; Maciver et al. 2010). At the same time, children's pain behaviour will elicit more caring parental behaviour, when the parents have a tendency to catastrophise (Vervoort et al. 2011); this further reinforces pain. However, in our experience, there are also parents who increasingly react dismissingly and aversively to their child's pain. Unfortunately, there is only little research on this phenomenon (Goubert et al. 2005). Often the child's disorder results in substantial disturbances of the parent–child interaction (reproach: "You don't believe me that I am in pain!"), which causes stress and therefore amplifies pain.

Irrespective of the type of parental reaction, it is important to discuss the (mostly unintended) consequences of the parents' behaviour during treatment.

Parents or close attachment figures of children with chronic pain often suffer chronic pain themselves (Merlijn et al. 2003; Stone and Wilson 2016). Besides a genetic determinant, this may also hint at a process of observational learning and is in accordance with our clinical experience. However, other mechanisms may also be at play (e.g. processes of empathy (Palermo et al. 2014)). These underlying processes have not yet been fully identified.

2.2.2 The Role of Cognitions

Pain experience is influenced by the subjective appraisal of the situation and the personal coping capabilities. Appraisals have an impact on coping strategies, and coping strategies again have an impact on pain experience.

Coping with pain may be either behavioural or psychological (Hechler et al. 2010). Problem-focused coping aims to change the circumstances and, in most cases, results in active pain coping behaviour. Children who demonstrate less problem-focused coping usually are prone to show a more passive pain coping behaviour (Walker et al. 2007). Depending on the degree to which the coping aims at adapting to the circumstances, pain may either be accepted, or increasingly negative ideas will develop (Walker et al. 2007). Active pain coping along with acceptance of the pain are strategies proven effective in pain treatment (Feinstein et al. 2018; Wicksell et al. 2009). This illustrates the important relationship between pain-related cognitions and the coping behaviour (active versus passive). The close relationship of experience and behaviour is illustrated in the "Fear Avoidance Model" of chronic pain (Asmundson et al. 2012). The different therapeutic interventions that aim to change cognitive processes are presented in Sects. 9.3 and 10.5 with case reports.

Typical pain-related cognitive coping strategies are positive self-instruction, catastrophising thoughts or cognitive distraction.

Catastrophising in particular correlates with increased pain intensity and increased emotional burden (Feinstein et al. 2018). In the long run, this will lead to substantially increased perception of body signals, the so-called somatosensory amplification (Rief and Barsky 2005; Nakao and Barsky 2007). Section 9.6 elucidates the importance of somatosensory amplification in interoceptive conditioning. In contrast, mental distraction will reduce pain (Chambers et al. 2009; Verhoeven et al. 2012). Importantly, cognitive strategies are not equally suitable for all children. Sometimes acceptance-based interventions not aiming at mental distraction should be preferred over typical cognitive coping strategies (Wicksell et al. 2009). Section 9.3 suggests in detail which strategies aiming at cognition and appraisal are best suited to different patients.

Physical rest, avoidance and seeking social support are typical pain-related coping behaviours following dysfunctional cognitions. Coping behaviours following helpful cognitions are, for example, behaviour-related distraction and search for information. Passive pain coping strategies are positively associated with pain intensity, shown in an outpatient study on paediatric abdominal pain (Walker et al. 2007) and in an inpatient sample during the course of treatment (Dobe et al. 2011). The relationship between seeking social support and pain intensity is particularly strong in girls (Hechler et al. 2008, 2010). Both mental and behaviour-related distraction result in reduced pain intensity (Reid et al. 1998).

Pain self-efficacy is currently discussed as an important resilience factor for dealing with chronic pain (Cousins et al. 2015). Pain self-efficacy can be defined as the confidence for coping with pain, for being able to control the pain. Research consistently demonstrates that pain self-efficacy has a positive impact on pain-related disability, pain intensity and depression (Stahlschmidt et al. 2019; Tomlinson et al. 2017). Chapter 9 introduces pain coping strategies that enhance pain self-efficacy.

2.2.3 The Role of Emotions

Apart from cognitions, emotions are relevant in the understanding of chronic pain, since pain is always associated with feelings of fear and threat. The degree of emotional distress due to pain largely depends on individual factors. Individual cognitions and the coping strategies of the child and his/her parents have a huge impact on chronic pain. Catastrophising thoughts and seeking social support are relevant predictors of emotional distress in chronic pain (Eccleston et al. 2004). The association between chronic pain and emotions has been mostly investigated in studies focusing on depression, anxiety, critical life events and posttraumatic stress disorder (PTSD) (for a detailed discussion, see Sects. 10.2, 10.4 and 10.5).

In a recent outpatient study, nearly a quarter of the paediatric study population with severe chronic pain showed elevated levels of depression and anxiety (Zernikow et al. 2012b). In a study on inpatient pain treatment, nearly 50% of the patients reported elevated levels in at least either anxiety or depression before treatment (Dobe et al. 2011). Burba et al. (2006) were able to show that more than half of the patients with chronic pain were unable to perceive and describe their own feelings (alexithymia). This is partially compatible with our clinical experience. Many children are not or are only insufficiently able to assign their perceptions of physiological processes to the various emotional qualities. Whether this is a consequence of their pain disorder (according to their parents, many of these children were formerly well able to reflect on their thoughts and emotions) or a factor favouring the development of a pain disorder is still under dispute. Sections 4.3, 9.3 and 11.3 will describe various interventions designed to improve differential perception of feelings.

Depression and anxiety may arise from chronic pain or they may maintain or reinforce the pain due to social withdrawal or difficulties in falling asleep and/or remaining asleep. Numerous models try to explain the complex interactions between risk factors and resilience factors (Cousins et al. 2015; Fernandez and Boyle 2002). Evidence suggests a multifactorial process with mutual negative interactions, which may differ interindividually.

General anxiety, as well as school aversion, plays an important role in chronic pain (Zernikow et al. 2012b). In the assessment of chronic pain, it is always advisable to take any school problems (e.g. social conflicts, poor performance) into consideration. Testing for dyslexia may be indicated in order to exclude the possibility that continuous distress in school due to difficulties in reading and writing maintains chronic pain.

Pain-related fear is of special importance in the “Fear-Avoidance Model” of chronic paediatric pain (Asmundson et al. 2012). This model illustrates the interaction between chronic pain, fear of pain and pain-related disability. It is assumed that fear of pain is associated with avoidance behaviours in such a way that the fear of pain, and not the pain itself, maintains the avoidance behaviour. Research further suggests that anxiety sensitivity (e.g. the fear of bodily perceptions that are associated with dangerous physical, mental and/or social consequences) increases fear of pain and thus facilitates pain-related disability (e.g. Asmundson et al. 2002). Anxiety sensitivity has evolved as a central construct in recent research on pain disorders and interoceptive conditioning in, for example, posttraumatic stress disorder (PTSD). The scientific background and resulting interventions are demonstrated in Sect. 9.5.

A high comorbidity rate exists between PTSD and chronic pain. A recent study demonstrated that approximately 11% of children and adolescents who receive an inpatient pain treatment fulfil the criteria of a PTSD (Stahlschmidt et al. in prep.). Prevalence estimates of PTSD in community samples range between 0.5% and 5% (Copeland et al. 2007; Kilpatrick et al. 2003; Perkonigg et al. 2000). Even the experience of negative critical life events and permanent emotional distress can contribute to the chronification of somatoform disorders (Bonilla and Saps 2013; Wager et al. 2015). One study on chronic pain and critical life events was able to show that particularly for children and adolescents with CRPS, critical life events play an important role in the development and maintenance of the disorder (Wager et al. 2015). Due to the high comorbidity rate of pain disorders and adjustment disorder or PTSD, the respective scientific background and resulting interventions are presented in Sect. 10.2.

2.3 Social Determinants

In the discussion of learning processes, coping strategies and emotions, it became apparent that chronic pain in children and adolescents cannot be isolated from contextual factors. The social environment of the child, especially his/her family, peer group and school, also play a role in the development and maintenance of pain disorders.

The family's role in chronic pain and pain-related disability was illustrated in a model (Palermo and Chambers 2005) focusing on the individual parental features (e.g. catastrophising thoughts, worries). It is emphasised that these features must be seen in the context of dyadic relationships (e.g. quality of parent–child interaction) which are impacted by the whole family system. A social system can only be understood in its entirety.

So far, studies explicitly investigating the impact of the patient's peer group are scarce. A study by Merlijn and colleagues suggests that peers reward and reinforce pain-free behaviour (Merlijn et al. 2003). They were able to show that peers pay attention to their friends with chronic pain particularly during episodes free of pain, but lower their attention during pain episodes. In line with this, Forgeron et al. (2011) found that children with chronic pain often feel misunderstood by their peers since they desire increased attention and understanding especially when pain is severe. These diametrically opposed behaviours and expectations could explain our clinical impression that many children experience social exclusion in the course of their pain disease (and not the other way around). Furthermore, children with chronic pain were shown to have fewer friends and more frequently experience bullying (Forgeron et al. 2011).

Children with pain disorders tend to miss school very frequently (Jones et al. 2018; Zernikow et al. 2012b). Irregular attendance at school has numerous consequences for the child (Jones et al. 2018). Frequently, school achievement drops markedly (Logan et al. 2008), sometimes resulting in repeating a class and endangering the child's educational development. On the social level, these children become more and more distant from their classmates and lose contact with peers (see above). Finally, absenteeism from school provokes reactions and attributions of teachers. It is more the rule than the exception that teachers interpret chronic pain in a dualistic way; they attribute the pain either to an organic or a psychological cause (Logan et al. 2007). Dependent on his/her interpretation, the teacher's understanding may vary from overwhelming (organic cause) or lacking (psychological cause) empathy and understanding.

There is a paucity of scientific literature with respect to the social determinants of the development and maintenance of pain disorders in children. According to our clinical experience, social and psychosocial factors contribute to the development and maintenance of many children's pain disorders. Studies evaluating the effectiveness of our interdisciplinary inpatient pain treatment do not allow us to draw any firm conclusions on the role of the numerous social factors or the effectiveness of certain systemic interventions. However, during the interdisciplinary inpatient pain treatment many different social and psychosocial factors should be taken into account.

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Diagnostics of Chronic Pain in Children and Adolescents

3

Julia Wager, Holger Kriszio, Michael Frosch, Michael Dobe,
Lorin Stahlschmidt, and Boris Zernikow

Wow, that's a lot!
—Markus (14 years), when completing the questionnaires

Contents

Abstract

By definition, a pain disorder is a biopsychosocial disease. Irrespective of their individual proportion, diagnostics in pain disorders must always assess biological, psychological and social factors. Medical diagnostic procedures explore whether, for example, physical diseases have contributed to the development and maintenance of the pain disorder or whether they have a negative impact on it.

J. Wager (✉) · H. Kriszio · M. Frosch · M. Dobe · L. Stahlschmidt · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: j.wager@deutsches-kinderschmerzzentrum.de; H.Kriszio@kinderklinik-datteln.de; M.Frosch@kinderklinik-datteln.de; M.Dobe@kinderklinik-datteln.de; l.stahlschmidt@deutsches-kinderschmerzzentrum.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_3

Psychological diagnostics assess emotional determinants, the appearance of dysfunctional cognitions or coping strategies, and the degree of pain-related impairment of the child’s life. Diagnostics of social factors investigate possible dysfunctional behaviours within the family system or elsewhere, and the interaction between the pain disorder and dysfunctional behaviours within the family, school or peer group. Additionally, it is important to identify the child’s and his/her family’s specific resources. This chapter describes the procedures necessary for a comprehensive assessment.

Many patients and parents react in a similar way to Markus (see above) when seeing the battery of questionnaires for the first time. However, in most cases, the initial reaction changes after completion of the questionnaires, because they cover a wide range of important aspects of the medical history and the pain experience. As a result, the patient and his/her parents feel they have been taken seriously and have to answer questions they have never thought about before. Completing the questionnaires gives them a chance to gain a differentiated view of the pain.

Questionnaires are an important tool in the diagnostics of chronic pain. Generally, questionnaire-based diagnostics should not overburden the patient and his/her parents. On the other hand, all important aspects of the pain condition should be covered. Furthermore, questionnaire assessment always needs to be supplemented by diagnostic interviews and medical examinations.

In this chapter, we will first discuss the diagnostic criteria of pain disorders. This will be followed by a description of recommended medical diagnostic procedures usually performed without questionnaires. Questionnaires, however, are the standard tool for the assessment of the psychological and social aspects of the disorders.

3.1 Definition of Pain Disorders

In the upcoming International Classification of Diseases (ICD-11), pain disorders can be coded under the diagnosis of *chronic primary pain* (MG30.0). In this definition, the biopsychosocial approach to chronic pain is evident. The respective diagnostic criteria are presented in Table 3.1. Sub-diagnoses are available that are specified according to the pain location:

- *Chronic primary visceral pain* (MG30.00)
- *Chronic widespread pain* (MG30.01)
- *Chronic primary musculoskeletal pain* (MG30.02)
- *Chronic primary headache or orofacial pain* (MG30.03)
- *Complex regional pain syndrome* (8D8A.0)

Table 3.1 ICD-11 criteria for Chronic primary pain

MG30.0	*Chronic primary pain*
	Chronic primary pain is chronic pain in one or more anatomical regions that is characterized by significant emotional distress (anxiety, anger/frustration or depressed mood) or functional disability (interference in daily life activities and reduced participation in social roles). Chronic primary pain is multifactorial: biological, psychological and social factors contribute to the pain syndrome. The diagnosis is appropriate independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms. Other chronic pain diagnoses to be considered are chronic cancer-related pain, chronic postsurgical or posttraumatic pain, chronic neuropathic pain, chronic secondary headache or orofacial pain, chronic secondary visceral pain and chronic secondary musculoskeletal pain.

Table 3.2 DSM-5 criteria for Somatic symptoms disorder

A.	One or more somatic symptoms that are distressing or result in significant disruption of daily life.
B.	Excessive thoughts, feelings, or behaviours related to the somatic symptoms or associated health concerns as manifested by at least one of the following: 1. Disproportionate and persistent thoughts about the seriousness of one's symptoms. 2. Persistently high level of anxiety about health or symptoms. 3. Excessive time and energy devoted to these symptoms or health concerns.
C.	Although any one somatic symptom may not be continuously present, the state of being symptomatic is persistent (typically more than 6 months).
	Specify if:
	With predominant pain (previously pain disorder): This specifier is for individuals whose somatic symptoms predominantly involve pain.

In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), there is only one diagnosis regarding pain disorders, the *somatic symptoms disorder* (300.82). The respective diagnostic criteria are presented in Table 3.2.

The duration (persistent, if more than 6 months) and the severity (mild, moderate, severe) of the diagnosis may be further specified. As with ICD-11, for this diagnosis, a biopsychosocial view is important since there are both physical (somatic symptoms) and psychosocial (thoughts, feelings, behaviours) determinants of the disorder. Compared with the previous version of the DSM, the criterion that the symptoms be medically unexplained has been removed.

However, for the treatment of pain disorders, it is important to identify any underlying physical disease, since repeatedly relapsing (inflammatory) processes may cause pain (e.g. migraine, juvenile arthritis). For these types of underlying diseases, pharmacological treatment is indicated (for details, see Sect. 12.1). Apart from that, the presence of any underlying chronic physical disease does not significantly change the further therapeutic approach to the pain disorder (for a more detailed view, see Sect. 14.6).

The biopsychosocial criteria relevant to the diagnostics of pain disorders underscore the importance of a detailed pain history comprising medical as well as psychosocial factors. Apart from the psychological diagnostic assessment, it is advisable to talk to the previously treating physician/therapist. It is also recommended to repeatedly assess the various dimensions of pain for the evaluation of treatment.

3.2 Medical Diagnostic Procedures

As in all areas of medicine, a detailed medical history is of utmost importance for pain disorders and may provide hints on which diagnostic steps should follow, apart from the obligatory thorough physical examination. In children and adolescents, physicians should try to apply the least burdening and least invasive procedure (which also applies to radiation exposure). Certain procedures depend on the patient's cooperation. If for an MRI examination a deep sedation or general anaesthesia is necessary (e.g. with younger children), risks and benefits should be carefully weighed.

Invasive procedures should only be applied in order to clarify a specific hypothesis.

Some diagnostic procedures may even cause iatrogenic chronification. Therefore, only necessary diagnostic procedures should be applied and invasive procedures should be avoided, if possible. Pain caused by taking blood for "routine blood chemistry" is unnecessary and avoidable, especially if there is no sound reason to expect a gain in information. Any necessary puncture should be performed under local anaesthesia, for instance using EMLA®. One should refrain from performing procedures explicitly requested by the parents, but not medically indicated. There is evidence that the number of invasive diagnostic and therapeutic procedures in children and adolescents suffering chronic pain has increased in the last years (Kaufman et al. 2017). Physicians should apply considerate action and provide comprehensive education to the patient and his/her parents concerning possible causes for pain and the resulting necessary and unnecessary examinations and treatments.

3.2.1 Exclusion of Secondary Headache

The physician should be aware of which cranial structures are sensitive to pain when trying to exclude secondary headaches. Pain-sensitive structures are the skin, periosteum and aponeuroses. With regard to ears, nose and throat, pain-sensitive structures are the nasal conchae, the paranasal sinuses and the ears. The eyes are pain sensitive as are the dura mater, arachnoid membrane and the cerebral vessels. The greater part of the brain itself is insensitive to pain, because nociceptors are missing. The posterior cranial fossa and its content are sensibly innervated by the upper three ipsilateral cervical roots, and the glossopharyngeal and the vagus nerve. The middle and the anterior cranial fossa are innervated by the ipsilateral trigeminal nerve. By experimental stimulation of the C1 root, pain sensation is provoked in the area of the ipsilateral eye, and the forehead, which shows that those areas are obviously innervated by C1.

This knowledge allows for the pinpointing of the causes of pain. In most children with headache there is no organ destruction. The goal is to identify those patients with secondary headache who will benefit from causal therapy. One should take into account:

1. Preceding head injury
2. Inflammation of the sinuses
3. Arterial hypertension
4. Increased pressure of cerebrospinal fluid (hydrocephalus; pseudotumour cerebri)
5. Any kind of space-occupying process
6. Vasculitis (arteritis)
7. Meningitis
8. Aneurism of cerebral vessels
9. Hypoglycaemia, especially in diabetics
10. Metabolic disorders like hypo- or hyperthyroidism
11. Any adverse effects of drugs

Apart from the neurological examination in headaches of so-far-unknown origin, an EEG and an ophthalmologic examination are often indicated. The latter should include testing visual acuity and a funduscopy in order to exclude the possibility of increased cerebral pressure, which may manifest as a papilledema. Adequate equipment allows for a sonography of the papilla via the eyeball. Medical imaging (computed tomography; MRI) helps detect anatomic anomalies, space-occupying processes, or inflammation and vascular diseases. The most appropriate procedure can best be chosen in discussion with the radiologist in order to avoid any unnecessary burden or diagnostics (possibly) not leading to the results necessary for confirming hypotheses.

3.2.2 Exclusion of Secondary Abdominal Pain

Abdominal pain in children is in most cases benign. But abdominal pain as a sign of an acute abdomen may indicate a life-threatening disease and may lead to permanent complaints limiting everyday activity. Since the interrelationships are complex, a physical cause should be excluded in any case of acute or chronic abdominal pain. Patients with functional abdominal pain not caused by an underlying organic disease sometimes undergo unnecessary invasive diagnostic procedures and long-lasting inappropriate medicinal therapeutic trials or diets. This frequently causes feelings of insecurity in the child and his/her parents. As a result, kindergarten or school is not attended regularly and quality of life is diminished due to the pain, but also due to the time spent seeing doctors or in hospital (for details, see Sect. 4.6.1).

Characteristics of abdominal pain differ. In most cases, children report unspecific periumbilical pain (around the belly button) normally attributed to functional pain (Sect. 4.6.2). In any case of persistent pain, basic diagnostics are indicated. A detailed medical history is helpful in order to rapidly start with necessary diagnostic measures. The following questions should always be checked:

1. Is there a circadian rhythm of complaints?
2. Is the pain associated with meals?
3. Is the pain associated with eating certain foods?
4. Is any food avoided due to intolerance?
5. How is the frequency of bowel movements and stool consistency? Any blood observed in the stool?
6. Are there any traces of stool (as an indicator of retentive encopresis in constipation)?
7. Is the pain constant or intermittent?
8. In girls, is there any association with menstruation?
9. Any unintended loss of weight?

Case Report: Nadia, 13 Years, Chronic Abdominal Pain

Nadia is the fourth child of a family with migration background and grew up with six siblings. She suffered from abdominal pain and the feeling of something moving in her belly for 1 year. Over a period of 10 months, she visited the doctor due to her abdominal pain up to three times a week. Her parents were not aware of these frequent doctor's visits. Nadia misses a lot of school lessons. Due to the abdominal distension she is prescribed dimethicone several times. Only after Nadia informs her parents that her belly is hard, a more detailed diagnostic is initiated. A sonography of the abdomen reveals a space-occupying process; diagnosis: dysgerminoma of the ovary. During the surgery, peritoneal metastasis is found. A tumour of more than 2.000 g weight is removed. Nadia receives polychemotherapy. The close oncological aftercare is inconspicuous.

Since the abdomen is mainly connected to C-fibres, the patient is usually unable to precisely localise the painful organ. As this is not the place to discuss the differential diagnosis of an acute abdomen, we will focus on chronic abdominal pain. Medical history and supplemental examinations are necessary in the diagnostic process. The following diseases should be excluded:

1. Chronic inflammation of the bowel (Crohn's disease; ulcerative colitis)
2. Ulcer disease
3. Gastrointestinal tumour
4. Mesenteric ischaemia
5. Meckel's diverticulum
6. Endometriosis
7. Ovarian tumour
8. Stenosis of the small intestine (following radiation; adhesions)
9. Post-surgery functional disorder (adhesions)
10. Carbohydrate malabsorption (fructose malabsorption; lactose malabsorption; sorbitol intolerance)

11. Celiac disease
12. Metabolic disorder (diabetes mellitus; Fabry's disease)
13. Chronic hereditary pancreatitis

The incidence of carbohydrate malabsorption has substantially increased in the last years. One should know that a pathologic H2 breathing test in the absence of adequate clinical signs under exercise *by no means* proves a fructose or lactose malabsorption. Be aware of all the therapeutic consequences following a false-positive diagnosis. Dietary restrictions will add to restrictions in everyday life and increase emotional burden. Balancing the risks and benefits, a diet only makes sense in severe cases of carbohydrate malabsorption.

By no means should a diet be prescribed in the absence of pathological clinical signs (Sect. 4.6).

3.2.3 Exclusion of Secondary Muscle or Joint Disease

Musculoskeletal pain may originate from various causes. In children it is advisable to reconstruct the medical history, asking both the parents and the child. The medical history should be extended to the weeks before the onset of disease. Especially in children, it is well-known that various (minor) infections may trigger reactive arthritis only after several weeks. There are reports of joint complaints after the use of certain antibiotics or other drugs.

(Non-invasive) joint sonography may deliver first clues to the diagnosis. Changes in the cortical bone may indicate an osteomyelitis. In case of any findings, sonography should be supplemented with conventional X-ray or MRI. Non-traumatic pain of the musculoskeletal system may be due to aseptic osteonecrosis (i.e. Perthes' disease) or chronic non-bacterial osteomyelitis. In most cases, radiological findings will lead to the correct diagnosis. The diagnosis of juvenile idiopathic arthritis requires evidence of synovitis by clinical examination or adequate imaging (sonography, MRI) and the exclusion of other causes.

Generally, it is recommended to exclude a secondary cause for back pain that is unresponsive to active measures such as training the back muscles or omitting excessive sports activities.

Further medical investigations may be needed, such as neurological diagnostics, X-ray imaging, MRI of the affected spinal part, or blood chemistry (particularly blood count and inflammatory parameters).

The following diseases are of importance in secondary back pain:

Diseases of the back:

1. Aneurysmal bone cyst
2. Non-inflamed necrosis
3. Disc herniation
4. Inflammation
5. Functional—"blockades" of the vertebral joints

6. Bone tumour (benign/malignant)
7. Osteoporosis
8. Post-accident (i.e. fracture)
9. Rheumatism
10. Scheuermann's disease
11. Spondylolisthesis

Diseases beyond the back:

1. Disorders of the inner organs
2. Leukaemia (blood cancer)

3.3 Psychological Diagnostic Procedures

In Chap. 2, we discussed the role of psychological factors, both in the development and the maintenance of chronic pain. It is important to identify these factors for successful pain treatment. Generally, questionnaires are a valuable basic psychological diagnostic tool. However, they should never act as a substitute for a clinical interview or in-person talk (Andrasik and Schwartz 2006); instead they are meant for screening or for building hypotheses.

3.3.1 Assessment of Pain-Related Cognitions and Coping Strategies

Passive coping strategies (e.g. social withdrawal) and negative thoughts about pain (e.g. catastrophising) are dysfunctional for dealing with pain and are associated with pain-related disability and depression (Kaczynski et al. 2011; Simons and Kaczynski 2012). Therefore, the goal of pain treatment is to reduce passive pain coping and encourage the use of active coping strategies. Sections 9.6, 10.3 and 11.3 focus on the implementation of active coping strategies into everyday life, both on the ward and in family life. Hechler et al. (2010) showed that passive pain coping was reduced 3 months after the inpatient treatment at the German Paediatric Pain Centre (GPPC). Changes in coping behaviour were associated with a decrease in pain intensity and pain-related disability in everyday life (Hechler et al. 2010). Questionnaires for the assessment of pain-related cognitions and coping strategies are the Pediatric Pain Coping Inventory (PPCI; Varni et al. 1996), the Pain Response Inventory (PRI; Walker et al. 1997) and the Pain Coping Questionnaire (PCQ; Reid et al. 1998) presented in Table 3.3. For the specific assessment of catastrophising, the Pain Catastrophizing Sale for Children (PCS-C; Crombez et al. 2003) can be used. In a recent systematic review (Stahlschmidt et al. 2019), two well-established questionnaires for the assessment of pain self-efficacy were identified, the Pain Beliefs Questionnaire (PBQ; Stone et al. 2016) for abdominal pain and the Child Self-Efficacy Scale (CSES; Bursch et al. 2006) for pain in general.

Table 3.3 Questionnaires for the assessment of psychological parameters in chronic pain

Construct	Questionnaire	Author(s)	Appropriate age (years)
Cognition and behaviour			
Cognitive self-instruction; seek social support; strive to rest, be alone; cognitive refocusing; problem-solving self-efficacy	Pediatric Pain Coping Inventory (PPCI)	Varni et al. (1996)	5–16
3 Higher-order factors: active, passive, accommodative coping; 13 subscales	Pain Response Inventory (PRI)	Walker et al. (1997)	8–18
3 Higher-order factors: approach, problem-focused avoidance, emotion-focused avoidance; 8 subscales	Pain Coping Questionnaire (PCQ)	Reid et al. (1998)	7–17
Rumination; magnification; helplessness	Pain Catastrophizing Scale for Children (PCS-C)	Crombez et al. (2003)	8–16
Pain self-efficacy	Child Self-Efficacy Scale (CSES)	Bursch et al. (2006)	8–18
Pain self-efficacy	Pain Beliefs Questionnaire (PBQ)	Stone et al. (2016)	7–18
Emotions			
Affective and evaluative pain perception	Pediatric Pain Questionnaire (PPQ)	Varni et al. (1987)	5–15
Affective and evaluative pain perception	Adolescent Pediatric Pain Tool (APPT)	Savedra et al. (1993)	8–17
Fear of pain	Fear of Pain Questionnaire for Children (FOPQ-C)	Simons et al. (2011)	8–17
Anxiety sensitivity	Childhood Anxiety Sensitivity Index (CASI)	Silverman et al. (1991)	6–17
General anxiety	Revised Children's Anxiety and Depression Scale (RCADS)	Chorpita et al. (2000)	8–18
Depression	Children's Depression Inventory (CDI)	Kovacs and Staff (2011)	7–17
	Revised Children's Anxiety and Depression Scale (RCADS)	Chorpita et al. (2000)	8–18
Emotional functioning	Pediatric Quality of Life Inventory (PedsQL)	Varni et al. (1999)	8–18
Psychological well-being	Kidscreen-27	Ravens-Sieberer (2006)	8–18
Posttraumatic symptoms	Child Report of Posttraumatic Symptoms (CROPS)	Greenwald and Rubin (1999)	7–17
Posttraumatic symptoms	Child PTSD Symptom Scale (CPSS)	Foa et al. (2001)	8–18

Note: This table lists a selection of tools for the assessment of important psychological parameters in a patient with a pain disorder. However, other validated questionnaires measuring those constructs may be used

3.3.2 Assessment of Emotion

Apart from assessing pain-related cognitions, the assessment of emotions is also important in the diagnostics of chronic pain. We would like to distinguish between pain-related and general constructs.

Affective pain perception, which reflects emotional impairment due to pain, may be assessed using the Pediatric Pain Questionnaire (PPQ; Varni et al. 1987). The child is asked to pick descriptions from a list of adjectives that best match his/her pain experience. Children describe their pain perception as “sad”, “cruel” or “tiring”. A further tool to assess the affective pain perception using an approach similar to the PPQ is the Adolescent Paediatric Pain Tool (APPT; Savedra et al. 1993).

For the assessment of pain-related fears and avoidance behaviour, the Fear of Pain Questionnaire (FOPQ-C; Simons et al. 2011; Table 3.3) is available. This questionnaire is constructed to assess fear of pain as well as avoidance of activities. Knowledge of the degree of pain-related fear is important to numerous therapeutic interventions, since in active pain coping, the exposure with the patient’s own fears is necessary.

Anxiety sensitivity is strongly associated with the degree of fear of pain (Martin et al. 2007). With ongoing chronification the anxiety sensitivity increases, repeatedly activating the fear system by a feedback loop. The Childhood Anxiety Sensitivity Index (CASI; Silverman et al. 1991) is a suitable tool for the assessment of this parameter. Sections 2.2.3 and 9.5.5 discuss in more detail the role of anxiety sensitivity in the development and maintenance of pain disorders, and suitable therapeutic interventions.

Avoidance behaviour based on pain-related fears leads among other things to impairment of everyday life and depression, again increasing pain-related fears (Simons and Kaczynski 2012). Furthermore, depression and fears may reinforce specific pain-related fears through passivity and avoidance behaviour. Hence, particularly in the field of chronic pain, one should also assess general emotional distress, such as depression or general anxiety. The degree of emotional distress is strongly associated with the type of coping strategy used (Eccleston et al. 2004). There are several tools for the assessment of general anxiety and depression; some are listed in Table 3.3. Psychological well-being as a subdimension of health-related quality of life may also be assessed. Additionally, due to the high comorbidity between chronic pain and posttraumatic stress disorder (PTSD), a trauma screening (e.g. Child Report of Posttraumatic Symptoms (CROPS; Greenwald and Rubin 1999); Child PTSD Symptom Scale (CPSS; Foa et al. 2001)) may also provide useful information.

3.3.3 Assessment of Resources, and Projective Diagnostics

Often, an examination of abilities, resources, aims and personal moments of happiness is omitted, though this information is as important for treatment planning as the assessment of current problems in the patient’s life. Chapter 15 provides six worksheets for projective diagnostics (#6 “Complete the sentences”), for the assessment of resources and to get to know each other (#1 “Everything I judge as good…”; #2 “Everything I judge as bad…”; #5 “‘Wanted’ Poster”), and for the assessment of special resources and stress factors (#3 “The five best events, the five worst events”; #4 “Three things that should change soon…”).

The worksheets presented in Chap. 15 are an addition to the validated diagnostic tools described earlier. The worksheets are meant to allow the child to express his/her own personality, goals, stress factors, family interactions, wishes, hopes and hobbies in a pleasant and discreet written way. The children may illustrate what is good for them, what moves and burdens them. In contrast to the other tools presented in this chapter, these worksheets are neither validated nor scientifically evaluated. Therefore, the worksheets are nothing but suggestions and may be extended or shortened at will. At the GPPC, all patients receive those six worksheets on the first day of their inpatient stay. Their task is to complete them before their first therapeutic appointment on the next day and hand them over to the nursing and educational team (NET) or directly to the therapist. After the therapist has introduced his/herself, the worksheets can be used as a basis to assess resources and stress factors in the first individual session (for detailed instructions about the first two individual therapeutic sessions, see Chap. 8).

3.4 Assessment of the Social Environment

Together with psychological aspects, social components like pain-related family interactions or general family stress factors are important determinants for the maintenance of pain disorders. In this respect, extreme caring/protective parental behaviour or constantly talking about pain may focus the patient on his/her pain and may thus intensify the pain (Walker et al. 2006). Distracting parental behaviour may reduce pain instead (Walker et al. 2006) (for more information on integrating the family into treatment, see Chap. 11). Non-family aspects may also be important in the development and maintenance of chronic pain. Stress, e.g. due to school problems or conflicts with peers, may favour the maintenance of pain (Miro et al. 2007).

The assessment of both parental behaviour and parental cognitions related to their child’s painful episodes is recommended. One questionnaire for the assessment of parental behaviour is the Adult Responses to Children’s Symptoms (ARCS; Van Slyke and Walker 2006), which examines protective, minimising and encouraging/monitoring parental behaviour towards the child’s pain. Since increased pain-related devotion and attention may contribute to the development and maintenance of paediatric pain disorders, it is generally helpful if distracting behaviour is increased within the family and attentive reactions are shown irrespective of the child’s pain (Sect. 11.3). Apart from pain-related interactions, the whole family system is of importance. Behaviour-related interactions in particular can be best assessed by direct observation, such as observing communication, or an extended interview with the child, his/her family, or the child’s therapist.

It is much easier to assess pain-related catastrophising thoughts with questionnaires. Parental cognitions can be examined using the Pain Catastrophizing Scale for Parents (PCS-P; Pielech et al. 2014). This tool determines the extent of catastrophising manifested as feelings of helplessness, rumination or magnification.

Another important aspect is the assessment of satisfaction with the family, school and peer setting (Kidscreen-27) (see Table 3.3).

3.4.1 Working with Genograms

In our experience it is always helpful to construct a family genogram in addition to the results received from questionnaire assessment. It may reveal further important factors for the cause of pain and thus for treatment.

This is not the right place to give detailed information on the theory, background or construction of a genogram. The reader is encouraged to get more information on working with genograms in a specific reference book. At the GPPC the construction of a genogram, starting with information on the grandparents, is part of the admission session with the child and his/her parents. The genogram is built together with the physician and a member of the NET (for more details, see Sect. 11.1).

3.5 Multimodal Pain Assessment Tools

As already mentioned, to diagnose pain disorders, several dimensions of the pain experience need to be examined. In clinical practice, the assessment of a multidimensional pain history is another important diagnostic approach, in addition to the previously described diagnostics, delivering lots of information about all three dimensions of pain within one questionnaire.

3.5.1 Pain Questionnaire for Children and Adolescents

The "*Pain Questionnaire for Children and Adolescents*" (PQCA; Schroeder et al. 2010) is a multidimensional questionnaire. It was originally developed in Germany and is now translated into English (to receive a copy free of charge, email info@german-paediatric-pain-centre.org).

The PQCA allows the structured assessment of general medical and pain history, makes an estimate of pain-related disability, appraisals and attitudes, and assesses other pain-triggering and intensifying factors. In addition, it delivers preliminary information on factors of the social environment (family, kindergarten, school) possibly relevant to the pain (Sect. 3.4). There are predefined answers as well as open questions where the child may describe his/her pain and its consequences. The following summary lists the main components of the PQCA:

1. Sociodemographic characteristics and family history
2. Pain characteristics

3. Pain triggers and pain modulating factors
4. Previous examinations and previous treatment
5. Pain-related disability
6. Cognitive-emotional and behavioural consequences of pain; subjective disease concept

Apart from the numerous single items assigned to the main components, the PQCA also includes two scales. Pain-related disability in everyday life is rated by the *Paediatric Pain Disability Index* (P-PDI; Hübner et al. 2009). This 12-item scale assesses how often the child is being kept from various everyday activities. Scores range from 12 to 60; a score of 36 or higher indicates an extremely high pain-related disability (Dobe et al. 2006, 2011). The questionnaire is validated in German for the self-assessment of children aged 11 years and up. In younger children, the parents' answers may be used. The Functional Disability Inventory (FDI; Walker and Greene 1991), which is not part of the PQCA, likewise enables the assessment of impairments in everyday life. Although the questionnaire does not explicitly ask for pain-related disability, its assessment is comparable to the P-PDI (Stahlschmidt et al. 2018). The FDI may be used with children aged 8 years and older (Walker and Greene 1991).

Another scale that is part of the PQCA is the Pain Perception Scale for Adolescents (Wager et al. 2010). This scale assesses the affective pain perception as a measure of pain-related emotional impairment (Sect. 3.3) as well as sensory pain qualities such as "pressing", "pulsating" or "burning" which may be useful in the differential diagnostics of migraine and tension-type headache. A validation study of the German version indicates that adolescents aged 11 years and up may rate their pain perceptions themselves. In younger children, parents' answers may be used.

In the PQCA, measures for assessing pain intensity vary according to the child's age. Adolescents aged 11 years or older rate their pain intensity on a Numerical Rating Scale (NRS; 0 = no pain at all, 10 = worst pain (von Baeyer et al. 2009)); however, a recent study showed that the NRS may be used from the age of 8 years (Castarlenas et al. 2017). The child version of the PQCA contains a faces pain scale (Faces Pain Scale Revised, FPS-R; Hicks et al. 2001).

There are three different versions of the PQCA, (1) for children aged 4–10 years; (2) for adolescents aged 11–18 years; and (3) for parents or the main attachment figure of the patient. The different versions were developed based on the patients' respective developmental level. Hence, the questionnaire for children comprises assessment modules different to those for adolescents, and is much shorter. In children lacking the necessary ability to read or write, their parents are asked to read the questions aloud and record their child's answers. The parent version of the questionnaire allows for an extended collection of information as well as the assessment of parental perspectives about their child's pain problem. The PQCA for the first contact is very comprehensive; there are shorter versions for the application in the course of treatment in order to assess treatment effects. The latter may be used every 3 months.

The PQCA is especially suitable for preparing an outpatient initial evaluation, as apart from a great deal of medical, psychological, and social information, it also assesses the criteria necessary for recommending (or not) inpatient pain treatment (Chap. 5).

3.5.2 Pain Diary

Especially in children with headache, a pain diary is a valuable tool for both diagnostics and the assessment of the effects of various therapeutic interventions. With respect to diagnosis, it may be helpful to use a pain diary in order to distinguish between different types of headache, especially migraine vs. tension-type headache. During the course of treatment, a pain diary may be applied in order to check the child's ability to distinguish between different kinds of headache, if therapeutic measures are effective, or if triggers can be identified.

Keeping a diary allows a continuous and prompt recording. Diaries are a reliable source of information in the diagnostics of headache (Phillip et al. 2007) and allow the child to directly recognise changes in the course of treatment, which helps strengthen self-controlled action. Diaries should record the main parameters of pain (intensity, frequency and duration). Of further interest are triggers, consequences of pain, pain medication, emotional well-being, impairment, attendant symptoms as well as applied coping strategies. If pain comes in attacks or is recurrent, the pain diary should be kept for an extended period of time (e.g. 3 months) (Kröner-Herwig et al. 1992). Much more problematic is the use of pain diaries in children with chronic pain disorders, as the diary may contribute to an intensified pain perception by making the patient focus on his/her pain. It is an individual decision if keeping a pain diary makes sense—there should be a considered balance between gaining information and pain reinforcement. During inpatient pain treatment at the GPPC, many children keep their diary just for the first few days of treatment. After 4–7 days, the pain diary is replaced by the documentation of distraction where the patient does not record the current pain intensity anymore but instead the active distraction strategy he/she used, and how effective this strategy was.

The authors have developed a headache diary which allows the assessment of the criteria of primary headache of the International Headache Society (IHS). Based on recorded pain intensity and accompanying symptoms, headache diaries are a good tool for diagnosing migraine at a glance. Because the time of drug application and its effectiveness is exactly recorded, they also allow one to rate the appropriateness of medication. Furthermore, documentation over the course of a week facilitates the recognition of any systematic pattern, or changes over time (to receive a copy of the English version of the diary free of charge email info@german-paediatric-pain-centre.org).

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The Basics of Treating Pain Disorders in Children and Adolescents

4

Michael Dobe, Michael Frosch, and Boris Zernikow

Contents

M. Dobe (✉) · M. Frosch · B. Zernikow
German Paediatric Pain Centre, Children’s and Adolescents’ Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; M.Frosch@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_4

Abstract

This chapter presents the essential basics necessary for providing effective treatment of pain disorders in children and adolescents. These basics are independent of the therapeutic setting, or the therapists' medical or therapeutic backgrounds. The reader will get to know the "Three Thought Traps" favouring the development of pain disorders. We then discuss the necessity of active pain coping, and of integrating the family into the treatment. We present important aspects of pharmacological treatment and medical background information on the most important biological determinants of chronic headache, abdominal pain, and back pain in childhood and adolescence. Finally, we discuss the therapeutic attitude and the functionality of pain.

In this chapter, we present several principles, which should be followed independent of the therapeutic setting or approach, in order to achieve the most beneficial treatment outcome in paediatric pain disorders. Therapeutic interventions based on these principles are presented in Chaps. 8–13. Some aspects (e.g. the "Three Thought Traps") are based on our own clinical experience. Other aspects arise from scientific knowledge (e.g. indication for and risk of analgesic usage). Certainly, the list of relevant aspects is endless. But, from our experience, adhering to the basics discussed in this chapter is sufficient for building a reliable therapeutic relationship with the child and his/her family, which is the foundation of successful paediatric pain treatment.

4.1 "Three Thought Traps"

From working with children with chronic pain and their parents, and from numerous therapists in this field, we have heard many different attempts to explain the phenomenon of pain disorders. Generally, all these attempts differ due to individual cultural, biographical, or professional backgrounds, but they tend to follow a dualistic world view: body (soma) versus mind (soul or spirit). These simple explanations seem to provide stability in times of helplessness, and by their straight relationship of cause and effect they give hope ("Having found the cause I will eliminate it, and with it the unpleasant effect (the pain)"). Following such a problem-solving strategy is understandable from a patient's and his/her family's point of view. However, it is damaging if a professional medical team supports, or even reinforces, such thinking. Of course, it is tempting to seek a monocausal explanation for pain disorders in the specific area the therapist is familiar with, but scientific findings show that such an approach is wrong, and according to our professional experience it hinders the healing process. A monocausal explanatory attempt and its respective treatment make further chronification of pain symptoms even more probable (Flor and Diers 2007).

In spite of their obvious differences, the various monocausal explanatory attempts may be classified into three approaches. We call them the "Three Thought Traps".

The First Thought Trap: "There Is Only a Psychological Cause"

In this Thought Trap, chronic pain is seen as the result of a suspected or actual mental conflict and the influence of any biological factors is neglected. Normally, it is not the affected child but his/her parent(s) (in most cases just one of them) and/or the therapist, physician or teacher being trapped in this thought. Many children report statements typical of this trap, such as "You are in pain because … (take one of the following: … you don't want to go to school; … you don't fight against it; … you have conflicts with your friend; … you are under too much stress; …)".

Certainly, psychological conflicts may negatively influence the experience of pain through tension and anxiety. But rarely would this alone cause chronic pain. Furthermore, this thought invalidates the child's own perception. His/her impairing pain experience is not taken seriously, or even worse, between the lines he/she is accused of exaggerating his/her pain in order to avoid unpleasant activities. Processes of sensitisation and conditioning, as well as clear somatic influences, such as migraine or irritable bowel syndrome, remain unconsidered. And even worse, there is no good way out for these children. The more they try to express how severe their pain is, the more they are perceived as being hysterical, or they are told that they just imagine their pain. If they try, however, to stay active despite their pain, nobody will believe that there actually is pain. According to our experience of the First Thought Trap, an impaired child–parent relationship and/or a discontinuation of therapy may result from one of the parents or the therapist remaining trapped. In such a situation, many children report feeling left alone and give up.

The Second Thought Trap: "There Is Only a Somatic Cause"

This Thought Trap is probably the most frequent approach to explain the suffering and the impairment caused by a pain disorder. The simple logic behind this Thought Trap is that something that "feels" so bad has to have a physical cause. This will lead to the paradoxical effect—well known to most physicians—that parents and their child are not relieved at all if medical examinations do not reveal any pathologic result, or at least no result with a causal relationship to the presented symptoms.

In consequence, the child will undergo more and more medical investigations all leading to the above-mentioned effect. As time goes by, the child will lose faith that he/she will find help since "no underlying cause" can be identified. The more investigations are performed, the higher the probability that a somewhat suspicious but clinically insignificant (random) result will arise. Laboratory investigations inherit a certain measurement error, and one should be aware that the human (error) factor is present in conducting, analysing, and evaluating the investigation. Standard values always reflect only a part of the population. Genetic variants where a "suspicious" result is normal are often not taken into account. Not being aware of those statistical considerations, a suspicious finding may result in even more insecurity for the patient, and in amateurish and bizarre explanations (often based on self-performed internet research) of how these findings could relate to the pain.

At the same time, the child and his/her parents may be encouraged in their Thought Trap by their contact with professionals. Repeatedly, parents report about therapists who assigned an abnormal occlusion, vertebral blockade, wrong nutrition, a special type of ametropia, or recently even intolerance of histamine, gluten or lactose as the *only* cause of the child's chronic pain. (In this regard, we would like to emphasise that we consider especially a monocausal explanation model as problematic. Some of the mentioned factors may well *contribute* to a pain disorder, but some of them are only examples of the current nutrition hypochondria in our society and a consequence of the Second Thought Trap.)

The effect is especially dramatic if therapeutic recommendations derived from a monocausal explanatory model result in a substantial financial burden for the family (e.g. treatment costs), a substantial restriction in quality of life (rigid change of nutritional habits), or physical endangering of the child (e.g. surgical procedures or daily intake of analgesics for several months). Luckily, many parents intuitively decline such treatment recommendations, or discontinue therapy if it does not result in the hoped-for improvement. Such decisions should not be considered a lack of compliance, but a sign of common sense.

Finally, with people following this Thought Trap we face the risk of further deterioration of the situation. The search for and the fight against what is seen as the somatic "cause" results in frustration and hopelessness and consequently more passivity and resignation.

The Third Thought Trap: "The Pain Must Vanish at All Costs"

Simplified, this Thought Trap is the exaggeration of the First or Second Thought Trap (mostly Thought Trap 2) combined with an additional very low acceptance of pain. The child, his/her parents and often the therapist(s) agree that under no circumstances should the pain be accepted, but it should be fought like an enemy.

It is our experience that especially for children stuck in the Third Thought Trap and suffering low pain tolerance, often other psychological or psychosocial factors play an important role. However, the focus is on the pain. This focus combined with low pain acceptance mostly results in a fast and pronounced increase in helplessness in the child and his/her parents.

In this Thought Trap a combination of such unfavourable factors bears the risk of a treatment endangering quality of life and health.

The lack of success in finding the "cause" leads to pronounced helplessness and puts a lot of pressure on the professionals to eventually "do something". Such a situation may result in a lack of objectivity, and in measures or therapies that are not indexed. A lack of objectivity may result in the long-term prescription of not medically indexed analgesics (in cases of headache or backache), or in surgical procedures (appendectomy when conservative treatment of abdominal pain is ineffective). Just as harmful are restrictive diets (e.g. free of lactose or even fructose despite only low intolerance and chronic abdominal pain not associated with nutrition), restriction of physical activity, or the drastic reduction of all kinds of stressors (e.g. commencing homeschooling instead of attending regular classes).

To summarise, the Three Thought Traps are based on our clinical experience and make no claim to completeness. In most cases, there is an artificial focus on just one aspect of the pain disorder, and ignorance of the other two factors (Chap. 2). Sometimes the child and his/her parents switch between the different Thought Traps. It is interesting to see that there are very few children and families with a fixation on social factors, such as "Other people are to blame for my child suffering chronic pain".

For the successful treatment of pain disorders, it is critical to acknowledge that a prerequisite is the resolution of the Thought Trap(s) in the child and his/her parents.

Hence, the right education from the very beginning (starting with the first contact with the therapist) is crucial for the course of treatment. For an in-depth discussion of age-appropriate education adapted to the child's developmental stage, see Sect. 8.2.

4.2 Active vs. Passive Pain Coping

It is important for an effective treatment to take the pain coping style favoured by the child and his/her family into account (Sects. 2.2 and 2.3). Put simply, all attempts to cope with pain may be classified into active or passive coping strategies. While both active and passive coping strategies have their place in everyday life and in acute pain, the rule of thumb for chronic pain disorders is: the more passive the worse. Why is that? After all, the child and his/her parents (mostly) concomitantly report that rest or passivity lead to a slight reduction of pain symptoms. However, the three main reasons for using active coping are as follows:

First, in pain disorders, rest or passivity (e.g. lying down) will—nearly inevitably—result in an increase in body awareness in the long run. In an environment nearly devoid of stimuli, the patient will focus more on any existing stimulus (in this case, specifically on pain), reinforcing pain perception and finally leading to consolidation of pain memory (Sect. 2.2).

Second, in the course of the pain disorder, there is a secondary dysfunctional development that is not specific to the pain. We are all familiar with the experience of the first day back at work after a holiday or a leave due to illness: the restorative effect only lasts a short time once we are again under the stress of work. This manual is not the right place to discuss the responsible complex regulatory loops of the sympathetic nervous system. Simplified, our ability to cope with daily hassles depends on biological laws that become obvious in endurance training. After some weeks of running three times a week for an hour, one would not be out of breath anymore. But, after a long interruption to the regular training, part of the training effect will vanish and will have to be re-established.

What does this have to do with chronic pain? If for several weeks or several months a child rests or is passive, his/her ability to cope with daily hassles is diminished, and he/she will experience exhaustion, distress, or tension more quickly. Exposing a child with a pain disorder to a normal amount of everyday activity will provoke a moderate to pronounced increase in pain at the beginning. Often, this will strengthen the child's and his/her family's belief that rest and passivity are best for pain reduction, and that confronting everyday life is best done when the pain "is gone" or at least significantly reduced. Such an interpretation—as understandable as it may be—turns the cause-and-effect relationship upside down and will consolidate the chronification of symptoms. As a consequence, this often results in social exclusion, fear of (non-)achievement, or fear of school.

Third, passivity and rest reduce self-esteem in the long run as the experience of success is missing, and self-doubts and fear of the future increase. In the end, this causes an increase of pain in a vicious cycle.

In our experience, especially at the beginning of pain treatment, individual and family sessions will focus on the topic of activity and passivity. Many parents fear hurting their child when trying to enforce active pain coping. The child's fear is that pain will become unbearable with more activity. The best way to show that those fears are unfounded is to give a brief overview of the scientific literature: for the treatment of chronic pain in both children *and* adults in outpatient and inpatient settings, *independent* of a possible somatic cause of pain (even after a disc herniation, an accident, a rheumatic disease, or any other inflammatory process), the implementation of active pain coping strategies is a *prerequisite* for long-term treatment success (Claar et al. 2008; Eccleston et al. 2004; Hermann et al. 2007; Hechler et al. 2010). Not to be misunderstood: in acute pain, e.g. immediately after an accident or a sports injury, physical rest is medically indicated for a short time, but not for weeks or months. In Sects. 11.2 and 11.3, we present in detail a method for getting the parents and their child involved in active pain coping.

4.3 Integration of the Family System

My mother's love doesn't help me.—Jan (12 years)

According to Sects. 4.1 and 4.2, the close integration of the family in the therapy is a prerequisite for successful paediatric pain treatment. But education with respect to the Thought Traps and the child's support in active pain coping strategies are not the only reasons why integrating the family system is necessary.

Often parents have strong ties with their child and can intuitively judge the situation quite well. However, they are trapped in (emotional) interdependencies with other important attachment figures and/or their perception is easily influenced by others. There is an abundance of more or less well-meaning advice. This starts with "The child doesn't drink enough" and extends to "You were never able to exert your will with your child" or "How could you send your child to school with so much pain? If I were you, I would look after my child in need". Parents or their children continuously report new variants of these forms of "advice" and reproaches. It is important for us to strengthen the parents with helpful information so that they are able to withstand this pressure (e.g. handing out the parents' guide "How to stop chronic pain in children" (Dobe and Zernikow 2014; eBook, available via Amazon);

Sect. 11.7); the same applies to dealing with teachers, or with physicians, or therapists not familiar with this matter. Strengthening the parents is also important in order to avert the jeopardy of ongoing medical investigations and treatment on a placebo level instead of effective but expensive therapy.

There are still some other reasons to integrate the family system; namely the presence of various interactions within the family before, during, or after pain treatment that maintain the pain.

1. There is evidence that decreased satisfaction in the parental relationship and specific concomitant interactions have a negative impact on paediatric headache (Ochs et al. 2004).
2. On the other hand, increased concerns and worries of the family may replace other conflicts while the child's pain becomes the main focus of family interaction (e.g. more frequent inquiry on pain, searching the internet for new treatment approaches, disputes on the right approach or the true diagnosis (especially explosive in separated parents), or permissive parenting style due to feelings of guilt).
3. Intensified questioning about the pain often results in a phenomenon we call "emotional pap" when casually speaking with the child and his/her family (Sect. 11.3). All kinds of negative emotions may reinforce the pain experience. The child, however, is asked about nothing else but the pain, thus putting nothing but the pain into focus. In this case, we observe that with ongoing pain chronification, many children increasingly lose the ability to distinguish between their various negative emotions. This is particularly harmful if the child's ability to distinguish between various emotions was insufficient beforehand.
4. If one or both of the parents also suffer from a pain disorder, this may impact family interactions and may have adverse effects on the child's pain symptoms. From a systemic point of view (e.g. Minuchin et al. 1975), a disease (e.g. pain) may have a functional role for family interactions. From this perspective, it would be "logical" if a child likewise develops chronic pain. Certainly, this is an extreme view that has not been proven so far. Furthermore, this is in contrast to our clinical experience. But, children with parents or attachment figures with a history of chronic pain are at an increased risk of developing a pain disorder themselves (Merlijn et al. 2003). And many children report being upset that the family member suffering the most pain gets the most care and attention. This does not necessarily mean that the child will adopt this mostly disliked pattern of interaction. But as it threatens the child's basic needs, it must be a part of education for the affected parent and has to be considered in pain treatment. Research suggests that mothers with chronic pain display dysfunctional behaviour when dealing with problems with their children and for example express worries for bodily symptoms of their children (Evans et al. 2006).
5. Affected parents may find it more difficult to encourage their child with active pain coping. Empathy is evoked via cerebral processes resulting in activation of mirrored processes in the observer (Loggia et al. 2008). Thus, in parents with chronic pain, perceiving their child's pain results in an increase in their own pain,

and vice versa. The child's pain is reinforced when he/she observes pain behaviour in his/her beloved parent. Thus, if parents with chronic pain support their child in active pain coping strategies, this is a significant success and should be reinforced by praise.

6. Finally, aspects of observational learning within the family play an important role in the development and maintenance of a pain disorder (e.g. to what degree parents cope actively or passively with demands or emotional crises). Certainly, not every unfavourable interaction pattern needs to be discussed in a family session. Usually, children are able to decide what is useful for them in the long run, and what is not. If, however, during her emotional crises a mother tends to lie weeping in her child's arms, in the long run the child will be overburdened by the situation, and alternative solutions have to be sought (e.g. outpatient psychotherapy for the mother).

While the logic underlying our approach (e.g. not asking about the pain but assumed emotions) should be evident by now, it is not yet clear at first glance which type of family interaction is counterproductive for long-term success *after having completed* pain treatment. The two most important inhibiting factors are:

1. After some time (on average, children receiving inpatient pain treatment have been suffering chronic pain for 3–4 years already (Dobe et al. 2011)), the pain disorder usually has a moderate to strong impact on the development of the child's autonomy, which is a consequence of increasing passivity along with social withdrawal. The resulting proximity to the family system is experienced as being either pleasant or unpleasant depending on the individual child and his/her family. The normal development of autonomy is hereby often hampered. Successful pain treatment in a child with chronic pain often results in "catching up" with the "missed" autonomy conflicts. In order to allow for a good long-term therapeutic relationship with the whole family system, we highly suggest discussing this aspect of treatment at the beginning of therapy, and asking the parents for their "consent" for this type of "adverse effect" of successful pain treatment (for details of our approach see Chap. 11).
2. Emotional exhaustion ("emptiness") or sometimes depression (mostly in mothers) is another aspect of family interaction frequently manifesting itself towards the end of effective pain treatment. This may happen once the "threat" (pain) to the well-being of the beloved child has been averted. The occurrence of such symptoms in the parents depends on numerous biographic factors. No outsider can grasp the emotional burden on the parents when their child suffers chronic pain. Hence, we recommend treating the parents with respect, and avoiding blaming them or making them feel causally responsible for their child's disorder. Whether a parent (mostly the mother) is likely to experience such problems can be cautiously explored with the following questions: "Is there anyone who is there for you, who gives you strength? Or do you have a hobby that helps you relax or recover? … (wait for an answer) We have the impression that you are very exhausted. Many mothers (and fathers) report that they are pushed to their limits

during the course of the disease and feel exhausted and empty. Do you experience feelings like this?" It is recommended to discuss this intervention with the child in advance in an individual session. Of course, the affected children perceive that their parents do not feel well and feel guilty ("It is my fault that my mother feels bad! If only pain would end, my mother and I would immediately feel much better."), which may reinforce the pain. If the child agrees to discussing his/her worries in the family session, family burden can be decreased. The affected parents do not want their children to worry about them and feel worse. On that basis, a family session may be helpful for clarifying that the children are not responsible for their parents' sadness (usually a number of factors account for this; most of which have nothing to do with the child). In the end, the parent may be asked if an outpatient psychotherapy could be helpful for improving stress coping.

To put it plainly: For long-lasting successful treatment of paediatric pain disorders, it is of the utmost importance that the whole family system be closely involved from the start.

4.4 Using Analgesics in Children with Pain Disorders

One should have a diagnosis before using analgesics in children, as is usual in pharmacological treatment. At this point, the physician decides if analgesic therapy is useful for this diagnosis. Pain medication has the potential for adverse effects, and additionally, its effectiveness is not proven for most types of chronic pain conditions. For instance, with ibuprofen adverse gastrointestinal effects are frequent (an inhibited prostaglandin synthesis results in the disturbance of the gastric mucosa).

Using analgesics makes sense only if a sustained nociceptive stimulus is part of the chronic pain condition (e.g. neuropathic pain, inflammation of joints, etc.), or in case of recurring acute pain in addition to chronic pain (e.g. migraine). In such cases it is important to inform the child and his/her parents of the effects that can be expected from the analgesic (it would not eliminate the pain disorder), and how to use it properly (e.g. take the *full* and correct dose *as soon as possible* during a migraine attack, and take an additional reduced dose "if pain becomes unbearable"). In pain disorders, common analgesics have frequently proven not very effective in clinical trials. Nevertheless, on a daily basis we see children at our outpatient clinic who have been taking analgesics for months or even years even though the desired effect has not been seen. They argue: "I fear my pain will become worse if I stop taking the medication".

This fear of increased pain when stopping medication makes them accept the risk of severe adverse effects. Frequently, the children become physically addicted (e.g. with opioids). During opioid weaning an increase in pain is indeed often observed. Section 4.5.4 deals especially with analgesics and their adverse effects in paediatric headache.

To summarise, neither scientific data nor our clinical experience indicates that analgesics are beneficial in paediatric pain disorders (except for acute pain).

In fact, continual and substantial use of analgesics may be an indicator for the Third Thought Trap (Sect. 4.1). Many children and their parents do not think too much about this issue (or they may not have been informed of the risks of analgesics abuse). They are shocked when learning about the possible adverse effects of daily drug consumption. Generally, we recommend limiting the usage of analgesics (e.g. if we are uncertain that there is an underlying rheumatic disease) to a certain time period. It is important to communicate this decision to the child and his/her parents, including discussion of the possible adverse effects.

A pain reduction after taking analgesics is not always an indicator of the positive effect of the drug.

To a great extent, seemingly successful pharmacological treatment in pain disorders is a brief *placebo*-effect *not* lasting very long and *not* resulting in decreased pain-related restrictions of daily activities.

4.5 The Basics of Paediatric Headache

Section 2.1.3 discussed the biological background of the most important types of paediatric headache (migraine; tension-type headache) in detail. Section 3.2.1 presented the medical diagnostic procedures necessary to exclude secondary paediatric headache. In this section, we shortly summarise the most important facts and terminologies of primary paediatric headache.

4.5.1 Primary vs. Secondary Headache

Every fifth to sixth child reports headache with a frequency of at least once a week (Perquin et al. 2000) which may be primary (headache not due to physical disease) or secondary (headache as a symptom of an underlying somatic disease). The International Headache Society (IHS) classifies headache into more than 100 different types. Fortunately, paediatric chronic headache is usually of primary origin; secondary headache is very rare in childhood and adolescence. How to differentiate primary from secondary headache is discussed in Sect. 3.2.1.

4.5.2 Paediatric Migraine with or Without Aura

About 6% of children and adolescents experience migraines (Bigal et al. 2007). Even infants may show symptoms typical of migraine that respond well to standard medical treatment. Often a migraine that is treated insufficiently, incorrectly, or not at all contributes to the development of a pain disorder with the head as the main pain location. Hence, for the planning and implementation of treatment for paediatric headache it is important to correctly diagnose the migraine with/without aura, and treat it sufficiently. The biological background of migraine was discussed in Sect. 2.1.3. Patients and their parents, however, need a much shorter summary focusing on the practical aspects of the subject.

How do you best educate a child and his/her parents on the complex biological interactions that happen during a migraine attack? In the following, you will find an example educational explanation aimed at older children and their parents.

Example: Migraine Education

> "The disposition towards migraine is inherited. Simply speaking, a child inherits a "migraine generator" from his/her parent. A migraine generator is an area of the brain where cerebral cells seem to be very sensitive to any kind of pronounced change. Those brain cells don't care about the nature of the change, be it psychological stress, a variation in hormone levels, daily schedule, sleep habit, or a change in the weather. In some children even certain smells or foods may stimulate those cells. Depending on the frequency and intensity of these changes, the migraine generator discharges in more or less regular intervals, in a similar way to a short-circuited battery. But how does this lead to pain or accompanying symptoms (nausea; vomiting; intolerance to noise or light; impaired vision) when the brain is devoid of nociceptors? The migraine generator is cross-linked with numerous brain areas. This neural network and changes in the cerebral neurotransmitters alter brain cells, the diameter of the blood vessels and their sensitivity to stimuli, so that even the blood pulsating through the vessels is perceived as pain ("pulsating" pain). Activation of the neural connections to the vomiting centre provokes nausea. You can imagine how busy the brain is with the numerous stimuli during a migraine attack. Therefore, children appear different during a migraine attack; often they become very tired, irritable, or very exhilarated."

The next step is to explain why it is important to take the analgesic as early as possible, and in the right dose.

> "The migraine attack causes chaos in the brain. Once it starts, it is difficult to interrupt it—especially as analgesics aren't quickly absorbed during a migraine attack. But if an analgesic (mostly ibuprofen) is taken at the very beginning of the migraine attack, there is enough time for the analgesic to be absorbed and transported into the brain. Luckily, this drug has the power to stop the migraine attack even before the attack reaches its peak. Thus, pain and the other symptoms of the attack are reduced and the child develops a feeling of control, resulting in less fear of the next attack, less stress, and therefore fewer migraine attacks in the long run. The child will use less medication by taking the analgesic on time because then he/she has to take them less often. Furthermore, the child will miss less school which will also lower the stress level and the number of migraine attacks."

People consistently say that a special diet is favourable in migraine. However, recent studies do *not* support this claim. The fact is that even before migraine-related headache is present some parts of the brain are dysfunctional. For instance, some migraine patients crave chocolate during a migraine attack and later develop a headache. They eat some chocolate, and when the attack is over, they think that the chocolate was the trigger, when in fact the appetite for chocolate was part of the attack. Consuming chocolate between migraine attacks (e.g. if we prompt them to do so) will not lead to an attack in these children. Children and adolescents rarely report always getting severe headache shortly after consuming a specific food (e.g. a specific type of nut, or some specific chocolate). These children are usually well aware of this relationship for a long time and avoid these foods. But there is *no* real need for a specific diet (e.g. diet free of lactose, or fructose, etc.).

We do not recommend any specific diet in patients suffering headache. Generally, a diet will lead to reduced quality of life and indirectly to a deterioration of symptoms.

It is clear that a healthy and balanced diet is good for any child independent of the presence of migraine.

4.5.3 Paediatric Tension-Type Headache

In contrast to what is seen in adults, paediatric patients often report similar symptoms during both migraine and tension-type headache. For instance, paediatric migraine is often bilateral, while in adults it is almost invariably unilateral and easily distinguished from tension-type headache. This is probably due to cerebral maturation during childhood and adolescence. At least 10% of all children and adolescents suffer tension-type headache (Anttila 2006). In contrast to migraine, tension-type headache should *not* be treated with analgesics. Frequently taking analgesics in tension-type headache increases the risk of developing medication overuse headache (Piazza et al. 2012; Sect. 4.5.4). In addition, tension-type headache is especially easy to handle using simple behavioural strategies (Chap. 9). In our experience it is sufficient for these patients to just have a few appointments for education, training of one or two psychological techniques, and educating the parents on how to react to their child's pain (Hechler et al. 2011). The following example illustrates education for tension-type headache.

Case Report: Education for Tension-Type Headache

> "Normally, tension-type headache is double-sided, of light to moderate intensity with a more or less pressing quality. Often it starts shortly before, during, or after psychological stress (e.g. having to concentrate in school; experiencing boredom), or with lack of physical exercise or poor posture (e.g. sitting crooked for hours in front of the computer playing games). Explained roughly, there is a cerebral dysregulation of neurotransmitters resulting in the perception of "too much" pain. Moving around and fresh air will lead to recovery from the pain. This table (show Table 2.1, see Chap. 2) displays typical symptoms of paediatric tension-type headache (advice: show the pain diary of the German Paediatric Pain Centre to the child and his/her parents; available via https://www.deutsches-kinderschmerzzentrum.de/en/doctors-and-therapists/questionnaires-and-diaries/pain-diaries/). Tension-type headache is one of the headaches most responsive to treatment, and it is completely harmless".

4.5.4 Paediatric Headache and Medication Overuse

In frequent headaches, a high risk of augmented use of pain medication exists. Continual or daily headaches in fact often conceal medication overuse headaches (i.e. headache of increased frequency due to the augmented use of analgesics).

Beware of medication overuse headache in any child taking analgesics for headache for a longer time (>10 days per month) (Piazza et al. 2012).

In these children, frequent analgesic use may induce cerebral changes resulting in increased pain perception (Zeeberg et al. 2009). The only way to get rid of this type of headache is a controlled withdrawal; this usually cannot be managed in an outpatient setting. The withdrawal should always be conducted under supervision of a specialised pain therapist, or in consultation with a specialised institution in order to provide adequate therapeutic support.

4.5.5 Summary

Medical examination is required for all cases of paediatric headache. Most cases are harmless, and generally accessible to treatment. Using a pain diary for close inspection is a prerequisite for sustained treatment effects. In addition to psychological and pain coping interventions, migraine also requires pharmacological treatment during attacks. It is our experience that good treatment of attacks will decrease their frequency. There is *no* proven connection between diet and headache. Since headache occurs with changes in lifestyle, experience, physical processes of the sympathetic or parasympathetic nervous systems, or neurobiological processes, there is generally a close temporal relationship between headache and the presence of psychological or social factors. This close temporal relationship will gradually disappear with increasing sensitisation or chronification until it has vanished as is the case in severe pain disorders with permanent headache.

4.6 The Basics of Paediatric Abdominal Pain

As in headache, we distinguish primary (benign, not originating from organic disease or inflammation) from secondary abdominal pain (originating from organic disease). As with headache, chronic abdominal pain is frequent in children and adolescents and mostly a primary symptom.

4.6.1 Primary vs. Secondary Abdominal Pain

For the differentiation of primary from secondary abdominal pain, the patient should undergo a detailed physical examination performed by a paediatrician experienced in paediatric gastroenterology who will decide on supplemental medical investigations according to the criteria from Sect. 3.2.2.

Functional abdominal pain is typically located around the belly button (periumbilical). The pain originates from the intestines and can be tracked down to hypersensitivity of the intestinal muscular layer induced by multiple factors like psychological stress, mucosal inflammation, hyperpermeability, phenotype changes of enteric glia cells and multiple hormonal influences as well as central sensitisation (Faure and Grunder 2017). Short-term versions of this phenomenon are well known from common sayings such as “having butterflies in one’s stomach”; “having a fist in one’s stomach out of rage”; “the way to someone’s heart is through the stomach”; or “soiling one’s pants out of fear”. These idioms reflect the close relationship between emotion and intestinal reaction or bodily sensation. Everyone knows the bad feelings in the stomach with concomitant nausea or loss of appetite just before a difficult exam.

Many children or parents are not satisfied with this explanation. They want to learn about the detailed pathophysiologic chain of events which leads to such tormenting abdominal pain, even in the absence of physical disease. Therefore, we present our disease model and our explanation for the patients and their parents here:

> The whole of the intestines, stomach included, are muscles. The stomach's task is to break up food into small pieces both mechanically and chemically (with the help of stomach acid) in order to allow food to pass through the intestines. The bowel is a very long folded tubular muscle located just beneath the belly button and ending at the anus. As with all our muscles, those of the stomach or the bowel react to hormonal stimuli provoked by all kinds of stress. One of those stimuli is the stress hormone adrenalin. The bowel is especially sensitive to these stimuli and reacts with increased muscle movements, constipation or increased flatulence (meteorism). Both strong muscular contractions and extension are very painful. Hormonal effects explain why in many anxious children just the idea of separation or anticipating a class test leads to abdominal pain. By no means is such abdominal pain just imagined or pretended. In fact, in such a situation abdominal pain is a normal reaction of the body to the emotional state and may accompany fear of any origin. Resting or passivity are not useful for pain coping, as the intestinal muscles are not "exhausted", needing time for rest. On the contrary, only active pain coping (where the child will gradually learn to influence his/her reactions to emotions) will help.

The different types of primary abdominal pain are discussed in detail in Sect. 4.6.2.

In spite of this evidence, an endless number of different diets are recommended in the treatment of abdominal pain. This approach is contradictory to the explained cause and background and also contradictory to current scientific knowledge. Diets rich in fibre show only a small positive therapeutic effect in a minority of children and adolescents with complaints clearly dependent on the type of food consumed or constipation (Huertas-Ceballos et al. 2008). A diet rich in fibre is identical to the normal nutritional "diet" recommended to all children and adults anyway.

The only reason to change a child's diet is the presence of a directly observed relationship between consuming a certain kind of food and subsequent abdominal pain. In such a case, it may be advisable to record nutrition and the occurrence of abdominal pain for a few days (*not weeks*). In children with intolerance to specific foods, we can typically observe an increase in abdominal pain and accompanying symptoms (e.g. diarrhoea, increased bowel movement, flatulence, or nausea (sometimes)) right after consuming the respective food.

During such documentation, the child should be closely guided by a paediatrician experienced in paediatric gastroenterology; otherwise there is the great risk of unbalanced nutrition and unnecessary restriction affecting the child's quality of life. In our outpatient clinic, we have seen many children on a diet free of lactose or fructose as recommended by friends, relatives, or even physicians without having undergone medically indicated tests for food allergy or intolerance. This is not only accompanied by an increased financial burden for the family but also by an impaired quality of life for the child. In most cases, the benefit of a diet free of lactose or fructose is minimal (if there is any benefit at all), but this “success” will perpetuate the diet. Since the child on a diet has to focus on his/her body and the pain in order to get to know which food in the individual case actually has any impact on the pain, pain sensitisation is one of the possible adverse effects of all these diets.

Most parents who initiate or consent to such a treatment refuse to abandon their previous explanations. Therefore, we usually arrange (together with the—in most cases—thankful patient) a nutritional “challenge” in which the patient (not accompanied by his/her parents) eats the food he/she has been avoiding for a long time. The child can check afterwards on his/her own by means of a questionnaire to see if the impairment expected by the food actually occurred.

In most cases, the re-implementation of a standard mixed “diet” rich in fibre (along with being allowed to eat sweets) does not result in an increase in pain or any symptoms at all; quite the contrary indeed, it results in a better quality of life.

4.6.2 Paediatric Functional Chronic Abdominal Pain

In the past, chronic abdominal pain was named “recurrent abdominal pain” (RAP; Apley 1958). However, that terminology did not allow for a differentiation of the various types of primary abdominal pain. Therefore, in 1999, functional abdominal pain was classified according to the criteria defined by the ROME-II conference (an international conference mainly on gastroenterology). *According to the updated ROME criteria of 2006 (ROME-III) and 2016 (ROME IV) functional chronic abdominal pain is present if abdominal pain is (1) observed for more than 2 months; (2) observed more than once a week; and (3) after appropriate medical evaluation, the symptoms cannot be attributed to another medical condition*. Functional abdominal pain can even be diagnosed when there are other defined conditions like Crohn’s disease, or ulcerative colitis when those conditions do not sufficiently explain the pain.

The ROME-IV criteria differentiate the following functional abdominal diagnoses:

1. Irritable bowel syndrome
2. Abdominal migraine
3. Functional dyspepsia, and
4. Functional Abdominal Pain—Not Otherwise Specified

For more information on definition, background, and differentiation from secondary abdominal pain, see the review by Bufler et al. (2011), or Hyams et al. (2016).

Irritable Bowel Syndrome

According to ROME-IV all three following criteria have to be fulfilled:

1. Abdominal pain at least 4 days per month associated with one or more of the following:
   (a) Related to defecation
   (b) A change in frequency of stool
   (c) A change in form (appearance) of stool
2. In children with constipation, the pain does not resolve with resolution of the constipation (children in whom the pain resolves have functional constipation, not irritable bowel syndrome)
3. After appropriate evaluation, the symptoms cannot be fully explained by another medical condition

Irritable bowel syndrome can only be diagnosed by exclusion (Sect. 4.6.1).

A large twin study ($n = 4480$) proved that both the environment and learned behavioural patterns contribute to the development of irritable bowel syndrome (Mohammed et al. 2005). Psychological factors primarily maintain or reinforce the disease (Mohammed et al. 2005).

From a biological viewpoint, the intestines of a patient with irritable bowel syndrome are more sensitive to stress, nervousness, worries, and fears, and more readily react with cramps and stool urgency compared with healthy people (Mohammed et al. 2005). Stool urgency may become so severe that many children with irritable bowel syndrome are afraid of not finding a toilet in time. These children benefit from relaxation techniques combined with psychotherapeutic pain interventions (Chap. 9).

Abdominal Migraine

According to ROME IV children with abdominal migraine must fulfil all of the following criteria occurring at least twice for at least 6 months:

1. Paroxysmal episodes of intense, acute periumbilical, midline, or diffuse abdominal pain lasting 1 h or more (should be the most severe and distressing symptom)
2. Episodes are separated by weeks to months
3. The pain is incapacitating and interferes with normal activities
4. Stereotypical pattern and symptoms in the individual patient
5. The pain is associated with two or more of the following:
   (a) Anorexia
   (b) Nausea
   (c) Vomiting
   (d) Headache
   (e) Photophobia
   (f) Pallor

After appropriate evaluation, the symptoms cannot be fully explained by another medical condition.

As in functional dyspepsia, pain related to abdominal migraine is independent of bowel movement and defecation habits. The pain is periumbilical, has severe to very severe pain intensity, and arises in attacks (similar to a headache migraine attack). Typically, pain is so severe that it is impossible for the patient to continue his/her everyday activities. Sometimes the child awakes from severe abdominal pain. Duration of an episode can range from less than 1 to more than 24 h.

According to older studies, this disease is most frequent in children aged 5–9 years (Rasquin et al. 2006). Of 600 children aged 1–21 years with chronic functional abdominal pain, only 4–5% have a confirmed diagnosis of abdominal migraine (Carson et al. 2011). Frequently, classic migraine is reported in the family. With increasing age, the symptoms of abdominal migraine change—abdominal pain moves into the background, and symptoms of classic migraine arise. This course of disease suggests that abdominal migraine might be a precursor of classic migraine (Carson et al. 2011). Pharmacological and behavioural treatment approaches are similar to ones for classic paediatric migraine. In more recent studies, higher prevalence rates have been reported and abdominal migraine was more prevalent in children >11 years of age (Scarpato et al. 2018; Bouzios et al. 2017).

In a female adolescent reporting cramp-like severe abdominal pain similar to the symptoms of abdominal migraine and starting at the age of 14, one should be cautious with the diagnosis of abdominal migraine especially if the patient's history is free of former abdominal pain attacks. In these adolescents, a history of traumatic events will often be revealed (Seng et al. 2005; Sansone et al. 2006) (Sect. 10.2).

Functional Dyspepsia

ROME IV defines functional dyspepsia as follows:

Must include one or more of the following bothersome symptoms at least 4 days per month:

1. Postprandial fullness
2. Early satiation
3. Epigastric pain or burning not associated with defecation

After appropriate evaluation, the symptoms cannot be fully explained by another medical condition.

Functional dyspepsia is a recurrent upper abdominal pain independent of bowel movement or constipation. Co-occurring symptoms are vomiting, nausea, bloating, or premature feeling of satiety. The estimated prevalence in childhood is 2.5% (Devanarayana et al. 2011). Its main cause is presumably impaired intestinal motility with delayed emptying of the stomach. In affected children, the speed of emptying is significantly correlated with the severity of symptoms (Devanarayana et al. 2011). Often, affected children suffer more from nausea, occasionally accompanied by vomiting, or from reflux esophagitis than from the upper abdominal pain. Children with functional dyspepsia seem to have an increased risk of anxiety disorders with a resulting reduced quality of life (Rippel et al. 2012). We believe that these children benefit from therapeutic interventions aiming at improving coping abilities in stressful situations in combination with biofeedback, relaxation techniques, or interoceptive exposure techniques (Sect. 9.5).

Functional Abdominal Pain

Following the somewhat confusing definitions of the ROME-III criteria, functional abdominal pain is a distinct entity, being a sub-diagnosis of functional chronic abdominal pain. More or less a diagnosis by exclusion, functional abdominal pain is characterised by periumbilical pain independent of defecation habits. Apart from an increased body awareness and a close relationship to both psychological and psychosocial factors, an enhanced visceral sensitivity seems to contribute to increased pain perception on a somatic level (Eccleston et al. 2009). According to ROME IV criteria functional abdominal pain (not otherwise specified) is defined as follows:

Criteria must be fulfilled at least four times per month and include all of the following:

1. Episodic or continuous abdominal pain that does not occur solely during physiologic events (e.g. eating, menses).
2. Insufficient criteria for irritable bowel syndrome, functional dyspepsia, or abdominal migraine.
3. After appropriate evaluation, the abdominal pain cannot be fully explained by another medical condition.

4.7 The Basics on Paediatric Back and Joint Pain

In adults, 90% of chronic backache is “unspecific”. Radicular pain is assumed to be of somatic origin in a complex interaction of neurogenic and muscular processes and inflammation (Deyo et al. 1992). In childhood, underlying simple somatic causes (e.g. disc degeneration) are very rare.

Lacking a better explanation, the weight of the child’s school bag was often held responsible for childhood back pain in the past; nowadays we know that this is definitely wrong (Kuovacs et al. 2003*).*

However, we still sometimes see children in our outpatient clinic who use a trolley instead of their school bag due to their back pain—a useless attempt often inducing teasing by peers.

While the theory that a deficit in physical activity and accompanying muscular deficits result in chronic back pain seems more reasonable, this assumption has also so far not been proven (Balagué et al. 1996; Kovacs et al. 2003). Not only too little activity, but also strongly competitive sports increase the risk of chronic paediatric back pain. The link may be an increased risk of injuries (Kovacs et al. 2003). Many patients presenting at our clinic with back pain practise competitive sports. Besides the enormous physical stress, the psychological pressure to succeed may contribute to back pain.

The current guideline “Back pain in children and adolescents” (AWMF register no. 027-00) aims to identify causes and risk factors of long-lasting and chronic back pain in childhood and adolescence with a systematic literature search.

As in headache or abdominal pain, any underlying disease should first be excluded.

4.7.1 Secondary Back Pain and Joint Pain

Secondary backache and joint pain are rarely seen in childhood. Even in adults no more than 10% of the cases have an underlying physical disease (Deyo et al. 1992). Section 3.2.3 described the important considerations for exclusion of secondary diseases.

Even if medical examination reveals a pathologic finding, this is not necessarily the only cause of pain. Carragee et al. (2005) found only a weak association between somatic findings in adults (MRI) and pain symptoms, both at the beginning of the disease and during its course. In children free of back or joint complaints, 26% showed degenerative changes, which was *not* significantly different to children with back pain (Tertti et al. 1991). In the healthy group, the most frequent pathological findings were intervertebral disc protrusion or changes of the upper and lower elements of the vertebral bodies. A herniated disc with a shift of the inner nucleus into the spinal canal constricting the nerves and nerve tracts is very rare in children. And even in those few cases, microsurgery is indicated only under special circumstances, i.e. if the pain or the poor posture continues for more than 3 months even with optimal physical therapy.

Spondylolisthesis is prevalent in about 5% of the general population. Many of the affected people have no complaints at all. Severe spondylolisthesis with pain triggered repeatedly in a similar manner is frequently seen in adolescents who train to excess in gymnastics or javelin. Treatment consists of pausing their sports and doing physical therapy to build up relevant muscles.

Scheuermann’s disease is a juvenile impairment of growth primarily of the thoracic and less frequently of the lumbar base and upper plates of the vertebral bodies. An X-ray reveals so-called Schmorl’s nodes. On physical examination we find a thoracic hump. Thirty percent of the affected adolescents suffer back pain; complaints are more frequent in the lumbar type of the disease. Treatment options are physical therapy, posture training, or regular swimming. Surgery is rarely needed.

Childhood back pain may also be caused by benign tumours or tumour-like changes, or malignant tumours. In such cases, imaging (X-ray, computed tomography, MRI) always reveals pathologic findings.

Causes of secondary back pain in children and adolescents significantly differ from those in adults. Therefore, the mentioned guideline “Back pain in children and adolescents” (AWMF register no. 027-00) will comprise a summary of different causes (so-called “red flags”) and useful diagnostic procedures.

4.7.2 The Origin of Chronic Back Pain

Apart from psychological factors (Sects. 2.2 and 2.3), passive (=avoiding) pain coping strategies contribute to pain maintenance and an increase in pain (Vlaeyen and Linton 2000; Asmundson et al. 2012).

4.7.3 Implementing Active Pain Coping Strategies

Chronic back pain or joint pain lasting more than a few weeks should *always* (even after herniated disc) be treated with active pain coping, no matter if it is primary or secondary pain. Medical diagnostic procedures mainly serve to check the indication for pain medication (analgesics are indicated, e.g. in rheumatic inflammatory disease, or in neuronal irritation in neuropathic pain) and for physical therapy. However, active pain coping is always indicated.

4.8 Gain from Illness: Fact or Fiction?

During the course of treatment of pain disorders, the parents or the physician sometimes ask if there is any gain from illness (e.g. "The only reason for the child's pain is that he/she doesn't want to go to school."), or any underlying psychological cause (e.g. "What is your *real* problem?"; or "There is something wrong within the family! Right?"). We think such an attitude originates from the First Thought Trap and *is a no-go* in the treatment of children with chronic pain.

Certainly, chronic pain may develop in a child with separation anxiety if he/she is separated from his/her parents; and certainly, there are children with acute school aversion who use their pain as a reason not to attend school. But a child with a pain disorder suffers pain even after the disliked situation is over. Not to forget, many of our patients and their parents communicate plausibly that many of their psychological problems developed in the course of the pain disorder.

Any child suffering severe pain is well-advised to try to get the most benefit out of this situation (do not forget that for the child the pain seems nearly unchangeable in stress situations). Why would any child voluntarily behave and feel worse than necessary?

It becomes clear that the concept of "gain from illness" as a cause of (simulated) pain is detrimental. It often leads to discontinuation of treatment because the child and his/her parents do not feel taken seriously. Finally, we should refrain from this mindset as it puts all children with chronic pain under general suspicion (Sect. 14.4).

In our experience, for very few children "gain from illness" is indeed an issue. But, since these children are a minority of the population of children suffering chronic pain (Sect. 14.4), we do not recommend favouring this explanation at the beginning of treatment. This would only lead to an increased risk of (an understandable) discontinuation of treatment, which will neither benefit the patient nor his/her family or therapist. On the contrary, this would be another step contributing to chronification.

4.9 Therapeutic Attitude

> *Why did you become a therapist, when you like to laugh so much?—Patricia (15 years) during her final therapeutic reflection*

Irrespective of the psychotherapeutic approach used and present symptoms, therapeutic attitude is an important part of successful treatment. There are some peculiarities with respect to the therapeutic attitude in pain disorders which are recapitulated here.

1. Pain is never of pure psychological or somatic origin.
2. Pain is the result of body signals, degree of distraction, emotional state, complex somatic processes, and pain memory.
3. It is the child who defines what is “the correct” pain perception, and not his/her parents, the physician or therapist.
4. Sometimes, pain medication is necessary and useful provided it is medically indexed (e.g. in paediatric migraine) and dosed correctly.
5. Apart from the pain, concomitant helplessness in itself results in a pronounced reduction in the child’s and his/her family’s quality of life.
6. Many emotional and interaction problems are direct or indirect consequences of the pain disorder. Problems that already existed before the pain disorder may have a negative impact on symptoms but should not be erroneously regarded as the only cause of the pain disorder.
7. A child never feigns pain in order to achieve something.
8. Sustained pain reduction cannot be expected unless active pain coping strategies are applied.
9. A humorous therapeutic attitude focusing on resources and problem solving is helpful, independent of the severity of (co-morbid) symptoms.

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Part II

The In-Patient Paediatric Pain Treatment Programme

5 When to Decide on In- or Outpatient Pain Treatment?

Michael Dobe and Boris Zernikow

Contents

Abstract

For many children experiencing chronic pain, effective treatment is possible in an outpatient setting. However, for children with a pain disorder that severely affects the patient's and his/her family's life (frequently missing school; social withdrawal), an inpatient interdisciplinary pain treatment is indicated. In this chapter, we first discuss the criteria used to determine the need and usefulness of inpatient pain treatment, then we discuss contraindications.

Severe pain disorder has a considerable negative impact on the psychological and psychosocial development of the affected child. Furthermore, if not treated properly, chronicity into adulthood can occur. Often, outpatient treatment is sufficient. In less severe cases, treatment by a general practitioner can suffice, and in more severe cases, individual or group treatment by specialised outpatient institutions is preferable (Palermo et al. 2010; Zernikow et al. 2012). But, if quality of life is already severely affected as reflected by a substantial number of missed school days as well

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M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_5

as a high emotional burden for the child and his/her parents, an outpatient therapeutic approach will probably fail and inpatient interdisciplinary pain treatment is indicated (Hagenah and Herpertz-Dahlmann 2005; Hechler et al. 2011; 2014; Dobe et al. 2011). The International Association for the Study of Pain (IASP) defines inpatient interdisciplinary pain treatment as follows:

> "Interdisciplinary treatment is defined as multimodal treatment provided by a multidisciplinary team collaborating in assessment and treatment using a shared biopsychosocial model and goals. For example: the prescription of an anti-depressant by a physician alongside exercise treatment from a physiotherapist, and cognitive behavioral treatment by a psychologist, all working closely together with regular team meetings (face to face or online), agreement on diagnosis, therapeutic aims and plans for treatment and review." (From: http://www.iasp-pain.org/PublicationsNews/NewsDetail.aspx?ItemNumber=6981)

5.1 Criteria Used to Decide on Inpatient Treatment at the German Paediatric Pain Centre (GPPC)

Our method of examining the need for inpatient pain treatment in children with chronic pain is a procedure long proven in clinical practice (Dobe et al. 2011; Hechler et al. 2014). Inpatient treatment is recommended if (1) pain-related impairment of quality of life is severe (as judged by the pain therapist); (2) the child and his/her parents are motivated for treatment; (3) they agree on at least one weekly family session, and (4) three of the following five criteria apply as checked in a previous outpatient contact:

1. Pain duration ≥6 months
2. Mean intensity of constant pain ≥5 (numerical rating scale (NRS) 0–10)
3. Pain peak with an intensity ≥8 (NRS 0–10) with a frequency of ≥2 times/week
4. Missing school on >5 days during the last 4 weeks
5. The patient *feels* severely impaired in his/her daily life (for example assessed with the Paediatric Pain Disability Index (P-PDI, Hübner et al. 2009); P-PDI-Score ≥ 36/60)

In Germany, if the inpatient interdisciplinary pain treatment is paid by health insurance, the criteria for operations and procedures need to be considered. Currently, for an inpatient interdisciplinary pain treatment with a length of either 14–20 or greater than 20 days, three of the following five criteria need to be met:

1. Manifest or impending impairment in quality of life and/or work ability, for example assessed with school days missed due to pain or a P-PDI-Score of 36 or more (P-PDI: Paediatric Pain Disability Index, see Sects. 3.3 and 3.5)
2. Failure of previous unimodal treatment, previous surgical procedure or a withdrawal treatment (Note: for example, failure of pain medication)
3. Overuse or misuse of analgesics
4. Psychological comorbidity that aggravates the pain disorder
5. Severe somatic comorbidity

5.2 Contraindications for Inpatient Treatment

The inpatient treatment programme as described in this manual is not appropriate for children suffering (atypical) anorexia nervosa, psychotic symptoms, severe borderline disorder or severe depression with self-harming behaviour (for details, see Sects. 14.2 and 14.7). If the child has a history of self-harm, endangering self or others or drug abuse, the patient and his/her parents should be specifically informed of the institutional rules to be followed before inpatient treatment can start. In particularly difficult cases, we found it helpful to invite the patient to write a letter on his/her motivation for treatment, declaring his/her consent to keep the institutional rules and testing his/her personal goals before starting inpatient treatment (see Sect. 13.3 for detailed instructions).

5.3 Advantages and Disadvantages of Inpatient Pain Treatment

Without a doubt, any inpatient treatment seriously interferes with the life of both the patient and his/her family. But it is the most reasonable treatment option if the pain disorder has led to a severe deterioration of life (Hechler et al. 2014; Zernikow et al. 2018). The necessity for inpatient treatment is indicated less by the pain itself than by the fact that passive pain coping strategies have been followed for such a long time that it has become impossible for the child to master a normal daily routine without substantial support. Often the circadian rhythm of day and night activities is disrupted due to physical rest and inactivity, resulting in pain enhancement and maintenance. Additionally, the family interaction often focuses on pain, which further maintains the pain. In such a vicious cycle, increased demands of any type—even those that must be met for successful outpatient therapy—result in deterioration. There is a high risk that recommendations will not be followed in everyday life, adding feelings of guilt to the worries already experienced by the patient and family.

Many children and their parents are stuck in one or more of the Three Thought Traps. This may impede change in the increased and fearful body awareness of patients with pain disorder, even if the patient and his/her parents are highly motivated for treatment. Furthermore, psychological comorbidities (e.g. adjustment disorder) may have a maintaining effect on pain. An outpatient treatment will quickly reach its limits when daily phone calls are necessary, because the patient is missing school or he/she is physically/emotionally not doing well. Importantly, in most cases, inpatient pain treatment is no substitute for continuing outpatient psychotherapy. It can however, create the premise for attending subsequent outpatient psychotherapy by giving the patient and his/her family a new structure to their everyday life and guidance for active pain coping.

Unfortunately, some disadvantages of inpatient pain treatment exist for the child and his/her family. As most families do not live close to a specialised paediatric pain centre, inpatient pain treatment means a substantial financial and temporal burden to the family due to time spent in travel to the institution and associated travel costs. During the course of inpatient treatment, the parents may need to visit the institution several times a week for family sessions or Stress Tests (see Sect. 11.6). Often the patient's brothers and sisters can feel neglected during the course of treatment (reinforcing the need for them to be integrated into inpatient treatment, e.g. in family sessions, if possible). Furthermore, the inpatient treatment will lead to a higher number of missed school days, a deficit which needs to be addressed. The belief that missed content can be made up during inpatient treatment is an illusion. Instead, the first 2–4 weeks of school after having finished inpatient treatment are especially strenuous, as the child must write all the missed class tests in addition to attending school as usual. This additional emotional burden is a critical test of the newly learned strategies. Although the mentioned disadvantages may be a deterrent, they should be discussed with the child and his/her parents before inpatient treatment begins to allow them to make an informed decision.

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Organisation and Procedure of Inpatient Admission

6

Michael Dobe and Boris Zernikow

Abstract

This chapter focuses on the organisation and procedure of inpatient admission at the German Paediatric Pain Centre (GPPC). We describe the first contact and the battery of questionnaires that children and their parents complete. Then, the initial evaluation and the ward visit are discussed.

Before admission to the inpatient programme at the GPPC, an initial evaluation in the outpatient clinic is required. Generally, the first contact with the outpatient clinic is by phone. At times, parents will contact the GPPC after having heard about it from friends, on the television or having read about it on the internet. Often, the patients are referred by paediatricians, general practitioners, neurologists, orthopaedic physicians or other hospitals. After contact is established, the child and parents receive diagnostic questionnaires by mail. An appointment for the first personal contact is arranged once the questionnaires are completed and returned to the clinic. Families are informed that it is advisable for both parents/guardians to attend the first appointment. The battery of questionnaires include the following (for a detailed description of the questionnaires, see Chap. 3):

1. Pain Questionnaire for Children and Adolescents (PQCA)
2. Revised Children's Anxiety and Depression Scale (RCADS)
3. Paediatric Pain Coping Inventory—Revised (PPCI-R)
4. *If trauma is suspected*: Child Report of Post traumatic Symptoms (CROPS)

M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_6

The initial evaluation at the outpatient clinic lasts between 1 and 2 h and is co-led by a paediatrician and a paediatric psychologist. During this appointment, the development and maintenance of the pain problem is discussed with the child and his/her parents (or guardians). We validate the child's and family's previous efforts in dealing with the pain and present the criteria for inpatient pain treatment. Then, we discuss the essentials of our programme: three to four individual psychotherapy sessions per week, one weekly mandatory therapeutic session with the patient's family, two stress tests (see Sect. 11.6) including attendance at the home school if possible, daily routine with normal activities and one stress day and active pain coping irrespective of mood and pain intensity. The challenge of experiencing this treatment approach and the demands of considerable therapeutic efforts may cause difficulty for the patient and his/her family at first.

Since the child's motivation for treatment is dependent on having realistic expectations, it is essential in this first appointment to provide a realistic impression of the efforts required and the successes to expect during and after inpatient pain treatment.

If both the patient and his/her parents are interested in inpatient pain treatment, they then visit the ward together with a member of the inpatient nursing and educational team (NET) in order to become familiar with the layout of the ward and the structure of the 3-week treatment (visiting hours, leisure time activities, own bedclothes, posters, stuffed animals, toys, musical instruments, mobile phones/smartphones allowed, portable gaming consoles allowed only during visiting hours). The ward visit takes between 10 to 15 min, during which all questions are addressed. The family is asked to indicate within the next week if they are interested in participating in the inpatient programme, and if so, they will be placed on a waiting list of approximately 6–8 weeks. When a place is available, parents are informed 7–10 days before, and a date for admission is confirmed.

Structure and Organisation of Inpatient Pain Treatment

7

Michael Dobe and Boris Zernikow

Contents

Abstract

This manual aims to provide details regarding the working structure of the German Paediatric Pain Centre (GPPC). Hence, in this chapter, we present some detailed structural aspects, beginning with the location and the team structure. Then, we describe the daily schedule, organisation of daily routine, structure of the ward round and the organisation of standard follow-up care.

7.1 Location

The inpatient treatment ward can accommodate 21 patients. During the 3-to-4-week treatment programme, patients live in two- or three-bed rooms. There are no single rooms available—not even on special request—in order to address, and not reinforce, the tendency for social withdrawal often observed in children with chronic pain. Interaction problems arising from the accommodation (children of different ages, social backgrounds or social competences together in one room) are utilised

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M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_7

for diagnostic purposes and are worked on in the various group therapy sessions. Patients are invited to individually decorate their rooms.

Patients are encouraged to bring posters, photographs, books, their own bedclothes, toys, musical instruments, mobile phones/smartphones, portable gaming consoles, etc. in order to facilitate familiarisation which is beneficial in light of the rather short stay.

Apart from the patients' rooms on the ward, there is a large dining room with integrated cooking facilities, a playroom, a time-out room equipped with a punching bag and a living room with television, PC with internet and gaming consoles.

7.2 Team Structure

The nursing and educational team (NET) of the Lighthouse ward has 12.5 established positions including nurses and two educators. They work in a three-shift schedule, with one nurse assigned to the night shift. In addition, nurse trainees support the NET. Apart from the NET, paediatricians and paediatric psychiatrists (3.5 positions), other medical disciplines (e.g. paediatric radiology) as well as paediatric psychotherapists (4.5 positions) are part of the permanent ward team which is supported by a secretary (0.5 position). The team is supervised by the head of the department and, if absent, by the senior physician. The psychologists are supervised by the leading psychologist and, if absent, by his deputy. Psychological diagnostics are performed by specifically trained psychologists who see patients 12 h per week. The team is supplemented by members of other pedagogic or therapeutic disciplines not exclusively working for the inpatient pain treatment of the GPPC (see Chap. 12 for detailed information on the various disciplines), including the following:

1. A music therapist, an art therapist, a body therapist and a social worker.
2. Physical therapists: There is good cooperation with the hospital physical therapy department. They work with the children up to twice a day according to the patients' individual needs (mostly patients with chronic backache, musculoskeletal pain or complex regional pain syndrome (CRPS) type I or II).

The NET cares for the patients following a primary nursing approach. Thus, for each child in each shift, there is one contact person within the team for the patient and his/her family, as well as the psychotherapists and physicians. This contact person is responsible for collecting all information concerning the patient, performing the daily therapeutic interventions together with the patient and documenting and transferring all relevant information to the next shift.

The work of the NET includes taking part in the admission session, the family sessions and the discharge session, care within the therapeutic daily life context and support in active pain management. Some team members are qualified in biofeedback or in supporting imaginary interventions.

7.3 Daily Routine and Organisation of Everyday Life on the Ward

The daily routine includes high-frequency intensive pain treatment with the following main elements:

1. Four individual psychotherapy sessions per week (during weeks without prolonged stress tests including attendance at the home school) or three individual psychotherapy sessions per week (during weeks with holidays or short stress tests; see below).
2. One family therapy session per week.
3. Two group therapy sessions per week.
4. Two stress tests (if possible, with attending home school). Depending on the distance between the family's home and the clinic, the stress test will last between 1 and 3 days.
5. One observation day for one parent on the ward once per stay.

Depending on the individual case, a child may undergo supplemental medical (e.g. blood sampling) or psychological investigations (e.g. intelligence test), use graded exercises (e.g. to increase activity or mobility), attend the clinic school (2–4 h daily) or visit physical therapy sessions. Three days a week for 90 min each, the patients have the opportunity to work through materials from their home schools under supervision of honorary teachers. In addition, the child has to take the time to accomplish his/her therapeutic homework, practice new therapeutic techniques and engage in transcutaneous electrical nerve stimulation (TENS) or biofeedback.

All sessions are embedded in a well-structured daily routine with fixed times for getting up, morning and evening rounds, "beef rounds" (where children can express complaints) as well as five meals.

In order to keep track of the sessions, in the morning, each child receives a note with all his/her individual appointments. It is mainly the child's responsibility to organise the appointments. If the child is not able to manage this organisation, this is an important diagnostic hint with respect to dealing with demands of everyday life and stressors. Those difficulties can then be worked on in additional interventions (interventions aimed at improving organisational skills are presented in Sect. 10.3).

Table 7.1 presents a prototypical daily schedule excluding the various therapeutic appointments (the latter are individually scheduled, and the exact times are given every morning).

Table 7.1 Prototypical daily schedule on the ward (without individual or family sessions)

Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
6:30 h Getting up	*6:30 h* Getting up	*6:30 h* Getting up	*6:30 h* Getting up	*6:30 h* Getting up	*7:30 h* Getting up	*8:00 h* Getting up
7:25 h Morning round	*7:25 h* Morning round	*7:25 h* Morning round	*7:25 h* Morning round	*7:25 h* Morning round	*8:00 h* Morning round	*9:00 h* Morning round
7:30 h Breakfast	*7:30 h* Breakfast	*7:30 h* Breakfast	*7:30 h* Breakfast	*7:30 h* Breakfast	*8:15 h* Breakfast	Breakfast
8:00–11:30 h School; *8:00–9:00 h* Psychomotor training, if necessary	*8:00–11:30 h* School	*8:00–11:30 h* School; *8:00–9:00 h* Psychomotor training, if necessary	*8:00–11:30 h* School	*8:00–11:30 h* School		
	9:00–10:00 h Swimming	*09:15–10:15 h* Psychomotor training	*9:30–10:30 h* Swimming		Tidying up the ward, cleaning rooms, changing bed sheets	Individual plans
	10:45–11:30 h Music therapy		*10:00–10:45 h* Music therapy		*10:00–11:30 h* Cooking	*9:00–16:30 h* Visiting time
11:30 h Lunch						
	12:10–13:00 h Group therapy session	*12:30 h* Music therapy (with the group)	*12:30–13:15 h* Psychomotor training	*12:10–13:00 h* Group therapy session		
13:15–14:00 h Break, time spent in the patient's room	*13:15–14:00 h* Break, time spent in the patient's room	*13:15–14:00 h* Break, time spent in the patient's room	*13:15–14:00 h* Break, time spent in the patient's room	*13:15–14:00 h* Break, time spent in the patient's room	*13:00 h* Start stress test	

14:00–15:30 h Art therapy; *14:00 h* Sports		*14:00 h* Sports		*14:00 h* Sports	*13:00–18:00 h* Visiting time	
15:30 h Snack	*14:30 h* Snack	*14:30 h* Snack	*14:30 h* Snack	*14:30 h* Snack	*14:30 h* Snack	*14:30 h* Snack
16:00–17:00 h Gym	*15:00–18:00 h* Visiting time	*15:00–18:00 h* Activity planned by NET	*15:00–17:30 h* Activity planned by NET	*15:00–17:30 h* Visiting time		*16:30 h* End of visiting hours or stress test
						17:00–18:00 h Swimming
17:45 or 18:00 h Dinner						
19:00 h Organisational round	*19:15 h* “Beef round”	*18:30–19:30 h* Visiting time	*18:00–19:30 h* Visiting time	*18:15 h* Sports/ self-defence		
19:30 h Evening round	*19:30 h* Evening round	*19:30 h* Evening round	*19:30 h* Evening round	*19:30 h* Evening round	*19:30 h* Evening round	*19:30 h* Evening round
19:45 h Night meal						
Sleep/quiet time	Sleep/quiet time	Sleep/quiet time	Sleep/quiet time	Sleep/quiet time	Sleep/quiet time	Sleep/quiet time

7.4 Grand Rounds

Twice per week, there are interdisciplinary team meetings lasting 2.5 h each. On the other 5 days, there are smaller rounds.

The permanent ward team (Sect. 7.2) and the various optional therapists (see Sect. 7.2) participate in the interdisciplinary team meetings. All patients are discussed, with a more extensive discussion of new referrals (approximately 15 min), including biopsychosocial and family backgrounds with the help of a genogram (Sect. 11.1). All planned interventions are recorded in the meeting notes.

A small round is held every other morning by the NET and the ward physicians to cover nursing and medical interventions. If any questions regarding therapeutic interventions arise, the psychotherapist in charge is called in.

7.5 Follow-Up Care

Strictly speaking, despite the stress tests during the stay (Sect. 11.6), inpatient pain treatment is nothing but a first preparation for the “real” pain treatment starting with the patient’s discharge. Discharge day marks the transition from the safe inpatient setting with all its intensive daily social, therapeutic and medical support into the stresses of everyday life. It is in everyday life that the child and his/her family are tested on the implementation of their newly learned active pain coping strategies in family life, with friends, in their daily activities and at school. Although they mostly succeed, unfortunately, this is not always the case (for treatment evaluation, see Chap. 16). Generally, patients visit the outpatient clinic 3 months after discharge for re-evaluation. Since the child and his/her family often establish a therapeutic relationship with the primary psychotherapist, this therapist *always* participates in follow-up appointments. During these appointments, the child and his/her parents decide whether a further follow-up appointment at 6 or 9 months after discharge would be considered useful. If the child and his/her family are able to implement the learned therapeutic interventions well into everyday life and/or contact with a primary care psychotherapist is established (Sect. 13.2), the family decides only to schedule another outpatient appointment in the event of pain escalation.

In the event of a pain escalation after inpatient pain treatment, patients can obtain appointments on short notice after talking to their primary psychotherapists (there is a quota of emergency appointments provided at the outpatient clinic). Since therapists know the individual problems, pain symptomatology and family dynamics, often a second inpatient treatment can be prevented by refreshing the strategies proven helpful during inpatient treatment. If indeed a second inpatient treatment seems necessary, motivation for therapy and readiness to change is tested beforehand using the interventions outlined in Sect. 13.3 (special case: readmission).

Inpatient Pain Treatment: Module 1 (Presentation, Setting Goals, Education)

8

Michael Dobe and Boris Zernikow

Stupid brain!
—Linja (12 years) during her education

Contents

Abstract

This chapter discusses general information that is provided in the first session regarding presentation, therapeutic setting and realistic goals. We then describe how the vicious cycle of pain can be introduced and provide specific recommendations for children and families with pronounced somatic fixation.

Education in the biopsychosocial model of chronic pain is a basic module of pain treatment. Starting with further interventions is not useful until the patient has understood this basic concept. This does not usually take more than two sessions.

At the beginning of the education session, the psychotherapist should introduce him-/herself and the therapeutic setting. The child's primary psychotherapist should address the patient by his/her first name and introduce him/herself giving his/her full name, age, professional development and experience; it may also be appropriate to provide information on the psychotherapist's family situation and his/her main

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M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_8

professional interests. We agree with the opinion, in trauma treatment, for example, that a reserved stance has a negative impact on therapy. We therefore recommend that none of the professionals involved in treatment takes a reserved stance towards the child. From the very beginning, staff members should interact with the child, being the main client, in the way of professional service persons; and this is not only because it is ethical but also because it enhances the child's motivation to participate. Adopting such an attitude has an impact on cooperation, which is important as certain rules are expected to be followed (e.g. it is expected that the child will complete the therapeutic homework as best he/she can). We further advise against a problem-oriented approach; the problem "pain" already has enough power over the child and his/her parents. Instead, taking the patients and families seriously, strengthening their resources and renewing their laughter are important basics for treatment and decrease the probability of resistance, lack of motivation and avoidance behaviours. It might be helpful if the psychotherapist outlines his/her therapeutic approach with an example in order to give the child a chance to adapt to it and/or express concerns.

> *Example: Clarifying the therapeutic setting*
>
> "You should know that I like laughing and I like talking about your personal strengths. But I would also like to be honest with you. If you can accept this, you won't have to wonder what I might mean when we talk. At the same time, it might be quite strange for you to hear someone else's honest opinion about you. Finally, you should know that doing your therapeutic homework regularly is a prerequisite for successful pain treatment. It is not important that you can always do them easily and successfully, but it is important that you try. If the exercises are difficult or not useful, we need to discuss this. But, if you don't do your homework, the next scheduled session will be cancelled, and you will lose time. A pain treatment without actively doing exercises is useless. As you probably know, the pain doesn't go away just by talking about it. If it happens several times (usually more than twice) that you 'forget' your homework, we have to conclude that you are lacking motivation at this time. In this hopefully very unlikely event, you will receive a yellow card, just like in soccer. But, if it happens again, unfortunately that would mean that we will have to discharge you before finishing the inpatient programme."

Some psychotherapists will find such an attitude too strict, particularly clarifying the respective points within the first few minutes of the first patient contact on the ward. However, our experience with this is very positive so far. For children with ambivalent motivation, such an approach has the advantage that factors negatively influencing motivation or a strong somatic fixation ("You can't help me, because there is something wrong with me. The cause of my pain needs to be treated before I can do anything!") can be detected and addressed early in treatment.

Often, children receiving inpatient pain treatment at the German Paediatric Pain Centre have a high number of missed school days and have already undergone many different outpatient treatments and in most cases at least one inpatient treatment. Previous physicians or psychotherapists sometimes describe them as being unmotivated and reserved. However, it consistently amazes us how easily children (and their parents) make progress when the treatment encompasses humour and positivity. In our experience, a positive therapeutic attitude increases treatment motivation for most of the children with a pain disorder—and also for families with a strong somatic focus at the start of the programme.

After the psychotherapist has introduced him-/herself and the therapeutic setting, the child is asked for any positive and negative experiences with previous pain treatment and his/her resulting wishes for the current treatment. Often, children wish that the therapist avoids the use of set phrases such as "I understand this…" or "Gee, that is horrible." Or they report negative experiences with relaxation therapy. Many children expect to be informed about the therapeutic methods so that they really understand what is happening. Some children state plainly what is likely a common wish: to be taken seriously. Usually, points made here can be easily addressed, so that in the next step, the therapeutic goal (Sect. 8.1) can be set. In most cases, information provided to this point is part of the first therapeutic session (generally taking place on the first day after admission).

Finally, we want to note that children prefer a direct and transparent style of communication.

As a consequence, treatment plans, therapeutic hypotheses, clinical observations and family sessions should be reviewed and discussed together with the child.

When the child's perception ("gut feeling") differs from the psychotherapist's, the working hypotheses should be reanalysed. Nearly all children appreciate being seen as equal partners in these discussions and in treatment. Such an approach will take time (and sometimes perseverance) and depends on the primary psychotherapist being informed of all aspects of treatment. It is well worth the effort, though, as it will decrease fracturing within the team, discontinuation of treatment and lack of motivation.

8.1 Setting Realistic Goals

> *The pain should go away forever.*
> *—Nina (9 years)*

Nina's wish is understandable. But, if uncritically adopted for therapy, this would be a classic error in treatment, right from the start, for the following reasons:

- Pain is an unpleasant and universal experience that is indispensable for survival due to its function as a warning signal. While this can be easily understood for acute pain, it is not obvious at first glance for chronic pain. Chronic pain is not, or at least not alone, signalling a somatic impairment. However, it is a signal that the patient's life is developing in an undesirable direction and that something needs to be done (e.g. changing to a more active way of life or better coping with stressors).
- If the goal is to be "free from pain," the patient will continuously perceive even the slightest pain as very disturbing, because "it is still there." This will make a sustained change in body awareness very difficult.

- Setting the goal to the total absence of pain is related to being stuck in the “Third Thought Trap” (“The pain must vanish at all costs”). As a consequence, any success in treatment is perceived as smaller than it actually is, and therapy might be devalued by the patient or his/her parents (“Therapy was unsuccessful since my child is still tortured by pain”). The child and his/her parents are at risk to get really stuck in the “Third Thought Trap” and follow the radical and potentially harmful approaches arising from it.

Realistically, research suggests that a reduction of pain intensity by one point (NRS, 0–10) is perceived as a significant success by the child (Hirschfeld et al. 2014). Therefore, we recommend negotiating with the child *and* the parents to aim for a two-point reduction in pain intensity during episodes of pain.

8.2 Education: The Vicious Cycle of Pain

Before starting with education on chronic pain, the difference between acute pain (e.g. due to tissue damage) and chronic pain needs to be explained. The following explanation is suitable for any 13-year-old adolescent with average intelligence:

> *Example: Education in acute pain*
>
> “We all know pain. Mostly, pain is a sign of injury or of another illness (e.g. cold, flu) or inflammation (e.g. infected wound, otitis media). Usually, this pain will vanish even without any effort, since the body can heal small injuries or infections. Sometimes, pain medication is helpful (e.g. with otitis media). This kind of pain is referred to as acute pain. It is caused by external or internal damage to the body.”

Although pain arises from physical damage, it is important for the child to understand that *only* our brain generates pain perception. Even with a burning pain in our hand when touching a hot stove, the pain perception is exclusively generated in one specialised cerebral area. The following explanation illustrates that pain perception is performed exclusively in our central nervous system:

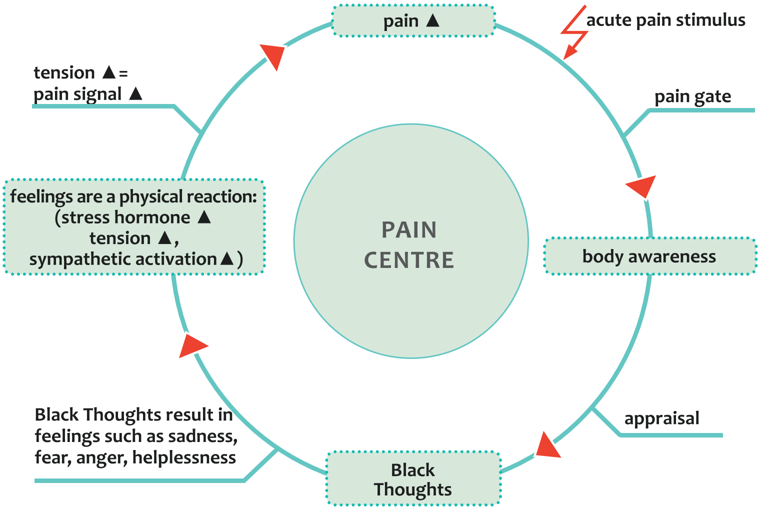
> *Example: Introduction of the pain centre*
>
> “In our example of the hand touching the hot stove, the pain signal is transmitted along neural tracts in our hand via the spinal cord along other neural tracts to the brain. This process is comparable to a telephone line. Much simplified, the pain signal is transmitted via several hubs to a type of ‘pain centre.’ In this centre, which is named the ‘somatosensory cortex,’ the whole body, from head to toe, is mapped like a topographic map. The somatosensory cortex comprises multiple subareas, just as if there was a separate office for each part of the body. Each office is directly connected to one distinct part of our body. The more important a body part is or the more complex the tasks it performs, the larger the office is. For instance, a pain signal originating in the hand is transmitted to the office that is responsible for the hand in the ‘pain centre.’ Together with other cerebral regions, this office triggers the perception of pain. This process takes some time. But sometimes our body needs to react faster, to, for example, pull away the hand from the hot stove. You probably have experienced that first the hand is pulled away, and only then you perceive the pain.

> But how can the body react faster than the 'pain centre'? Just imagine that the pain signals in the hand are transmitted to the spinal cord via telephone lines (neural tracts), before they reach the brain (note: the therapist should demonstrate the pathways from the body to the brain with his/her hands). The neuronal connections in the spinal cord are not able to 'think,' but they can elicit actions, such as making your hand retract. The perception of pain caused by the 'pain centre' will then make you more careful in the future. As you can see, due to this acute pain, you only get a minor blister instead of a serious burn."

This explanation should be more or less detailed depending on the age and knowledge of the patient. Afterwards, it is time to discuss any questions or misunderstandings that arise. If the child has no questions, the psychotherapist should continue.

> "Now you know how acute pain is generated. But still, there is no explanation for how it is possible that you perceive pain even if there is no hot stove around or no illness. Chronic pain doesn't signal acute danger; indeed, it is no warning signal at all. Factors triggering the pain can no longer be identified, or pain intensity is poorly correlated with physical factors. The origin of chronic pain is best explained with the help of the following chart."

Now hand the chart "The vicious cycle of pain" over to the child and start explaining (Worksheet #10, Fig. 8.1).



Modified from: Dobe M, Zernikow B (2013) „Stop the pain!". A Guide for children and parents to understanding and escaping the vicious cycle of chronic pain. Carl-Auer-Verlag, Heidelberg . Printed with permission

Fig. 8.1 Vicious cycle of pain

> “The chart ‘The vicious cycle of pain’ provides a schematic description of the mechanisms generating chronic pain. Let us start at the top. In the beginning, there is an acute pain signal which is sent to our brain. It is important to know that perhaps an infection, an inflammation or a muscle tension initially caused the pain. If we pay more attention to bodily signals, or the pain signal is just strong enough, it is considered ‘important’ by our brain and is consciously perceived. This, in turn, means that there are a lot of pain signals we are never aware of. I’m sure you can remember a time when you suddenly noticed a bruise or a small scrape that you didn’t notice when it occurred. This may even be the case with more severe pain signals. Sometimes, football players are fouled and injured during a game, but can shortly afterwards focus on the ball and their opponent again, even though their body is still sending strong pain signals to the brain. I am sure you can imagine other situations when the pain signal is reaching the pain centre only weakly, or not at all, because of distraction (ask the child for one or two examples). The most important question is: How is this possible? And why is this important to your pain?”

At this point, you should carefully check that the child fully understood everything. Some of the children have their own interesting ideas concerning the last question. This is a good way to get to know and validate the child’s resources. But, since most children are not familiar with the mechanisms underlying chronic pain, it is advisable that the psychotherapist answers the question him-/herself.

> “Pain inhibition is possible because the brain is able to choose to focus on or ignore things. The more attention we pay to our body, the stronger the body perception and thus the pain perception. Imagine you rush to school in the morning and bash your knee on your desk. Most probably, you won’t notice it. Do you have an idea why this pain inhibition is ‘installed’ in our body, why we can switch off acute pain, when necessary? (Give the child time to think about it. Some older children may find the association themselves, a good opportunity to value the child’s comprehension.) Actually, this has its roots in the Stone Age, a time without doctors, smartphones and little free time. Life was all about surviving the day, hunting food and defending your home. Imagine these people not being able to switch off acute pain in emergency, such as fighting with a mammoth or a sabre-toothed tiger. Mankind would probably not have survived! Nowadays, we rarely meet mammoths or sabre-toothed tigers, but more often we meet people we don’t like. Additionally, we have a lot of leisure time and don’t have to struggle to survive. We have a lot more time for thinking, which is not always beneficial. If you lie down with severe pain, doing nothing else but focusing on the pain, you will perceive your pain more intensely than when you are distracted. Everyone who has had the flu knows that. This is how it is normally, but having a pain disorder makes everything different.
>
> This is what happens: Although you are distracted (you are meeting friends or playing games), you more or less continuously perceive the pain. You may even wake up in the morning and know for sure that you had pain even while you were sleeping. For children with a less severe pain problem, their permanent pain may be influenced by external factors (e.g. class test, quarrel, DVD night with friends) or distractions (e.g. music, movie, games). Children with severe pain disorders perceive their pain as unchangeable by any situation or thought. It is important that you understand that this process can easily be explained, though not when a severe bacterial or viral infection, inflammation, cancer or other disease is the cause of pain. Actually, we know that exactly the opposite applies: the more pain cannot be influenced by any external factor and the longer the pain persists, the higher the probability that it is not caused by one of those underlying somatic diseases (infection, inflammation, cancer, etc.). How do we know that? Because viruses and bacteria multiply, inflammations spread, a tumour grows and all other diseases cause a high number of symptoms overtime. Of course, our body is not inactive, and our immune defence fights these symptoms. Mostly,

> it is very successful: You get sick, you notice symptoms and your body heals on its own (as with a cold or flu). Your body can even heal inflammations on its own. Only if your body is overstrained, your symptoms will increase, and you will see a doctor. You probably notice that this has nothing to do with your pain. If you had a severe inflammation, you would not only experience pain but many other symptoms as well.
>
> Of course, there was a point in your life when your pain began. And at the beginning of a chronic pain condition, we can often identify an infection, inflammation, another disease, muscle tension or an accident (note: here, you should show an interest in what might have been the patient's biologic trigger). But those somatic processes tend to either worsen or heal. Viruses, bacteria and inflammation could certainly not permanently cause pain over several months or years while not showing up in medical tests. Furthermore, acute pain caused by infection or inflammation can easily be influenced by factors such as distraction.
>
> Before I proceed with chronic pain, I would like to ask you whether you have any questions. What about you? Can you still change your pain, or has it already become inaccessible? By how many points can you lower your pain intensity under best conditions (great movie in the cinema, holiday with your best friend, going for a horseback ride in the forest, thrilling computer game, etc.)? Are you still worried that an unknown somatic disease is underlying your pain and complaints?"

After all questions are satisfactorily answered, a summary is provided of what has been learned so far on the vicious cycle of pain.

> "Well now, how can we explain chronic pain? As you see on the chart (Worksheet #10, Fig. 8.1), the pain has started somehow. It doesn't come out of nowhere just to bother you. As you know by now, the degree of body awareness is of great importance. Depending on what you are focusing on, you perceive your pain as more or less severe, or you may not notice it at all. That mechanism can be compared to a gate. Let us call it the 'pain gate.' If you are well distracted, the gate is kept closed or opens just a little bit, so that you perceive a small amount or no pain. But if you aren't distracted or if you focus on your body, the gate is wide open, and you perceive your pain more easily. You are here because you feel your pain almost permanently. Why doesn't the pain gate close anymore? How did that happen? In order to understand what's going on, we should follow the vicious cycle up to the step called 'appraisal' (see chart). What does that mean? Human beings tend to think a lot, maybe too much sometimes. We evaluate everything that happens. We think about anything that comes to mind, our pain included.
>
> I suspect you worry about your pain, rather than thinking, 'Hey, it's fine. I am finally in pain. I am really glad it is here.' Otherwise, you wouldn't be sitting here with me right now, would you? (Wait for the child's – in most cases – unambiguous reaction.) Okay. I don't know you well; but many of the patients report thinking, 'Why me?' or 'Oh no, not again! Will it ever stop?' or 'With the pain, there is no joy left in my life' or 'I can't stand it any longer' or 'If I don't lie down, the pain will definitely increase.' Maybe you have had these or other thoughts (wait for the child's reaction). As you have already noticed, these thoughts don't make things better. As time goes by, there are often more of these and other even more negative thoughts – we call these 'Black Thoughts.' Many of our patients describe this as a feeling of falling into a pain 'pit' from which they find it difficult to escape by themselves. Typical Black Thoughts are 'All this doesn't make any sense,' 'Damn, no matter what I try I can't focus anymore,' 'I can't go on like this' or 'It makes me mad.'
>
> Our brain is programmed to associate things that are similar. Therefore, it is likely that irrespective of our pain and the associated Black Thoughts, further Black Thoughts arise that may be related to our pain (e.g. former painful injury or surgical procedure) or sometimes not pain related at all. Actually, severe pain combined with Black Thoughts may well trigger stressful and traumatic life events *and* vice versa, *if experienced*.

> Hence, it is essential to consider how we judge our pain. According to our experience, it is likely that you will remember any stressful or traumatic life events together with the Black Thoughts during episodes of severe pain, if you have experienced such events. Severe pain perception can trigger memories of a painful surgery, an accident or the death of a loved one (note: when physical or sexual violence is suspected, the therapist should add: 'Some children report that they remember bad things they would actually like to forget. This makes them feel very bad. Do you know this, too?'). If this happens repeatedly, the association is learned (note: classical conditioning); and memories, thoughts and pain mutually trigger and maintain each other. Have you personally had similar experiences?"

This is the time to check if the child reports associations of Black Thoughts and memories and resulting increased emotional distress. If this is the case (even if the child simply nods with an inward gaze), we recommend responding "Yes, you seem to know," then proceeding with the education and exploring the associations in the next session. Otherwise, this bears the risk of focusing on possible psychological comorbidities too early and losing the focus on the so far successful education. This could confuse the child. Only if the child starts reporting situations and memories, the child's need to communicate comes first.

The next part of the education deals with the associations between thoughts, appraisals, emotions and the resulting somatic responses.

> "Black Thoughts alone don't worsen the pain; otherwise, there would be many people walking through life and screaming in pain. That is not the case. However, if Black Thoughts accumulate, our mood tends to darken; and depending on individual appraisals, helplessness, sadness, anger or fear may become the predominant feeling(s). This means that Black Thoughts result in negative feelings. Feelings are named feelings because you can (wait for the child's reaction) *feel* them. A feeling always includes a physical response. For instance, if you are totally relaxed with your heart beating smoothly and regularly, this shows you are free of fear. But you can't feel happy if your body is tense or if you frown and look angry."

A fun and vivid way to do this part of the education is to try together with the child to provoke feelings contrasting the bodily situation: sit down very relaxed—also relax your belly—and smile and simultaneously try to get angry but stay relaxed, or try to think about happy experiences while frowning and clenching your fists. The next section illustrates how the resulting stress reaction leads to intensified pain.

> "In the end, all those negative feelings are based on a physical stress reaction which will arise whenever something threatens our personal well-being. Sometimes, it is enough to not be in the mood to perform an activity (e.g. housework or homework) and to have to force oneself to get it done. This stress reaction will be even stronger when negative thoughts or bad memories are present or even when you have negative appraisals. Of course, stress reactions differ in their intensity. It is essential to understand that *each* Black Thought and *each* negative appraisal will result in a small to large somatic reaction depending on the intensity of the thought. These stress reactions will then lead to feelings such as fear, helplessness, sadness or anger. Brief stress reactions are totally normal; everyone has Black Thoughts every day. However, some people don't pay much attention to their thoughts and don't notice them. But each and every person thinks about something all the time. These

> thoughts are responsible for most of our bodily reactions. What about you? Do you perceive your thoughts, or do you have trouble with this?
>
> However, much more problematic than isolated Black Thoughts or brief stress reactions are *prolonged* ones, meaning that the stressful situation or the negative thought and appraisal is ongoing. Pain itself will contribute to a stress reaction. It is, however, essential to know that not the pain itself but the appraisal of the pain is the main cause of the stress reaction. We have met children with incurable diseases who can do anything they want despite the pain, although this may harm their body. Other children have painful muscle tensions and avoid all stress, because they have realised that stress has a negative effect on pain. How is this possible? What different appraisals characterise these children? And what about you? What makes a prolonged stress reaction so unfavourable, apart from the increased muscle tension, is its ability to cause pain sensitisation.
>
> What does this mean? It means that the same physical pain signal will be perceived as more intense; the body has become more sensitive to pain. The sensitisation can be compared to a highway being broadened from two to three lanes in order to make the traffic flow better (or to improve processing of the pain signal). The pain signal is on the fast lane and always has the right of way. In the 'pain centre,' the enhanced pain signal provokes an intensified pain perception. Former pain experiences may lead to a further increase in pain.
>
> From that point on, everything depends on how much I anticipate my pain or how much I see the pain as a threat. The more I anticipate my pain, the easier the pain gate opens; and the more I worry about my pain, the more pronounced the resulting physical reaction is. In the end, the result is the same: pain is perceived more strongly due to the increased activity of the pain centre. We are alarmed. Chances to focus even more on the painful area of the body increase, opening the pain gate wider. Consequently, body awareness will increase, and all fears and worries (Black Thoughts) are confirmed. The next round of the vicious cycle has begun. This process explains why it is more and more difficult for us to inhibit pain. Actually, the brain has a protective function and is able to stop pain with the help of its own internal painkillers. This ability can be traced back to the daily struggle to survive in the Stone Age. Back then, an injury in a fight or in the wilderness would have meant certain death if even severe pain could not be inhibited. But, if I focus attention on my body or worry due to pain or am passive and rest a lot (note: use the statement that best describes the child), my brain cannot make use of its own protective functions, and the vicious cycle will go on. In the end, the cerebral pain inhibition will be switched off, and the vicious cycle will turn more quickly."

At this point, the child should summarise the essential points of the education in his/her own words. Most patients already know the vicious cycle from their own experience; therefore, the task is not too difficult, and they won't need to ask many questions. In the last section of the education programme, we sketch the mechanisms of how chronic pain can turn into a pain disorder affecting all areas of life.

> "If the vicious cycle repeats itself (three months with pain on most days will suffice), pain memory starts to be consolidated. The same way our brain stores memories of a wonderful holiday, foreign language vocabularies, memories of a funeral or the result of 100 minus 53, it will also store (learn) pain – and it does this rather effectively. Once pain memory is established, it doesn't matter anymore at which point of the vicious cycle the process starts. Your mother or grandmother asking "Are you in pain?" will be sufficient to start the vicious cycle, even if up to that moment you were free of pain or not aware of it. Many children report that even a concerned look can start the vicious cycle. Negative feelings (anxiety, sadness) or muscle tension due to distress or physical (in)activity may activate the cycle, even if they are not associated with the pain. Overtime, the pain memory is consolidated until pain has become permanent, small signals evoke severe pain and the pain gate is

> always open. The pain becomes more and more independent of bodily processes outside the brain. Slowly, the body awareness will increase, and at the same time the ability to be distracted will decrease. In the end, the pain is permanent and very strong, and there is no way to influence it anymore.
>
> In addition, parents or friends worry about you and will remind you of your pain by asking you about it. Recommendations to rest or lie down are useless and even reinforce the pain. The search for a somatic cause of the pain along with many doctor's appointments and various investigations make you more and more focused on your body. And since the one and only 'cause' cannot be found, both Black Thoughts and passive pain coping increase. Moreover, many patients worry about their parents, who suffer from pain themselves. Or the family atmosphere may have become tense and unhappy. Of course, all this has an additional negative impact on Black Thoughts and body tension. Unfortunately, often the parents' worries will turn into irritability, and parents may start reproaching or querying pain (note: see Fales et al. 2014). What about your parents? Do they both behave in a similar way? Have you ever experienced thoughts like 'It's my fault that my parents feel so bad'?."

At this point, you should review and discuss with the child how far his/her pain disorder has advanced. A lot of information was given, and you should offer time for further questions. If the child has no questions, the psychotherapist should ask, and answer, the most important question of all: "Will this pain processing remain unchanged, or can we do something to change it?"

> "No, this pain processing does not have to remain the way it is now. It can change, since our brain has the ability to change. Fortunately, you are still young. Your brain is learning much faster than that of an adult as you may have already seen with your parents. The premise for change is that you understand that chronic pain is an independent disease, which you can influence by altering attentional processes, appraisals and physical reactions. In conjunction with active pain coping (doing a lot of activities despite pain), your intrinsic cerebral pain-inhibiting system is reactivated, and distraction and periods free of pain become possible again."

If some of the older children (especially if intellectually gifted or very concerned about their body) wish more detailed education, we recommend explaining neuroanatomy with the help of charts (e.g. see Chap. 2, Fig. 2.1).

Regarding education on a neurobiological basis, these are the four essential points:

1. The patients should understand the limbic system and its importance for pain reinforcement. The limbic system is primarily responsible for the fight-or-flight response. Some of the pain pathways reach the limbic system. An increased activation of the limbic system is thought to be associated with an increase in pain (for pain patients). For instance, when I worry about pain, pain signals will be enhanced. Unfortunately, this is also the case when I worry about something else or when I am anxious or feel threatened. Conversely, the pain signals will diminish when I feel safe. At the end of the education, it should be clear that due to the operating principle of the limbic system, a purely somatic-oriented treatment of chronic pain is not useful.
2. The patients should understand that the thalamus is responsible for the perception of all bodily signals ("pain gate"). It filters these signals, so that not

all signals are consciously perceived (selective attention). To manage this, the thalamus needs information about the importance of each signal which is provided by the prefrontal cortex. Roughly speaking, the prefrontal cortex is responsible for managing conscious attentional processes. Due to its "filter" function, the thalamus is important for pain perception. A high bodily awareness will make the thalamus more aware of pain signals. When the patient is passive and there is no distraction, there is not much to "filter," and more pain signals are consciously perceived.

3. Education concerning the somatosensory cortex comprises information on neuronal plasticity. The patient needs to understand that frequent activation of neural networks that are responsible for pain perception will lower the threshold for activation. This will lead to central pain sensitisation. Even weak bodily signals from pain regions may then elicit pain perception, although they were not associated with pain before the pain disorder. Many patients report that even slight pressure (such as a low TENS level; see Sect. 9.4) can elicit severe pain. In the end, no input is needed for the neuronal networks; they are permanently activated. Patients will notice that their pain perception is independent of situation, mood or muscle tension.
4. Whether the thalamus allows pain signals to pass through to consciousness depends on the danger and unpleasantness that is attributed to them. This appraisal process is thought to be associated with activation of the anterior cingulate cortex (ACC). This part of the limbic system in turn affects the thalamus. The more the pain signals are perceived as threatening, the more the pain gate in the thalamus opens. This mechanism explains why people with a painful underlying disease who accepted pain as part of their lives may perceive less pain (and suffer less) than people who fear that their pain is a symptom of a dangerous disease. Unfortunately, the pain gate also opens if one gets upset about the pain, although it is clear that there is no dangerous underlying disease.

At the end of the education programme, the children should be familiar with the biopsychosocial dimensions of the vicious cycle of pain. Interestingly, knowing this background makes it possible for many children to step back from their dualistic world view (somatic vs. mental pain) and the Three Thought Traps.

After this first education session, the child's homework is to summarise the theory in his/her own words with the help of the chart. This is essential in order to have a good idea of what was really understood. A basic understanding of the topic is an absolute prerequisite for a successful sustained treatment. According to our experience, even children with learning difficulties or dyslexia will do their homework if it was discussed as part of the therapeutic session at the very beginning of the education (see earlier in the chapter). In addition, the child should make brief notes on what he/she has tried so far to distract him-/herself from pain (→ interruption of body awareness), which Colourful Thoughts he/she has tried (→ interruption of Black Thoughts) or which technique he/she has tried to relax (→ interruption of muscle tension).

The child is explicitly told to note all efforts undertaken irrespective of their effectiveness. In addition, patients are asked to read pages 16–39 of the advisory book *How to Stop Chronic Pain in Children: A Practical Guide* (Dobe and Zernikow 2014). These pages include a clear and comprehensible summary of the main parts of the education for children and adolescents. Furthermore, the children are asked to watch the educational movie (if possible together with their parents) *Understanding Pain—and What's to Be Done about It in 10 min* (available in more than 25 languages at our website: www.deutsches-kinderschmerzzentrum.de/en). This homework is a good basis for evaluating treatment motivation and deciding which pain coping strategies (Chap. 9) are the best to begin with in this patient. The following written summary is the homework of Rabea, 14 years old, average intelligence (IQ) 105, and illustrates the amount of information a child can typically learn in one session:

> *Example: Rabea (14 years), pain disorder, underlying migraine*
>
> "Pain results from transmission of signals. The pain signals reach the brain along neural tracts and have to pass a gate where they either ricochet or pass. The gate determines the intensity and the amount of pain that may pass. How much pain will pass depends on current body awareness. When we focus on our body, pain is stronger than when we are distracted. Pain may be relieved or enhanced by joy, anxiety, good memories or bad ones, as well as by muscle tension or relaxation. All this happens simultaneously and the pain is generated within the brain, in its pain centre. The pain centre memorises the pain. So, if similar pain signals reach the brain repeatedly, the brain assumes that it is much easier to continuously produce pain than to transmit each signal individually. This is how chronic pain is generated, even if no pain signal reaches the brain anymore."

8.3 Somatic Fixation: Pain-Related Fears and Anxiety Sensitivity

But I do feel that there is something real. This can't be just imagination.
—Mirjam (16 years)

The education session, as described in Sect. 8.2, will be sufficient for most children and their families to be motivated for pain treatment irrespective of the severity or chronicity of symptoms. However, in families with pronounced somatic fixation, education is a big challenge, as they have a selectively distorted perception of bodily signals and fear a malignant somatic underlying disease.

People with a tendency towards somatic fixation do not necessarily doubt the truth of the education or the process of modulating pain, since the relations are familiar to the child and the family from everyday life experiences. Rather than having a problem with the pain itself, they worry that the pain is a symptom of a threatening somatic process. As long as the child and the parents are stuck in this assumption, pain treatment doesn't make sense and will not be successful. Therapeutic interventions should not be implemented before the pain education is understood and somatic fixation is reduced. The following section is on the special educational needs necessary to build up a trusting relationship with a child and his/her family with somatic fixation.

8.3.1 Supplemental Background Information on Chronic Pain

Acute pain alerts the body to make us quickly realise potential threats and initiate action to eliminate the cause of pain and thus relieve the pain. Hence, pain is always accompanied by feelings of fear and threat. In a child, the degree of increased pain-related anxiety is determined by three processes. These are attention to the pain, the amount of pain-related catastrophising and pain-related behaviour. The most important facts are summarised as follows:

1. Any acute pain signal results in increased *vigilance and attention* to that signal, as it is perceived as a potential threat. Any acute pain signal will interrupt attention to other signals (Crombez et al. 2005). Crombez et al. extensively investigated hypervigilance towards pain signals and concluded that it is outside conscious control and results from threat perception and activation of the limbic system.
2. People differ as to how much they direct their attention to painful stimuli. Thus, apart from genetic and social factors (see below), intraindividual factors likely influence the extent of pain-related hypervigilance. According to our experience, three intraindividual factors are primarily important. First, *early pain experiences* may determine sensitisation to and focusing on painful stimuli (Hermann et al. 2006; Hohmeister et al. 2010). These may be accidents, painful surgical procedures, physical violence or many painful medical procedures. It is essential that these experiences were associated with a significant level of helplessness and anxiety. This teaches the brain that pain is dangerous and alarms it. Second, people with a *high emotional burden* seem to perceive pain more easily and as more threatening (Jenewein et al. 2016). This high emotional burden may arise from feelings of helplessness with regard to memories, current stress or future challenges and a lack of resources to change. This results in a tensed and alarmed state of expectation and will lead to emerging pain (due to the high physical tension or physiological activation or irrespective of it) being seen as a threat. Finally, some patients seem to perceive physical processes in their body more easily and as more threatening (*anxiety sensitivity*—a fearfully increased body awareness). Increased anxiety sensitivity is believed to result from genetic factors and learning processes and is closely associated with fear of pain. Martin et al. (2007) were able to demonstrate that premorbid anxiety sensitivity is a predictor of fear of pain.
3. *Catastrophising*—the habitual and fast appraisal of a situation as extremely threatening has become the central construct for the understanding of cognitive processing in patients with chronic pain. In many investigations, catastrophising

was a significant predictor of pain intensity and functional or emotional impairment (Sullivan et al. 2006). In studies with children and adolescents, those with increased catastrophising relating to a painful event reported more severe pain and impairment (Crombez et al. 2003).

4. Not only the child's but also his/her *parents' catastrophising* has a great impact (Goubert et al. 2006). The latter is significantly correlated with the patient's pain perception and impairment. Perhaps parental fears lead to increased parental distress which is interpreted by the child as a warning signal ("If my parents are concerned, the situation must be precarious"), resulting in increased anxiety and impairment of the child. Although parental worries are understandable, they have the "side effect" that parents will monitor their child more closely. In terms of classical conditioning, the child will associate the worried (or sometimes irritated) parental look with the pain perception, which will intensify the pain. According to Eccleston and Crombez (2007), the *daily worry* about existing pain is also important for treatment. These authors see these worries as a chain of negative thoughts and the precursor of catastrophising.
5. The degree to which *pain-related behaviour* predicts the pain perception of children or adolescents is explained by the "fear avoidance model" of Vlaeyen and Linton (2000) which was validated for paediatric pain (Asmundson et al. 2012). Pain as a potential threat leads to increased anxiety and tension. Cognitive processes such as fear of pain may result in situations or movements being erroneously considered as threatening. Those (wrong) appraisals lead to avoidance of these situations or movements in order to evade the pain. Particularly in patients with backache, such behaviour will result in increasingly restricted mobility and even more pain in the long run.

According to the theory of Vlaeyen and Linton (2000), the fear of pain has more impact on the patient's life than indeed the perceived pain itself.

But what are the practical consequences of all this theory for the education session?

8.3.2 Education for Families with Increased Somatic Fixation

It is important for children and parents with somatic fixation that all their perceptions and fears are taken seriously. From a psychotherapist's viewpoint, it is important to validate the somatic observations but at the same time refuse the underlying irrational assumptions (malignant disease; all physiological symptoms imply disease). This may be a challenge since every child knows at least one case from the family, the newspaper or TV in which a malignant disease was not recognised in time. Counteracting these fears, by recognising them as being normal, may help to avoid any unhelpful conflict about the "right" perception. Most patients will usually be willing to follow the pain education supplemented by the information above. Asking the child to explicitly scrutinise the information with respect to his/her own case will motivate him/her to continue to work. As a next step, we discuss the child's own biological concept of permanent pain. If he/she has a sense of humour, it is quite easy to quickly find a common basis, as the following example will illustrate:

Case report: Dustin (age 15 years), pain disorder with abdominal pain

> "I mean… how could it be possible? There cannot be viruses or bacteria that spread so much that it permanently causes the same amount of pain. Then, it can't be a tumour or inflammation. What kind of tumour or inflammation would not grow or spread? Any tumour grows, increasing in size, causing more and more pain. Any inflammation either gets worse if the body can't stop it, or is extinguished or at least attenuated by the body's immune system. Sometimes inflammation may change like waves. But it will never remain at the same biological level for long, provoking stimuli of constant intensity. Did you ever think about that? And to be honest, your body would fight against it and not just wait while thinking 'How lovely, a tumour or inflammation!' Of course, it is true what you say or perceive. But, over time, the neural tracts in the spinal cord that transmit the pain will change. Additionally, the brain will become more sensitive to pain, so that equal pain signals will be perceived as more and more intense. Even if the highly improbable case is true and there is still a small, undetectable inflammation in the body – did the search for it so far help you in any way to better deal with the pain? Was the benefit worth the effort? Or wouldn't it be better to at least be able to alter the pain irrespective of its cause? And honestly, what's the use in resting all the time? It will only lead to less feelings of success, but more physical decline, muscle tension and poor posture."

Questions aiming at the cost/benefit ratio are easy to understand by the affected children.

> "Do you think it would hurt you to let go of 'the search for the origin of your pain'? Various investigations have shown that currently your body does not seem to be endangered."

Even if no question about the child's physiological processes and their interactions with body signals was left unanswered, we have to acknowledge that there will never be 100% certainty in life, as some of the smart children will point out. In those cases, it has always been helpful to ask the child to make a list of pros and cons with respect to a so-far-undetected severe somatic disease being responsible for the pain. This task ends with a decision as to which way to go and which way is worth living. This decision should be made solely by the child (or, if too young, together with the family) taking all the facts into account—try to leave your personal opinion out. If the decision is not to give up the search for "the" one and only cause (the still undetected disease), pain treatment doesn't make sense and should be stopped. The psychotherapist should never be hurt by such a decision. Instead, he/she should offer to start pain treatment when the child and the family are ready.

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Inpatient Pain Treatment: Module 2 (Pain Coping Strategies)

9

Michael Dobe and Boris Zernikow

The pain is always there, no matter what I do.
—Mirco (15 years) at admission

Contents

M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children’s and Adolescents’ Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_9

Abstract

In the following chapter, we describe the pain coping strategies we use for inpatient pain treatment at the German Paediatric Pain Centre (GPPC). The Vicious Cycle of Pain (Sect. 8.2) may be interrupted at several points. Body awareness can be altered through behavioural distraction, mindfulness strategies and imagery. Cognitive restructuring and acceptance-based approaches aim at minimising Black Thoughts. Muscle tension can be reduced by (imaginative and behavioural) relaxation techniques. Various types of exposure techniques aim at reversing the process of chronification and sensitisation by decreasing fear of pain and resulting pain catastrophising, or by reducing the association between negative emotions and related pain perception. Six to ten therapeutic sessions are required to teach these strategies. In addition, basal social competence training (group sessions) and interventions aimed at restructuring everyday life (e.g. daily schedule) are offered to patients. Transcutaneous Electrical Nerve Stimulation (TENS) and/or biofeedback therapy is undertaken with all children (except in abdominal pain) from the very beginning of inpatient treatment and is performed by specially trained staff of the nursing and educational team (NET). Pain provocation, an interoceptive exposure technique (see Chap. 9.5), is not offered until the end of the stay and not before at least one pain coping strategy has been successfully implemented.

Having clarified all questions with regard to the education sessions and therapeutic homework, and having praised the child, a decision is made jointly as to which pain coping strategy is to be implemented first. Many children report negative experiences with relaxation techniques and feel uncomfortable with relaxation itself or the associated setting. Instead, they prefer TENS or biofeedback therapy.

Although the children may only start learning their first pain coping strategies on the third day of the stay, an active daily routine (in vivo exposure) irrespective of pain is pursued by the NET starting from day one. Education and the need for an active daily structure should be constantly reinforced during the normal routine on the ward.

9.1 Techniques That Alter Body Awareness

> *Try to distract yourself!*
>
> *—A mother prompting her child with chronic pain (This is a typical but not very helpful intervention in families with children suffering from chronic pain).*

Although this prompt may seem helpful, from the child's point of view it is not. It may be seen as an expression of the parents' helplessness or irritability. Why is this prompt not helpful?

Distraction, that is, a decrease in attention towards painful stimuli resulting in pain inhibition belongs to the standard repertoire of human behaviour. Fearfully increased pain-related body awareness, combined with passive pain coping and an exaggerated tendency to catastrophise, make it more and more difficult to actively diminish attention towards physical processes. With severely prolonged pain, even the best distraction techniques (e.g. watching a thrilling movie together with a best friend) will only cause a very small pain reduction. A child telling us that the pain remained unchanged during the movie is not lying and trying to get attention, but probably adequately describing his/her experience. With less prolonged pain, pleasant activities like horseback riding, playing, or being with friends results in better distraction and pain reduction.

Before working on a new distraction strategy, you should ask your patient about his/her current ability to distract him/herself. A numerical rating scale (0 = no distraction at all; 10 = maximal possible distraction) serves this purpose best. You may ask:

> ‘Well, Jenny, how much do you think you are currently able to distract yourself? As I know, you like going to the movies with your friend or listening to loud music. Imagine you are sitting in the cinema together with your friend, you are thrilled, and the music is as loud as it can be: tell me how much your maximum distraction is then? Please use the scale from 0 to 10 that you are already familiar with.’

What does the child’s feedback imply for the therapeutic process? If a child reports a degree of distraction of eight or higher, his/her body awareness and pain perception can still be modulated. A degree of four, however, indicates that external stimuli have only little or no impact on the pain perception. In such a case, it may be advisable to introduce elements of acceptance-based techniques early in the therapeutic process (Sect. 9.3), since altering body awareness may be impossible (due to a comorbid depression or a prolonged chronicity of body awareness) and distraction strategies are not helpful. Additionally, imagery may be more useful to reduce inner tension instead of pain. But, before such a decision is made, the child should rate the benefit of the reported distraction for the pain. Sometimes, a degree of distraction as low as three is reported to be helpful.

Usually, even children with a very severe chronic pain disorder report changes in pain perception depending on the context. Basically, there are two approaches to reducing body awareness (‘closing the pain gate’). First, a reduction in body awareness can be achieved by an increased focus on cognitive or behavioural tasks so that there is no capacity left for body awareness and pain perception is reduced (distraction-based approach). Second, mindfulness-based techniques reduce body awareness by strengthening the focus on sensory perceptions ‘here and now’ (mindfulness-based approach). Both approaches take advantage of the brain’s limited ability for divided attention.

These interventions are only of limited value for children with severe depression or social phobia. For children with severe depressive symptoms, initially, only behavioural activation strategies (particularly daily schedule) are useful, because they are too preoccupied with negative thought processes. Children with pronounced social phobia are in a permanent state of devaluating introspection (→ accurately described as the ‘inner critic’ in literature). In such a state, strategies for altering body awareness may even intensify critical introspection when difficulties arise (‘You can’t even manage this, it’s embarrassing!’). In general, children with social phobia can benefit from such techniques, if they are able to question their cognitions. In this case, the therapist should be experienced with distraction strategies and mindfulness-based techniques and in building a relationship with children with social phobia.

9.1.1 Mindfulness-Based Techniques

Body awareness may be reduced by focusing on sensory perceptions incompatible with pain perception. Parents often use this technique to direct the attention of their small child to an aircraft, a balloon or the sound of a tractor, when the child has hurt him/herself and is crying. In general, it is about focusing on the present moment and on what you can see, hear, feel or smell right now. Due to differences in structuring attention, it is important to adapt the technique to every child. This will also help the therapist to get to know the child better and how he/she perceives his/her body and the world around them.

How can you effectively adapt a mindfulness-based technique to the child? The easiest way is to start with a popular technique that was specifically adapted to children with a pain disorder, the 5-4-3-2-1-technique (instructions included; Chap. 15, worksheet #8). This technique is suitable for children aged 13 years and older. After the child has tried the exercise, easy and more difficult parts need to be discussed. Some children report that focusing on seeing was easy, whereas focusing on feeling was difficult. Then the exercise should be repeated without feeling to see if this modification improves the effect. Other children have no trouble with hearing and feeling, but report that focusing on seeing was disturbing. Further modifications concern the speed (slowly vs. fast) and whether perceptions are recited in their mind or out loud. Some children prefer the structure and order of the technique (5-4-3-2-1 or 3-2-1), other children dislike the given structure and simply focus on ‘here and now’. These modifications may result in very different versions of the exercise (e.g. fast 3-2-1 exercise with hearing and seeing only, spoken quietly to themselves—implemented in stressful situations during the day; very slow 5-4-3-2-1 exercise with hearing and feeling, within their mind—implemented as sleeping aid or relaxation technique). You should plan on 30 min for giving the instructions as well as teaching the technique. An additional 10–20 min are required in further sessions to discuss success and difficulties. Children should try out various versions to decide which suits them best. Therefore, the child should practise the technique (at least three times a day) and should write down the time, the version and how successful it was (Chap. 15, worksheet #12). Over time, the exercise will be more and more adapted to the child, so that it matches the attentional resources of the child and feels ‘normal’ in the end. The procedure is illustrated in the next case report.

Case Report: Marlies (15 years), pain disorder with back pain

Marlies (15 years) reports that the exercise did not work very well (version: alternating sequence of seeing, hearing, feeling; speed: fast, describing the sensations out loud to herself). When discussing the exercise, it turned out that particularly the 'seeing' part didn't work (degree of distraction: 3), while hearing (degree of distraction: 7) and feeling (degree of distraction: 9) worked well. Whenever Marlies focused on seeing she lost distraction which made the whole technique less successful (degree of distraction: 4–5). In consequence, we decided to eliminate the 'seeing' part. When practising the modified technique, a distraction of seven was reached.

Another positive effect of mindfulness-based techniques is that focusing on external stimuli is also well suited to the regulation of emotions and for controlling stressful memories (e.g. for children experiencing flashbacks of traumatic events or other unpleasant thoughts; Sects. 10.2 and 14.3). That is why these techniques are also used in trauma therapy.

Other helpful mindfulness-based techniques also exist, such as mindful breathing or mindful daily routines. All of these strategies should be adapted to the needs and abilities of the child.

9.1.2 Distraction Techniques

Body awareness can be reduced by focusing on topics incompatible with pain perception. As often practised in everyday life or in the treatment of acute pain, in its simplest form, this technique may comprise remembering one's birthday or great holidays, or doing simple counting exercises. But, this is often not enough to reach an elevated degree of distraction as needed in the treatment of pain disorders.

The distraction-ABC technique has been observed to be particularly beneficial to children from about the age of eight, as it can be adapted to each child's age and abilities. The basic idea is that body awareness is decreased by focusing attention on a well-known topic. Exercises that involve language are most suitable. In this exercise, the child has to think of words on a specific topic beginning with each letter of the alphabet in ascending order. Often this is too easy for older patients, in which case they should try the exercise in descending alphabetical order. An even more complex version (requiring more attention) comprises a descending alphabetical order, in which the second last letter of the words is the searched for letter (e.g. animal alphabet: z, y, x = nothing found, w = hawk, v = dove, u = walrus, t = coyote, s = horse, etc.). Of course, the child may also freely associate all that he/she can think of concerning one topic (e.g. love, school). Most children find the exercise a bit easier when a structure is given.

Distraction-ABC may be roughly categorised into 4 levels of complexity.

1. Level 1. Easy versions: Animals, cars, horse breeds, super heroes, football players, single sentences (each sentence has to start with the next letter). More complex versions: chaos-ABC in a foreign language (the first word the child can think of for the letter), short poems in which the lines start with randomly selected letters, foreign words that end with the searched for letter.

2. Level 2. For this level of complexity, we add another sensory channel. In the ‘juke box’ for example (10–20 s of a song are imagined, with the title or artist in alphabetical order), a level 1 distraction-ABC is combined with the auditory channel. For this level, the child must be able to imagine the respective sensory channel(s) well which usually becomes clear in a resource-oriented exploration during the first two appointments. Further examples include animal video clips watched in alphabetical order or a Harry-Potter-ABC, in which the words are illustrated in small videos (as in the wizard’s newspaper in the films). Some children love going through physical exercises in their mind (e.g. one child imagined vaulting exercises).
3. Level 3. Distraction-ABCs with *two* additional sensory channels are even more complex. The favoured version is the ‘music video’ where not only the music but also the respective video clip must be played in alphabetical order (level 1 distraction-ABC + auditory channel + visual channel). YouTube videos of the favourite YouTuber are also possible. Other possibilities are to imagine alternative ends of films or watching film scenes from different perspectives. This is very popular among older children who like Fanfiction or Cosplay. A level 3 distraction-ABC can also involve daydreams.
4. Level 4. The distraction-ABC can be combined with or integrated into other imaginative techniques. For instance, the child and an imagined assistant perform a distraction-ABC together at a ‘Safe Place’ (see Sect. 9.2 for a description of ‘Safe place’).

In Chap. 15 (worksheet #7), you will find instructions for the technique, and several examples. Adolescents especially love the numerous possibilities and are eager to develop their own distraction-ABC.

The child practises the distraction-ABC with the therapist. To introduce the technique, an easy version should be chosen (level 1 distraction-ABC with animals, football players, names, …). Afterwards, the complexity can be increased according to the resources and abilities of the child. The child should then practise the exercise for homework and write down the time (to check if the effectiveness of the exercise is dependent on the time of the day), the version (keywords) and the degree of distraction (0–10; 0 = no distraction; 10 = maximum distraction). It is important to point out that the child writes down the degree of distraction and not pain reduction. The latter automatically implies a higher focus on pain once the child has finished the exercise. Additionally, children are instructed to implement the exercise independent of their pain perception to avoid a conditioning of exercise and pain perception.

Success and difficulties are discussed in the next session. It will take approximately 2 × 20 min for the child to feel comfortable with the chosen exercise. A reliable indicator of success is the degree of distraction. Usually, a degree of 7/10 is reported to be helpful. Some children also report a degree of 3–4/10 as beneficial. The degree of distraction that represents a minimal positive effect for the child should be explored. Finally, it is important to discuss how long the distraction continues after the exercise is completed. Is the pain intensity as high as it was before the exercise? Or is it even higher? Or does the pain perception stop for a couple of seconds or minutes? Or does distraction help focus on other things which lengthens its effect? It is useful to graph and discuss the course of distraction. Usually, children with a fearfully increased body awareness (and children with social phobia or pronounced perfectionism) report an increase in pain intensity so that it is as high as it was before the exercise, or even higher. Other children mostly report a longer lasting effect of pain reduction following the distraction exercise. The graphs can be used to discuss psychological factors and to validate the biopsychosocial model.

Some children prefer maths instead of language (for example, due to disorders of reading and/or writing). These children can use complex chains of numbers (e.g. $1000\text{-}1^2\text{-}2^2\text{-}3^2\text{-}4^2\text{-}5^2\text{-}6^2\text{-}\ldots$; and subsequently $1000\text{-}1^2\text{-}1\text{-}2^2 + 1\text{-}3^2\text{-}1\text{-}4^2 + 1\text{-}5^2\text{-}1\text{-}6^2 + 1\ldots$) or pascal’s triangles. If the children have good imaginative abilities, they can imagine geometrical or abstract patterns or solve complex exercises (e.g. play a game of chess or a Sudoku puzzle). For mathematically gifted children, these exercises are a lot of fun, whereas linguistic exercises would lead to frustration and resistance. It is important to remember that every child has the ability to distract him/herself but has stopped using it.

For children with depressive symptoms or with social phobia, these techniques should not be used at the beginning of the treatment. These techniques can only work well when these children have started questioning their negative appraisals. If this is not possible, cognitive techniques should be implemented first. In general, distraction techniques should not be implemented if the pain perception has become completely independent of context.

9.1.3 Combining Mindfulness and Distraction

The 5-4-3-2-1-technique and the distraction-ABC may also be combined. Such a combination is especially suited to children with increased general anxiety or hypervigilance due to trauma. An increased external focus predisposes a child to the 5-4-3-2-1-technique, but the effect of this rather low-stimulus technique alone is sometimes not strong enough. In the combined version, the child searches for visual or auditory clues (seeing, hearing, *not* feeling) in alphabetical sequence (A = seeing an aircraft; B = hearing one’s own breath; C = seeing a car; D = hearing the barking of a dog; E = …).

9.1.4 Modification for Younger Children or Children with Learning Disabilities

The distraction techniques presented here are not suitable for children younger than 8 years or with a pronounced learning disability. They benefit more from variations of the game ‘I spy with my little eye’, or the search of the surrounding area for a certain number of things with a certain colour or shape (‘Find 10 blue objects, then 10 red objects’). Another technique is to imagine stories on a given subject, for example, the favourite doll. For older children with a learning disability, simpler versions of the distraction-ABC may be useful (depending on the degree of impairment).

In simpler versions, the number of words or objects can be restricted (e.g. finding animals that start with ten different letters) or simple counting tasks can be used (e.g. finding ten football players, ten cars, ten swearwords, etc.). Furthermore, worksheets should be simplified. Instead of the exact time, children should simply note ‘in the morning’, ‘at noon’ or ‘in the evening’. Only one keyword should be noted for the version (animal, soccer, car, …) and the degree of distraction may be noted with a smiley (e.g. ☺ or ☹).

With ongoing practice, the effect of the techniques will extend. This is why the child has to practise several times daily in addition to the therapeutic sessions.

9.2 Imagery Techniques—Improving Mood

Whenever I’m down I visit my Caribbean island.
—Jana (age 12 years)

All imaginative techniques aim at the regulation of emotions and thus the conscious modulation of one’s mood. Apart from that, these exercises require a lot of attention and lead to relaxation due to an improved mood. For this reason, imagery techniques are well suited for pain treatment.

The standard procedure for imagery techniques is the implementation of the ‘Safe Place’ in an age-appropriate way. For younger children, we use modified versions called ‘Pet on my Belly’ or ‘Pain Fighter’ (see below).

We teach other imagery techniques like the ‘Screen technique’ or the ‘Safe’ only if there is a substantial emotional burden caused by stressful or traumatic memories in addition to chronic pain. These two techniques are presented briefly in Sect. 10.2.

9.2.1 Safe Place

The child is invited to imagine a place (a real place from the past or present, or an imaginary place) with as many sensory qualities as possible (seeing, hearing, feeling, smelling, tasting). For the individual child this ‘Safe Place’ should be associated with feelings of security and safety. The aim is to positively influence both mood and body awareness and possibly also the intrusiveness of stressful thoughts or perceptions through positive physiological reactions (relaxation).

Depending on the patient’s familiarity with imagery techniques and his/her ability to visualise, it will take two to four individual sessions lasting between 10 and 40 min to teach and discuss the respective technique.

The right introduction of the exercise is important, because patients with chronic pain are often sceptical about imaginative techniques. They can’t believe that these techniques may affect physical reactions, such as pain. It should be pointed out that every person has this ability and uses it (in a negative way) every day. Therefore, we recommend introducing the exercise with a 'Terrible Place':

> 'Today, I would like to introduce an exercise that has been used for thousands of years to positively influence mood and physical well-being. The good thing is that each and every person is able to do this, even you. People have the innate ability to imagine things that are not really happening. We might visualise something in the past or imagine something in the future. Or we might think of our parents or friends who are not present at the moment. Presumably, only human beings have this ability, as well as some highly developed primates, such as chimpanzees. This ability is called 'imagination'. Almost everyone uses imagination every day, unfortunately mostly in a negative way. They more or less consciously create their own Terrible Place. Do you have an idea what this could mean? People tend to focus on problems, which triggers worries. These worries are an alarm signal for the brain indicating danger. How can you prepare for this danger? Usually, the problem won't come up to you saying: 'Hi, I am the problem! Please find a solution'. That's why we imagine the problem to try to find solutions. We use imagination. But, how do we feel when we internally deal with our problems? At best, we only temporarily feel tense until we have found a solution that can be implemented. As you probably know, there are many people who worry a lot and are busy with their problems (the child may find some examples). In these cases, imagination has a negative effect on mood and will lead to increased tension. Under these circumstances, chronic pain will not improve. These people have created a Terrible Place. Wouldn't it be much better to use imagination to create a Safe Place where you can be calm and relax? Of course, it would be! Unfortunately, many people have never used imagination in a positive way or have forgotten to do this. When you observe small children playing a game, you will notice that they all have the ability to experience adventures in their minds and imagine things that are not present. Do you remember how to do this? Do you have an idea of which place you can imagine that may give you a feeling of safety and well-being?'

The first session is used to explain the exercise and its goal. When the child fully understands all information, explore his/her ability to evoke vivid imagery (use questions like 'Can you imagine things in pictures?', or 'If you imagine your last holiday, do you *see* any pictures with your inner eyes?'). Most patients will react unambiguously (e.g. intense thinking with a frown versus, 'Sure, everybody can do that'). If children with a vivid imagination agree to try the technique, the next step is to find a suitable 'Safe Place'. It could be a real place from their last holiday, the child's room at home, a magical place, a place in the future or a fantasy construct (e.g. from Pokémon's world). Any place is allowed that is associated with security and safety by the child (or well-being). Having identified a suitable place, the patient's homework is to write down in keywords what precisely he/she is seeing, hearing, feeling, smelling, or tasting at his/her 'Safe Place' (Chap. 15, worksheet #11). Some children may want the therapist to be present while doing this homework.

In most cases, no real people should be present at the 'Safe Place' (animals and fictitious people are allowed, that is, from books, films, games). Relationship problems with a real person could be transferred to the 'Safe Place' which would make it unhelpful. It doesn't matter if the child is unable to describe the 'Safe Place' with all the mentioned sensory qualities. In case the child spontaneously names two 'Safe Places', he/she should try a detailed description using all sensory qualities for both places. Usually, the child will know intuitively which one is better suited. In the next therapeutic session, the ‘Safe Place’ is practised.

Instruction on the ‘Safe Place’

Ask the child how much he/she is satisfied with his/her notes (or if anything should be added or omitted), and how well he/she could already imagine the ‘Safe Place’ while taking notes (scale 0–10; 0 = I couldn’t imagine it at all; 10 = I *visited* my ‘Safe Place’). A score of 6 or less should trigger the question concerning what exactly the difficulty was (e.g. too loud; impossible to *picture* the place; bad memories or body feeling).

Generally, all difficulties arising during the task should be taken seriously, because they usually reveal important aspects for pain treatment.

If the child can imagine his/her ‘Safe Place’ well and all difficulties have been overcome, the child is instructed to sit in a comfortable position, eyes open or closed—just as he/she likes. He/she is told to listen to the therapist reading out the description of the ‘Safe Place’. Having finished, the child is asked how well he/she could imagine the ‘Safe Place’, if anything should be added or omitted, and if reading speed and intonation have been pleasant. The therapist may help with changes (e.g. for a ‘Safe Place’ that describes an island, has the child noted sand, beach, sea? The therapist could ask: Can you only see the sea or also the sky? Is the colour of the sea important? Is the beach empty or are there important things to see? Shall there be animals?). Then, the technique is practised in this and the following sessions (don’t forget the homework) until the degree of imagination is 7 or 8. A degree of 9 or higher requires a lot of details, but will usually lead to a considerable pain reduction (for the moment). A 16-year-old boy with neuropathic pain in the groin was able to imagine a holiday memory (a bay with boats) very well (degree of imagination 7/10). But only when the stimuli were ordered according to their distance from near to far, he was able to reach a score of 9. During the course of pain treatment, this ‘Safe Place’ then became the most important exercise. A 17-year-old girl who had experienced physical violence (fled from Eastern Europe to Germany to escape her violent father) and suffered from pain all over the body, was only able to feel safe when remembering her grandparents’ home (a small hill with a tree in an East European country). Although she had good imaginative abilities, the girl only reached a degree of imagination of 6–7/10. It was obvious that something prevented better imagination. When the girl was asked to describe her ‘Safe Place’ in her native language imagination improved significantly. Obviously, the memory was associated with words in her native tongue. Every ‘Safe Place’ is very special and often details determine whether the exercise is beneficial or not.

As a homework task, the child is asked to practise the ‘Safe Place’ and to document the degree of imagination. In addition, a talented child may paint his/her ‘Safe Place’ in order to establish another emotional approach to the exercise. For a less talented child, this may decrease the effectiveness of the intervention due to the tendency towards over-achievement and self-criticism often found in children with chronic pain. Since it is not the aim of the exercise to discuss the patient’s dysfunctional thoughts, you should ask the child in advance if he/she feels confident in painting the ‘Safe Place’ in a way that will satisfy him/her. If the ‘Safe Place’ is a real place, and photographs of this place exist, it makes sense to look at them while doing the exercise.

The therapist should only read what the child has written down (word by word) and shouldn’t elaborate the ‘Safe Place’. In this way, the therapist will bring less of his/her own associations in the instruction and adhere to the child’s imagination. A ‘Safe Place’ can be a movement (e.g. dancing) or a place that the therapist finds horrible (e.g. Sauron’s dark throne, roller-coaster or hunting). These special places will only be ‘explored’ when few metaphors are used. That is why we do not recommend the combined use of imaginary journeys and the ‘Safe Place’ for pain treatment.

Traumatised children may not know the feeling of safety, because they have never experienced it. In this case, the term ‘Place of Well-being’ (or another personal term) should be used instead of ‘Safe Place’.

9.2.2 Pet on My Belly

A special version of the ‘Safe Place’ is named ‘Pet on my Belly’. Instead of a place, in this exercise, an animal (usually a pet) conveys safety and security. This version is less dependent on the ability of abstract thinking and is thus well suited to younger patients. However, the child must be able to imagine emotions and touch. Since the exercise is meant to be a relaxation technique which is predefined in the instructions, we modified this technique. Especially younger children who see their pet as a source of comfort are very susceptible to exercises involving their pet. Also, children with a strong imagination who like animals but do not have a pet themselves often enjoy imagination exercises with animals. The pet involved should not be sick or very old such that its death is foreseeable, a point that should be determined explicitly. Younger children may repress these facts. To maintain the positive features of animal imagination independent of the context, biography and the child’s abilities, we recommend a procedure following that of the ‘Safe Place’. In younger children, it is helpful if the therapist collects the keywords together with the child and writes them down. Often, a numerical rating scale (NRS) is too abstract for children younger than 9 years. In this case, the degree of imagination (0–10) should rather be indicated by verbal anchors such as ‘excellent’, ‘good’, ‘moderate’, ‘bad’.

9.2.3 Pain Fighter

Imagining a Pain Fighter or a creature from fairy tales can reduce the child’s helplessness by supporting the child in his/her efforts to cope with the pain. In accordance with the previously presented imagery techniques, the child is instructed to imagine with as much detail as possible. The therapist should discuss with the child in which way the Pain Fighter could support pain coping. Please find below three examples:

1. The Pain Fighter has magical power and will transfer the power necessary for active pain coping to the child.
2. The Pain Fighter is a huge eagle, carrying the child through the sky to easily escape his/her severe pain.
3. The Pain Fighter is a tall knight who puts the malicious pain monster to flight with his sword.

Before this imaginative technique is practised, the therapist should discuss the Pain Fighter (how does it fight against pain?), the shape of pain (is it inside the child's body or is it a 'pain monster' that threatens the child?) and the end of the story. The child should be able to describe in detail why it is obvious that the pain has no chance. Furthermore, it has to be discussed how the Pain Fighter can be called for help and where it goes/flies/disappears to. It is also important to describe what happens with the pain. For some children, the Pain Fighter is rather a healing creature that heals the pain monster and enables peaceful togetherness. Just as with the 'Safe Place', the therapist should keep his/her preferences and ethical principles to him/herself and should not provide tips of pedagogical value.

Then, the exercise is trained and practised together with the therapist. The child should specify in advance whether the therapist should provide support (e.g. with questions like: 'OK, the pain monster is standing right before you. Do you call the eagle now? What does the eagle do with the pain monster? How does it protect you? Where do you fly? How do you say goodbye?').

This technique particularly suits children younger than 12 years. The Pain Fighter arises from an infantile fantasy in which the pain is considered an opponent. The Pain Fighter imaginatively fights the pain, solves the problem and elicits pain inhibition (at the 'pain gate'). As with all imaginative techniques, the exercise needs to be as vivid and imaginable as possible to be perceived as helpful. This technique (at least as presented) is *not* recommended for children aged 13 years and older. In those patients, it should not be the primary aim to fight the pain as an enemy.

9.3 Cognitive Strategies—Seeing Things Differently

> *My therapy includes evaluating my thoughts. By now, I'm confident that a life with pain is possible, and I am much more relaxed in many situations. I would have never thought that in the beginning.*
>
> *—Maria (age 15 years)*

The approach for children aged 8–12 years tends to differ from that for older patients. The former will benefit from classical positive self-instructions and can generally modify their thoughts more easily.

Approaches where thoughts are extensively discussed are of only limited use in children aged 10–12 years and not suited at all for younger children.

There are two fundamentally different approaches to deal with dysfunctional thoughts and appraisals that maintain the pain. Dysfunctional thoughts and appraisals are either modified or replaced by more helpful thoughts (cognitive restructuring). Otherwise, the patient has to learn to accept and observe the various dysfunctional thoughts, appraisals and cognitions in a neutral way (cognitive defusion) and direct his/her behaviour towards positive long-term goals, independent of dysfunctional thoughts and perceptions (acceptance-based approach). Both approaches are based on being aware of one's own thoughts and appraisals and of one's cognitive model of pain. Most often, pain chronification has not yet progressed too much in childhood and pain is not yet perceived as unchangeable. In our experience, cognitive restructuring is the best strategy for those cases. In severe pain disorders, it may, however, be advisable to apply an acceptance-based approach. Importantly, this approach is less suitable for children aged 12 years and younger. Their pain can still be modulated, and they better agree on a worldview based on change.

First, we present several cognitive interventions that help children with dysfunctional cognitions challenge and dispute their cognitions in order to be able to use more helpful thoughts and appraisals in future. If applicable, we provide age-specific recommendations. Then, we present an acceptance-based approach, suited for older patients with long-standing constant pain symptoms, where cognitive interventions aiming at modification are less promising.

9.3.1 Methods for Cognitive Restructuring

Usually children are very quick to uncover dysfunctional thoughts, and change them with the appropriate support. As with adults, cognitive restructuring is a multi-step approach.

1. Developing an age-appropriate cognitive model—the 'ABC-Model' from Rational Emotive Therapy (according to A. Ellis) is best suited
2. Identifying dysfunctional cognitions and assumptions
3. Questioning old dysfunctional cognitions and creating functional new ones ('Colourful Thoughts')
4. Practising the new functional thoughts

This chapter is limited to the description of the implementation of cognitive restructuring in pain treatment.

Step 1: Development of an Age-Appropriate Cognitive Model

It is fundamental to any cognitive approach that the child understands why examining his/her thoughts is a significant part of treatment. This understanding will motivate him/her to search for dysfunctional patterns in his/her thoughts. The basic assumption of the cognitive approach is that dysfunctional thoughts and assumptions result in negative feelings and behaviour.

A prototypical dysfunctional pain-related cognition is the set of assumptions underlying somatic fixation. If a child believes that the physicians did not search long and hard enough for a physical cause of the pain, he/she will be fearful or insecure, and ask for further investigations. Those additional investigations will either yield no pathological findings, thus confirming the child's thoughts ('They can't find the underlying cause'), or will deliver pathological findings which are, however, not to blame for the pain symptoms and have no clinical relevance, (e.g. a slightly conspicuous EEG, or an increased C-reactive protein) but will further increase the fear ('Who knows if the EEG does not indicate a brain tumour?').

It is best to start psychoeducation with informing the child about dysfunctional thoughts and their significance. The 'ABC-scheme' (according to A. Ellis) has proven helpful in the search for dysfunctional thoughts (A = Activating Event; B = Beliefs; C = Consequences).

For cognitive interventions, the child must be able to examine his/her thoughts and name his/her feelings. Often, practising those abilities is the first therapeutic step.

Children with a pain disorder often do not initially succeed in reliably differentiating between levels of the cognitive model (thoughts vs. feelings) (e.g. '…then I think I am sad'). How can you explain the ABC-scheme so that these children quickly understand that thoughts influence the physical reactions (and thus emotions) of everyone all the time? It is best to introduce the ABC-scheme step by step with a situation from everyday life:

> 'Have you ever noticed that you, and every other person, think all the time? Some people are good at noticing their thoughts. Others have never learned to pay attention to inner processes and are only rarely aware of their thoughts. This has nothing to do with intelligence, but with education, sex and interests. On average, girls pay more attention to their body and more frequently wonder what others think of them than boys. Thus, it is clear that girls often have better access to their thoughts. Furthermore, children are more able to access their thoughts when their parents discuss their own thoughts and feelings with their child than when they keep them to themselves. A child who often talks about his/her preferences and problems with a friend will be more trained in introspection than a child who is primarily interested in soccer, Star Wars and playing computer games (Note: this introduction is important to demonstrate that it is completely normal if the patient has no access to thoughts and feelings, since this is often the case in patients with a pain disorder). But why could this ability be important? Why did we develop this ability so well? The advantage is that I can think about myself, identify problems and solve them, independent of other people, dangers or places. Depending on my conclusion, I may either think: 'Everything is fine, I will manage this!' or 'Oh my God…!'. This conclusion will impact my body and it will either relax or prepare for (supposed) danger. Let us examine these associations in two situations from everyday life. Imagine that a child who lies in bed at night and whose parents have gone to bed, suddenly hears a loud noise: Do you think that all children would react in the same way or would they react differently? (…collect the different suggestions…) Right, some children would probably roll over and try to fall asleep; others would pull their blanket over their ears; others would scream or wake the parents. There may also be children, who would briefly sit up and take notice and go to sleep if nothing happens. Why do these children react so differently, although the situation is the same? Right, it depends on what the children think and fear. It is always the same scheme: There is a situation (=A in the 'ABC-model'). It may be real or imagined, but we always experience or think something. Depending on how we appraise this situation or what we are thinking (=B in the 'ABC-model'), we will experience the appropriate feeling and bodily reaction (=C in the 'ABC-model'). Do you understand this (clarify all questions)? Let's see what reactions you could observe during the last maths test in your class. The situation was the same for everyone.'

Table 9.1 Exemplary ABC-model

Situation (A)	Thought (B)	Feeling and reaction (C)
Loud noise in the evening	What is that? Is there a burglar? Oh my God, I don't know what to do	Feeling: fear Reaction: hide under the blanket
Loud noise in the evening	It happened again: someone has broken something. This is really annoying	Feeling: a bit annoyed, slight anger Reaction: roll over, try to fall asleep

At this point, you work through the 'ABC-scheme' the way you did with the above-mentioned situation in bed. Afterwards, it can be helpful to demonstrate the universal applicability of the scheme with the current situation.

> 'What we have just worked out happens all the time. Right now, I am trying to explain this scheme to you (=A). I am thinking 'Hopefully, I can explain this well and don't use too much technical jargon'. (=B) I can sense a slight tension in my neck and in my belly (=C). What about you? Do you perceive your thoughts regularly or only rarely? Let's see what happens when you are in pain. What situation could that be? What other bodily reactions do you perceive? What could you think when you are in pain? 'Cool! The pain is finally back'. or rather 'Not again. I can't stand it any longer'. or maybe 'Why is it always me?' or 'There must be something wrong with me!' (the therapist should provide more or less help depending on the child's ability to perceive thoughts).

Table 9.1 illustrates the example above. With younger children the psychotherapist should be more active and give input, that is, suggestions that the child understands well, such as thoughts closely connected with behaviour. The older the child, the more elaborate the chains of thoughts that can be worked on.

When the children feel that they are able to perceive their thoughts and emotions, they should try to note their 'ABC-scheme' each time they feel pain or strong emotions (fear, anger, frustration, joy, …) as homework. If they did this exercise well, you may go on with Step 2. In case the children cannot yet reliably differentiate thoughts and emotions, the homework should be adapted, so that the child starts with his/her bodily reaction (=C) and describes the situation in keywords (=A). Then he/she should try to identify thoughts (=B) that could have elicited or reinforced the bodily reaction. The therapist should point out that it is not important to be able to directly identify a thought, but that the child should try as best as he/she can and bring the notes to the next sessions.

Subsequently, the child should be able to differentiate his/her bodily reactions and name the associated feeling. Sometimes children need more help in assigning feelings to physiological processes. This is particularly true for children with a long persisting chronic pain disorder. Over months and years, these children have associated each aversive physical state with pain perception. When they have only paid attention to their pain, they are not able to separate pain from feelings of stress, grief, anger or fear anymore.

These children need more assistance. They have to learn that a slight tension in their belly, a trembling in their body or an increased heart rate or breathing may indicate fear (or nervousness, excitement—some children don't like the term 'anxious'). They have to relearn the associations between bodily perceptions and feelings. Some children benefit from photos that show actors or other children portraying feelings.

The 'Mood Barometer' is another tool to train the child's ability to differentiate between various feelings.

The Mood Barometer

The child writes down his/her feelings and puts them in a hierarchical sequence (similar to a thermometer, or barometer), or clockwise order. With the help of a slider or watch hand the child can report his/her current feelings, and at the same time becomes aware of them. Two to three times a day one member of the NET prompts the child to assess his/her feelings using the Mood Barometer. If the child has difficulty answering, the NET may give some feedback or pose a hypothesis ('Your shoulders and your gaze are down. It looks like you are sad'). Then this observation is discussed with the child.

Gradually, the child will learn to recognise and to express feelings. Many children show great difficulty differentiating between various feelings and tend to repeatedly express similar or the same feelings. Those are the children in need of reflection with and detailed feedback from the NET.

For some children, the pain perception is associated with strong tension due to a comorbid psychiatric disorder. The following case illustrates our practical approach to create an ABC-model in a child with chronic pain and accompanying strong timidity.

Case Report: (Maria, 15 years, pain disorder + anxiety disorder. (T = therapist; C = child)

T: When we discussed the vicious cycle, I explained how thoughts may have an impact on the pain experience. The way we appraise a situation has some impact on what and how we feel. Does that still make sense to you? Or do you have some more questions?

C: Well, often my impression is that I do not think at all. I just feel helpless when I am in pain.

T: Right. Thoughts are often ultra-fast, as quick as lightning, being nearly unrecognisable for us. That's why we call them automatic thoughts. I'd like to illustrate the significance of thoughts with a short story.

Imagine, holidays are over and you are getting on the school bus. A boy you have never seen before looks at you and smiles. In that moment you think: 'Nice boy. Maybe he also goes to my school? I think I should speak to him'. How do you think you feel?

C: I would be a little tense and maybe curious.

T: What will you do?

C: I think I will remain seated and look up to him from time to time. Maybe I would sit next to him.

T: Okay, let's write that down (T: makes a note in the ABC-model). Now imagine, the same situation, the same boy, exactly the same smile. But, in this moment you are thinking 'Oh dear, why is the boy laughing? I don't know him. I will certainly blush. Oh my God, it's embarrassing!' – How do you feel, and what will you be doing?

C: I know that well. I will blush, turn around and sit somewhere else in the bus.

T: Great. Could you please write this down in the model? What did you learn from this example?

C: Well, depending on what I'm thinking there will be different emotions.

T: That is correct! Do you mind if I ask you about your feelings and thoughts while you are experiencing pain every now and then in the upcoming sessions?

With the newly created ABC-scheme, you can now work on the patient's pain-related examples. Admittedly, the given example is somewhat prototypical. Mostly, the analysis of relationships between situations, thoughts and feelings is not that simple. But, with some support, most patients will quickly recognise the interrelations. Often, it is advantageous to ask the patient about the thoughts he/she had in former stressful situations. Then, the patient's homework is to fill in his/her worksheet with his/her observations, for example, as a 'diary of thoughts'. To prepare the worksheet, use a white sheet with three equal columns with the headlines 'A', 'B', and 'C'. The child is asked to write down any stressful or unpleasant situation, a detailed description of Black Thoughts arising in this situation and the physical response to them.

Step 2: Identifying Dysfunctional Cognitions and Assumptions

Once the model is finalised and the child has documented his/her negative thoughts, the second step aims to identify the stressful thoughts that should be examined. It is not the goal of cognitive therapy to change all negative thoughts or feelings. Instead, we focus on those that are particularly stressful and dysfunctional. The following questions proved helpful in the identification of automatic thoughts:

1. *Basic question: 'What were your thoughts in this situation?*
   (a) The basic question may be asked if the patient's mood changes during the session or you notice a physiological change.
   (b) The therapist may ask the patient to describe a difficult situation and then ask the basic question.
   (c) The therapist may ask the child to imagine the situation and then ask the basic question.
   (d) Have the patient re-experience the situation in a role play, and then ask the basic question.
2. *More questions to identify automatic thoughts*
   (a) 'What do you guess you were thinking about?'
   (b) 'Is it possible that you were thinking about _________ or _________? (therapist proposes a plausible alternative)
   (c) 'Did you imagine something that could happen, or did you remember something?'
   (d) 'What did this situation mean to you?'
   (e) 'Did you think: _________?' (therapist proposes the opposite of the assumed answer) You should overstate your suggestion to make sure that the child understands that you didn't really assume he/she was thinking this. For instance, 'Great, it's pain again!', or 'Great, I may finally discuss my thoughts with my therapist'.
3. *An alternative approach is indicated if there are any problems with the implementation of the previous approaches*
   (a) With a child having great difficulty with the approach described under (2) or children too young to have the required cognitive ability for reflection, it may be helpful to name several examples of Black Thoughts and ask directly if the child has ever had that specific thought.

(b) It goes without saying that in addition to what is proposed in paragraph (2), it is also possible to go through the Black Thoughts most often mentioned by children with chronic pain. These are:
   - ‘When I am in pain, I can’t perform well in school’.
   - ‘I can’t do anything about my pain’.
   - ‘Perhaps the physicians did miss something after all?’
   - ‘Why me?’
   - ‘I can’t stand any more pain’.
   - ‘Being ill is awful’.
   - ‘Nobody can help me’.
   - ‘A life with pain is futile because I can’t achieve anything’.
   - ‘Nobody believes that I am in pain’.
   - ‘I hate my body for its pain’.

Before dysfunctional thoughts are questioned and changed in the next step, the therapist should take some time to discuss that Black Thoughts are normal. Black Thoughts only become dysfunctional when we believe them and when they can influence our body awareness and the resulting release of stress hormones leads to increased muscle tension. When several dysfunctional appraisals and cognitions have been discussed, the child may choose the cognitions to start with in the next step. It will be questioned to what extend these cognitions are realistic. If the child cooperates well, the therapist may ask for core beliefs: ‘Have you ever had thoughts like ‘I am not able to do anything!’ or ‘Something awful is going to happen’ or ‘Everything I do is wrong!’?’ In case the child has an elevated score in the depression screening, the therapist should ask for core beliefs, such as: ‘Nobody loves me!’, ‘I hate myself’, ‘I am worthless!’. The child should rate how often these thoughts occur (e.g. several times a day, daily, one or more times a week, once a month, less frequently). When the most important Black Thoughts have been identified, the next step is how to change these Black Thoughts. It is not always advisable to start with the ‘Blackest’ Thoughts (i.e. ‘My mother hates me’, or ‘Something awful will happen to me’). It is better to begin with thoughts that are more easily scrutinised in order to make the child see the success of the exercise.

Step 3: Questioning Old Dysfunctional Cognitions and Creating Functional New Ones (‘Colourful Thoughts’)

Some of the pain-related Black Thoughts (e.g. ‘I can’t do anything about my pain’) may already start to change after the first few days of inpatient pain treatment. The children may learn from other patients, or experience themselves that pain is not as unchangeable as previously thought. This is a typical patient report:

> ‘I used to think I couldn’t do anything about my pain. Now I know that with the help of various techniques (e.g. distraction-ABC) I can manage my pain and be more active’.

In case a child reports this, you should point out that he/she has performed a reality check on his/her own, without any instruction, and compliment him/her for that. Since the child proved by him/herself the mutability of Black Thoughts, he/she will be highly motivated to continue working on other Black Thoughts. Sometimes it may be helpful to ask for previous positive exceptions from Black Thoughts in order to emphasise the modifiability of thoughts and appraisals. Regarding dysfunctional cognitions, we use the following disputation techniques.

1. *'Is it really true what I am thinking?'—Proof/counterproof (logical disputing)*: First, the child is prompted to describe his/her Black Thought in detail: 'Let's start with the thought: 'I can't do anything about my pain!' – If this is true, how can you manage to listen to me (… go to school, … engage in activities, … meet friends – use examples from the child's life)? What made you think you really can't do anything about your pain? (wait for examples) Alright, and you conclude that you can't do anything about your pain, because you could not impact your pain in these special circumstances?' Now collect proofs for and against the validity of the Black Thought. Typically, this technique will work only with older children who show the necessary ability for reflection and abstraction. It may well be that the child cannot generate any ideas with Black Thoughts that devalue his/her personality or cause stress. In this case, the therapist could provide one or two obvious ideas as to how to counterprove the thoughts. In the end, the situation is re-evaluated.
2. *'Will it really be that terrible?'—facing and questioning the worst case (balancing out)*: This strategy is helpful for children who are prone to catastrophising, but have a minimum sense of reality. We start searching for the worst-case scenario together with the child ('I will have to leave school before graduation, and I will have to live on the street in winter'). Then we describe the best possible scenario ('I am able to try hard and perform very well independent of pain'). Then the therapist and child discuss how realistic these extreme situations are. Finally, the child should depict the most probable scenario ('Sometimes it will be difficult to perform well while in pain. But sometimes I will perform as well as I did before my pain problem began'). The child is asked to implement this strategy each time he/she notices catastrophising thoughts. In addition, he/she is asked to take notes on success and failure with this balancing out technique.
3. *'What's the use of this Black Thought?' (hedonistic disputing)*: We instruct the child to make a cost/benefit analysis of his/her thoughts and appraisals. This strategy is quite effective, but requires a relatively strong ability for reflection and introspection. That's why it is rather useful for older children. This technique rather resembles acceptance-based techniques, because the aim rather is to be aware of consequences of thoughts than to question the whole thought itself. It is helpful to differentiate between short-term and long-term consequences. Table 9.2 gives an example of a hedonistic disputing of the thought 'Being in pain is awful and I can't do anything about it!'.
4. *'Replacing Black Thoughts by positive ones'.—Positive self-instruction*: This classical strategy is about replacing a dysfunctional Black Thought by a functional Colourful Thought. First, Black Thoughts need to be identified. Second, a better 'colourful' thought needs to be found that causes less stress and does not increase the pain. Children younger than 12 years benefit from a much reduced

Table 9.2 Hedonistic disputing of the thought ‘Being in pain is awful’

	Cost	Benefit
Short term	I start getting anxious and tense, which makes the pain worse. I am worried and I can’t sleep well. I can’t concentrate well due to the worries	When I complain I get more help from other people. When I am not feeling good my teachers are less strict
Long term	I don’t search for solutions but keep on focusing on the pain. My pain will get worse; the pain gate opens up more and more	There is no long-term benefit

disputational approach. Typically, their thoughts are less complex, and often they benefit from a simple dichotomous division into ‘black’ and ‘colourful’ thoughts. Furthermore, counterthoughts are well suited to younger children (e.g. thinking ‘Somehow I will manage this’ instead of ‘I can’t do anything’). Sometimes, younger children like finding Colourful Thoughts that rhyme (e.g. ‘When I am in pain, I say: Stop, dear brain!’). For older children, it is useful to integrate the context (‘I don’t give up. Come on now, focus on school!’). This strategy is not suitable for generalised negative self-centred cognitions. In this case, we recommend the use of strategy 1, 2, 3 or 5 (or acceptance-based techniques).

5. *Behavioural experiments (empirical disputing)*: The validity of dysfunctional thoughts may also be tested by means of formal reality tests (behavioural experiments), a stepped procedure more suited to children aged 12 years and older.
   (a) Identify the thought to be tested (e.g. ‘I can’t do anything while in pain’). You may use the cognitive techniques mentioned before (e.g. proof/counterproof) in order to increase the child’s motivation to conduct a behavioural experiment.
   (b) Depict a detailed scenario suited to testing the thought (e.g. ‘I can’t concentrate while I am in pain’). Then make an exact plan of all the variables to be tested during the behavioural experiment (e.g. ‘For how long would you have to concentrate in order to have a counterproof?’). This strategy is particularly helpful with the frequent thought ‘I can’t do … due to pain’, because it is a cognitive illusion. Pain is only able to prevent activities in very extreme cases. From an evolutionary viewpoint, pain is an alarm signal. If we could not concentrate or do anything while in pain, mankind would probably not have survived. When your foot is broken, you can’t move, because it is functionally impossible, but not because of the pain. Numerous examples from everyday life prove that everything is possible despite pain, if necessary. Of course, this is often not advisable, but in a behavioural experiment, it is important to prove how ridiculous this thought is. The fact itself that the child is able to listen and ask questions is proof enough that the child is able to concentrate. Appropriate thoughts would be: ‘It is more difficult for me to concentrate when I am in pain!’ or ‘It is more exhausting to go to school or meet my friends when I am in pain’.
   (c) Conducting the behavioural experiment.
   (d) Drawing a conclusion and working on a new functional thought (e.g. ‘I can’t concentrate as good as before, but it works better than I thought’).

Step 4: Practising the New Functional Thoughts

Towards the end of this exercise, the child will have acquired one or more functional cognitions. These new thoughts should be phrased in the child's own words, use the 'I' mode and be as detailed as possible (a bad example would be: 'Everything will be okay'). Unfortunately, just gaining insight isn't enough to have a long-lasting positive effect on the child's experience. The psychotherapist should discuss this with the child ('It is the same as with learning vocabulary. It is not enough to read the words once in order to be able to reproduce them in an exam'). It is essential to regularly apply the new helpful cognitions and evaluate them for their effectiveness. To this end, behavioural experiments may be used (Step 3). In addition, the following training methods have proven effective.

1. *Creative techniques*. The patient creates a collage with the new functional thoughts. Depending on the patient's creativity, he/she may write or paint a comic around those helpful thoughts together with the therapist. Painting a Pain Fighter (Sect. 9.2) is the combination of a cognitive and an imaginative technique. The collage should be placed in a prominent location to be seen in everyday life. Together with the therapist, the child decides how those thoughts portrayed in the collage could also be practised in everyday life (e.g. starting a list of thoughts (see method 4) on a sheet of paper fixed to the cover of the child's school book, etc.).
2. *Extended protocol of thoughts with the help of the ABC-scheme*. To implement this method, children need to understand the ABC-scheme (see Step 1. *Development of an age-appropriate cognitive model*). Unlike the usual procedure, this method starts with the bodily reaction (C). This procedure is useful for children and adolescents with chronic pain, as they particularly perceive negative physical symptoms (pain, fatigue, tension) as distressing and don't focus on feelings or thoughts as much as other children. In **Step 1**, the child should write down the *negative changes in physical symptoms* (C) he/she perceives, for example, 'tension in the neck, more severe headache, being annoyed and fatigue'. In **Step 2**, the child *shortly describes the situation* (A) in which the stressing bodily reaction occurred (e.g. 'lying in bed at night and not being able to fall asleep'). In **Step 3**, the child *thinks about appraisals and thoughts* (B) that could be responsible for provoking the bodily symptoms (C) in the specific situation (A). In the beginning, the child will probably need some support from the therapist. With a little training the child will be able to do this on his/her own. Once the patients are good at performing these three steps, they decide which of the above presented strategies is best suited for them. In **Step 4**, the *child implements one of these strategies* (B+) and writes it down (e.g. logical disputing, positive self-instruction). Finally, in **Step 5**, the child *evaluates the positive changes in physical symptoms* (C+; e.g. slight relaxation, reduction of pain and fatigue) associated with the implemented strategy (B+). In the beginning, many children have difficulties differentiating between feelings/bodily symptoms (C) and thoughts/appraisals (B). A child may for example note 'I was not doing very well!' for (B).

In such cases, the therapist should acknowledge the motivation (at least the child did his/her homework) and correct the notes for (B) and (C) together with the child: 'Ok, you were not doing very well. What exactly did you physically feel? What were your physical symptoms? (write down the answers for (C)). And what exactly were your thoughts in this situation that made you feel so bad?' It can be helpful to ask the child to literally write down his/her thoughts.

3. *Imagination*. If the child has good imaginative abilities, the therapist may encourage him/her to imagine the difficult situation and practise the helpful thoughts. It is important that the child experiences a positive effect on bodily reactions, because otherwise negative appraisals will not change. Children with a strong problem-focused thinking may be more motivated to cooperate if they first experience the effects of an extremely negative appraisal of their imagined situation. The resulting negative bodily reactions will help the child understand the influence of appraisals on body symptoms.
4. *Tally sheet for thoughts/interruption of thoughts and positive self-instruction*. Children can be instructed to pay more attention to actually applying Colourful Thoughts by using a tally sheet. One possible way of doing so is to interrupt a Black Thought whenever it is noticed (e.g. by saying out loud 'STOP') and replace it with a Colourful Thought. When the child has succeeded in doing so, he/she should mark this with a tally mark on the tally sheet (other signs, such as a paper clip changing from the right to the left jean pocket are also possible).

9.3.2 Three Letters

During the course of treatment, the child sometimes has to make difficult decisions about a problem that cannot be solved easily. For example, a child may experience one of the following problems: a conflict of objectives (e.g. 'Should I avoid assessments or partake in a trial that may maintain the pain?'), an uncertain future (e.g. 'Should I live with my mother or my father?', 'Should I stay in school despite pain or repeat the last year/change the school?'), or considerable emotional problems that maintain the pain (e.g. 'Should I address the conflicts with my father in the family session, although he might get angry?' or 'Should I tell my parents about my self-harming behaviour or will I only disappoint them again?'). Often, these problems severely inhibit successful pain treatment. A purely cognitive approach may not be helpful, because these children have difficulties in developing a clear inner attitude. In these cases, the following intervention ('Three Letters') might be beneficial. This intervention is further suitable for progress monitoring in the middle of the treatment or for identification of factors that are important for relapse prevention at the end of the treatment. In principle, this intervention is about exaggerating fears and inner attitudes. This self-reflection may help the patient recognise these, as well as how he/she can influence his/her future. In many cases, decision-making in emotionally difficult situations is hindered, because we don't dare to think through all consequences of our fears and wishes. This is what the Three Letters is all about.

Three Letters

This technique will work only if the child has the necessary cognitive ability (typically from 13 years and up) and is willing to take on the required homework.

The therapist asks the child to write Three Letters (for a detailed instruction, see Chap. 15, worksheet #16). The third letter should be written immediately after the second letter is finished (only a short break is allowed). Each letter should comprise about one written page. Some of the children will pack all necessary information into a letter of no longer than half a page; others will need 2–3 pages each.

1. *Letter 1*. In this letter, the patient describes how his/her life will be for the next 2 years (alternatively, until his/her next birthday or another significant future event) *in the best case* after this therapeutic session (alternatively, inpatient treatment programme; outpatient psychotherapy; …). The challenge is to write the letter from a future and first-person perspective to oneself in the present ('Dear Martin, two years have passed since you decided to do an inpatient pain treatment. Since then, …'). It is important that the patient describes his/her development in *all* relevant aspects of life very precisely (i.e. not just concerning pain but also friends, relationships, school, family, leisure activities, etc.) and comments on which *own* decisions, appraisals, and behaviour contributed to steering life into just that direction (*incorrect*: 'I won the lottery, and suddenly everybody was overwhelmingly nice to me'; *Correct:* the child is supposed to focus on *his/her own* efforts and changes).
2. *Letter 2*. The second letter is the counterpart of the first one. As in the first letter, it is written from the future to oneself living in the present and reports about the worst imaginable course of the pain condition (same formal criteria as for letter 1). The letter should describe precisely the patient's *own* behaviour, appraisals, and decisions contributing to that disastrous course. It should be emphasised again how important it is to continue with writing letter 3 immediately after the second letter and *not* to pause. Otherwise, there is the risk that the negative feelings evoked by writing letter 2 will result in a negative trance that may have a negative impact on the pain and the mood for days.
3. *Letter 3*. Most patients regard this letter as the one most difficult to write. While it is quite simple to imagine the best possible, or the worst possible course, it is a challenge to imagine a realistic one, taking into account one's own personality and perception of abilities. And that is exactly the aim of letter 3: to find a *realistic* course; somewhere between the extremes described in letters 1 and 2 considering one's *own* behaviour, appraisals and decisions.

These letters are very helpful in gaining an overview of all relevant parts of the child's life, his/her own perspectives of change, important resources, and critical (cognitive) factors relevant for therapy.

It is then quite easy to identify important negative cognitions in the Three Letters together with the child. Often, they are explicitly written down. An invaluable benefit of that intervention is that it will help the child better understand his/her situation. The child can be proud, because he/she reached this by his/her own effort.

Writing the Three Letters allows the child to reflect on all relevant areas of life, presumably for the first time.

This intervention should be avoided with children with a current depressive episode. If suicide is the only solution given at the end of letter 2, the child should be complimented for his/her courage in writing down and revealing his/her worst fears. Further action regarding a comorbid depressive disorder is only required if the patient indicates a real danger of a suicide attempt.

9.3.3 Acceptance-Based Methods

Acceptance-based methods are an alternative to the previously described cognitive strategies. Contrary to cognitive strategies, acceptance-based techniques do *not* focus on the modification of thoughts and appraisals to achieve a reduction of pain and negative physical symptoms. More specifically, the aim is to develop an accepting active attitude that does not fight negative symptoms. Pain is no longer considered an alarm signal so that defocusing is possible without distraction strategies. An acceptance-based approach is not only effective for adults, but also for children and adolescents with severe chronic pain (Kanstrup et al. 2016; Kallesøe et al. 2016). In children with a pain disorder, the acceptance of pain may improve the quality of life (Feinstein et al. 2011). Low levels of pain acceptance seem to be associated with high levels of emotional distress and pain intensity (Wallace et al. 2011).

What exactly is the difference between a cognitive and an acceptance-based approach? And how can the difference between acceptance and resignation be explained to the patient and his/her parents?

Contrary to the cognitive approach, the focus of an acceptance-based approach is not to teach alternative appraisals or thoughts concerning pain but to reach the goals important to the patient in the intermediate or long-term future, irrespective of pain intensity.

The focus of pain treatment shifts from pain reduction to a meaningful and happy life even if it is still painful (Wicksell et al. 2007). *The Three Letters are a good starting point for identifying important long-term goals of the child.*

The advantage of an acceptance-based approach is that pain is no longer regarded as an enemy that should be modified, reduced, or circumvented. Thus, the *symptom distress* of the whole family system arising from the battle of pain reduction can be eased. This approach is especially helpful if long-standing chronic pain makes quick pain reduction improbable. Often, these children are at high risk of leaving school without graduation due to their severe impairment in school. Therefore, action is urgently needed although options for change are minimal. The acceptance-based approach can be implemented in four steps.

Step 1: Understanding the Basic Idea of the Acceptance-Based Approach

The acceptance-based approach aims to build mindfulness towards, and acceptance of, one's own situation and to value one's own abilities. It also aims to increase distance from cognitive processes to reduce identification with negative appraisals (*cognitive defusion*, see below). The procedure should be discussed with the parents and their child in advance, because many families believe they have to fight the pain. If not fully informed, they may misunderstand this approach as a sign of resignation, which may lead to a premature termination of treatment. The first step is to make the patient and his/her family familiar with the specific idea of the acceptance-based approach and the differences between acceptance and resignation. The following exercise can be helpful:

> *Exercise 1—Getting familiar with the acceptance-based attitude*
>
> 'Today I'd like you to write down all your thoughts about your pain on index cards. When you are done please stand up in front of me. I will throw the cards at you one by one. You should try not to let the cards touch you. After this, we will do a second exercise. This time you will just stand there and hold your hand in front of you, palm up. I will place the cards in your hand, and the only thing you have to do is look at them'.

Having finished the exercise, the therapist will ask the child which one of the exercises was more exhausting and took more effort (usually it will be the first one—avoiding the cards—if the therapist is a good pitcher). Another more cognitive alternative is the following exercise:

> *Exercise 2—Getting familiar with the acceptance-based attitude*
>
> 'Competitive athletes are masters of pain acceptance. They know that severe pain is part of their life and training. Of course, they perceive the pain in just the same way as you and me. Basically, they just don't care about their pain, because they have one goal in mind that they want to reach despite pain. That's the secret as to why competitive athletes don't develop a pain disorder. It would be the same with you: If you didn't care about the pain, you would not be here, would you? Well, the problem is that pain, as you already know, is an alarm signal. Usually, it is perceived as very unpleasant and is avoided at any cost. However, this is not predetermined biologically. If we evaluate pain as less important, the pain gate automatically closes a bit. There are different ways of achieving this goal. One possibility is to stop believing in your thoughts. No one forces you to think: 'When I am in pain, I really can't do anything'. From a biological viewpoint, this statement is simply untrue, because pain is not meant to inhibit behaviour. But, if I absolutely believe in this thought, it becomes reality. I won't do anything because of the pain. It is very important to be aware of this difference. How can you practise to have less faith in your thoughts? The first step is to distance yourself from your thoughts. You may think (use a dysfunctional thought that has already been identified; for example, I can't do anything): 'I really can't do anything due to the pain!' – Now repeat this sentence in indirect speech, for example, 'I see, I have the thought that I can't do anything due to the pain!' Do you feel a difference between these sentences? Which sentence increases inner tension?'

Therapist and child will figure out the essentials of an acceptance-based approach together and discuss whether it seems suitable for the child. It is essential to clarify the difference between an acceptance-based approach and resignation. For many children, acceptance is not that different from resignation. The difference may be illustrated as follows:

> *Example—Explanation of the difference between acceptance and resignation*
>
> 'With an acceptance-based approach I choose a life following my own goals, irrespective of the existence of one, two or more aspects of life that bother me. In other words, with active pain coping I can achieve all those things in everyday life that I planned for a pain-free life.

> Resignation is if I give up the battle against pain due to exhaustion or desperation, assuming my life will never change for the better, and could even deteriorate'.

This shows that acceptance and resignation are very different attitudes, and although the word 'acceptance' is suggestive of passivity, the acceptance-based approach is an *active* coping approach. An acceptance-based attitude contributes to the disconnection of emotional distress and pain perception (Wicksell et al. 2009, 2011).

Step 2: Training a Neutral and Mindful Perception

Once the patient has recognised the difference between an acceptance-based and a resignation-based attitude, he/she should understand that the thoughts and appraisals ('If in pain, I can't attend school'), and perceptions of body signals (i.e. pressing pain on the forehead; a pulling intestinal pain; shallow breathing; etc.) that so far have determined everyday life are nothing more and nothing less than—thoughts, appraisals, and perceptions. This can only be fully understood if the child is aware of his/her thoughts, appraisals, and body signals.

Mindfulness is one central idea of acceptance-based therapy and describes an active process of perception and an attitude of neutrality that is free from judgement. Mindfulness is defined as consciously perceiving what is going on right here and now. In the beginning, this task is neither simple for children nor adults. Thus, it is important to practise mindful perception, using the 5-4-3-2-1-technique (Sect. 9.1) or several other perception exercises (e.g. to mindfully focus on one's own breathing or on what is perceived with one's own senses in this moment).

Step 3: Cognitive Defusion

If a child succeeds in being aware of his/her thoughts, appraisals and feelings, Step 3 is about *just* perceiving one's thoughts, appraisals and body signals from the position of a mindful observer. This implies that thoughts, appraisals or perceptions of body signals are neither devalued nor followed; instead, they are observed from a distance (like clouds passing by). This mental state is called *cognitive defusion*. The aim is not to change the content of the thoughts, appraisals or perceptions, but to create some sort of inner distance (metalevel: I *have* a thought or feeling, but *I'm not* the thought or feeling). Cognitive defusion creates a distance from one's own experience (this is, for example, comparable to various distancing techniques used in trauma therapy) and enables a reduction of the emotional burden. The following example illustrates this:

Case Report: Caroline (aged 17 years)—Pain disorder with back pain

> 'You have already achieved a lot. First of all, now you know the basic ideas contributing to a happy life irrespective of the pain. By observing your thoughts, you have learned that most of them follow a simple logic: 'I can't do _______ because I am in so much pain. Therefore, I will never achieve ____ and will stay unhappy'. Now it's time to introduce a small modification to this logic. Instead of 'I can't do _____ because I am in so much pain', please think 'I have the thought that I can't achieve ____ because of my severe pain'. Do you see a difference in your thinking and feeling? Please write down until tomorrow in which situations you could use this strategy and if you feel a difference when you use it'.

Another form of cognitive defusion for children is to give names to one's thoughts (e.g. 'pain monster'). This may be done in a humorous way. Maybe the child could even portray his/her pain monster with handicrafts, or find other methods to attain greater inner distance by externalising his/her thoughts ('The pain monster wants to scare me, but I told the monster that I don't care!')

Another form of cognitive defusion is to alienate the dysfunctional thoughts. This is achieved if the child repeats his/her thought in his/her head with a distorted voice, or with a modified speech melody. Even if 'pure neutrality' can't be achieved, this exercise will create an inner distance to those thoughts.

Here are a few examples of how some adolescents alienated their dysfunctional thoughts so that they had to smile about it:

1. Lennart (16 years, fan of Lord of the Rings) imagined Gandalf in the third part of the film version of Lord of the Rings screaming 'I am just too dumb!' instead of his actual battle cry in front of the gate of Mordor.
2. Merle (15 years, metal fan) imagines her favourite band shouting 'I am dumb, fat and ugly!' in the chorus.
3. Lilli (14 years, likes the film 'Finding Nemo') imagines Dori saying 'I can't do anything because of the pain'. in Whale in the film 'Finding Nemo'.

A number of apps for smartphones exist, in which cute birds or smurfs repeat phrases in a distorted voice. This is a popular way for children and adolescents of externalising and alienating their negative thoughts.

Step 4: Departure into a New Life

Once the child has learned how to attain some distance from his/her thoughts, he/she is asked to identify important *goals* for his/her future life and essential *inner values* that they are based on (i.e. honesty, discipline and self-confidence). Finally, we will reflect on how the patient's behaviour (e.g. passive pain coping) matches those goals, and whether the goals can be achieved by continuing with this behaviour. In case the patient decides that his/her behaviour (e.g. not attending school when in pain) has not helped him/her so far, the child can explore future steps to reach the desired goals with the therapist (e.g. active pain coping). This is usually a lengthy process. Thus, it is essential to regularly practise the exercises presented above and record their success for the next therapeutic session. Similar to the protocol of thoughts described above, the simplest way is to write down the situation, the dysfunctional thought, the distancing or alienating technique and the effectiveness of the exercise (with a smiley scale or an NRS from 0–10). The exercise is only effective if it results in a positive change of physical symptoms (e.g. slight relaxation).

In closing, we would like to report an interesting clinical observation from children who have successfully practised mindfulness techniques for a longer period. They unanimously report that at first, they perceived their pain as less stressful but of unchanged intensity. Within a short time, however, their pain perception was reduced. In many children, with further practice, it was reduced to such a degree that they felt (nearly) pain-free. They ‘just stopped thinking about’ their pain. This clinical observation is in accordance with the findings of Wicksell et al. (2011) who detected a major decrease in pain intensity in Swedish adolescents with chronic pain when using an acceptance-based approach.

9.4 Techniques to Reduce Physical Tension—Staying Cool

Great! I can watch my body relax.
—Chris (14 years) during a biofeedback session

Procedures reducing physical tension are of great importance in pain treatment and their use with children is well investigated, with a meta-analysis concluding that relaxation techniques are recommended as a procedure of choice in chronic paediatric pain (Palermo et al. 2010). Unfortunately, this recommendation does not take into account the fact that the studies included in this meta-analysis were mostly investigations of children with migraine or tension-type headache with only moderate pain-related disability. In many studies, the participants were recruited via newspaper advertisements—thus some of the participants were not pain *patients* but children with pain who neither *suffered* that much from pain, nor reported strong pain-related fears, great impairment in everyday life or changes in behaviour. We believe that it is not advisable to generalise these results to children with severe chronic pain. In our experience, in the treatment of paediatric chronic pain patients, both Autogenic Training (AT) and—to a lesser degree—Progressive Muscle Relaxation according to Jacobson (PMR) may even have a *negative* impact on the patient.

How can this discrepancy be explained? Children with severe chronic pain have an increased, often fearfully increased, body awareness. Furthermore, for many of these children, severe pain may be associated with stressful memories or thoughts. In these patients, calm or relaxation activities often result in increased interoceptive pain perception and/or exposure with aversive thoughts. Thus, they experience an increase in tension instead of relaxation.

Hence, classical relaxation techniques should only be used after detailed education and when the technique seems to be suitable for the patient.

Consequently, during inpatient pain treatment classical relaxation techniques are not the routinely implemented components of the treatment. In contrast, all patients are trained in TENS therapy (with the exception of children with abdominal pain) and biofeedback, as these techniques increase one’s distance from interoceptive stimuli. Irrespective of which technique is trained, the implementation of relaxation techniques has three goals:

1. To learn self-initiated and voluntary relaxation in stressful situations
2. To gain active control of physiological activity in order to decrease pain
3. To strengthen the patient’s self-efficacy believes

Training in relaxation techniques takes several sessions. The patient should practise daily and record his/her success, especially during stressful situations (scale 0–10).

9.4.1 Progressive Muscle Relaxation According to Jacobson (PMR)

This technique is about tensing and relaxing groups of muscles in a predefined sequence, always starting with the large muscles of the extremities, proceeding to the trunk muscles, and finally to the small muscles of the face.

1. Tensing the muscle group
2. Perceiving the muscle tension
3. Gradual relaxation of the respective muscle group
4. Focusing one's attention on the feeling of relaxation within the relaxed muscles

The children receive a CD with auditory instructions (partially supplemented with music) for their daily exercises. Apart from the extended instructions (45 min) found on PMR CDs, some also contain short versions (15 min). We recommend using the short versions as the patients' adherence to the extended version is low. Muscle relaxation techniques may be used before, during or after stressful situations as well as to fall asleep. Many children with chronic pain are mentally but not physically exhausted in the evening due to their established passivity and inactivity. Apart from an active daily structure including active pain coping, PMR may help individuals to fall asleep in the evening. Many children consider PMR helpful but dislike the accompanying music. In this case, they should do the exercises without music. Other children don't want to implement the technique, because they dislike the music and/or believe that 15 min are still too long. In this case, the therapist can record an even shorter version (approximately 7–8 min) on the patient's smartphone.

9.4.2 Autogenic Training (AT)

In its simplest form, AT comprises a sequence of six exercises. In the first two exercises, set verbalisations (e.g. 'My right arm is becoming pleasantly warm') are combined with imagery directed towards the respective sensory perception (warmth: the sun is shining on the respective part of the body; heaviness: lying beneath a pleasantly heavy blanket). Not every child has the necessary imaginative ability.

Exercises
1. Heaviness: hands, arms, feet, legs, neck, shoulder, whole body
2. Warmth: hands, arms, feet, legs, neck, shoulder, whole body
3. Breathing exercise
4. Sensing one's heartbeat
5. Exercise for the solar plexus/abdominal organs
6. Sensing the coolness of the forehead

In pain treatment, these exercises are frequently supplemented with positive self-verbalisations aiming to modify pain perception. Compared to PMR, AT has several disadvantages, such as a longer time needed for practising and a lower suitability for daily use. Although AT is often implemented in paediatric pain treatment and is very popular with therapists, so far, only one controlled study has indicated that AT is effective in inducing relaxation in children suffering from chronic headache (Labbé 1995). The problems with AT in paediatric pain treatment are that the patients have to become calm (and not respond with increased tension or pain) and must have a good imaginative ability. AT may be suitable for older girls and boys who have experiences with yoga or like daydreaming.*We believe AT is less suitable for children and adolescents with a pain disorder and may rarely be indicated in pain treatment.*

9.4.3 Relaxation Stories

A relaxation story is an abbreviated version of PMR or AT presented as a story for use in children up to 11 years—older patients may feel that this technique is below their level of maturity. A relaxation story aims to familiarise the child with relaxation techniques in a narrative and age-appropriate way. Its narrative character enables the patient to distance him/herself from the story, which decreases the risk of being flooded with interoceptive stimuli or memories compared to AT. On the other hand, it is difficult for a child to perform a relaxation story on his/her own. Thus, normally the child depends on an adult (e.g. his/her parents) to perform the relaxation. Its narrative character makes the relaxation story well suited to combination with hypnotherapeutic elements. This may be a suitable treatment supplement for younger children. Basically, the same premises apply as with PMR. But particularly younger children may better concentrate on a story. Due to the low risk of negative side effects, the suitability of this exercise can easily be tested by trial and error.

9.4.4 Biofeedback Therapy

Biofeedback therapy is a training technique, usually giving the patient visual (on a screen) or acoustical (with sounds) feedback on a psychophysiological process not accessible to direct perception. In this way, these processes are made visual or audible. This technique supports the patient in learning self-management strategies and improves self-esteem. Biofeedback is based on classical conditioning.

This technique can be implemented in an inpatient pain treatment as follows:

Biofeedback is introduced for children and adolescents 6 years and older by special trainers (at the GPPC, the training is implemented by nurses with special qualifications in biofeedback therapy). One biofeedback session should comprise 7–10 min of practical exercise, which is discussed afterwards. First, the patients evaluate their performance, before the trainer provides feedback. Two to three sessions per week should be conducted, with a total of ten sessions during the whole inpatient stay. There are large differences in how fast the technique is acquired. Once patients succeeded in relaxing, it should be tested whether this effect is also achieved without the biofeedback device. Only then can the relaxation be integrated into everyday life.

Procedure: Children and adolescents sit in front of a screen. A probe—the so-called multi-sensor—is placed on the ring finger of the non-dominant hand. This multi-sensor measures skin conductance as an indicator of the activity of the autonomic nervous system. This measurement is displayed on the screen (for example, with a curve diagram) and provides constant feedback on current physiological mechanisms. Further parameters can be measured via electrodes on the skin surface or via a respiratory sensor. For patients with migraine, a measure of pulse amplitude on the temporal artery (A. temporalis) can be used to train vasoconstriction. In the first session, the physiological parameters are measured but not displayed on the screen. Instead, the child sees a relaxing picture on the screen. At the end of the session, when the patient's performance is discussed, the trainer reveals his/her measurements and the patient realises how his/her thoughts and feelings about nice and difficult situations affected his/her breathing, skin conductance, physical tension and the cardiovascular system. The reaction patterns are very different. The feedback enables the patients to better perceive their bodily reaction and to distinguish between relaxation and tension. The measurements are often elevated at the beginning of the sessions, of which patients are not always aware. Biofeedback aims to create an awareness of one's own inner states. It is a training of interoceptive ability.

After having understood how thoughts and feelings influence physiological parameters, patients are asked to try to change these parameters, for example, reducing skin conductance or muscle tension, or breathing slowly and regularly. Biofeedback can be combined with relaxation techniques, such as mindfulness-based approaches or PMR to evaluate their effectiveness. The direct feedback on the success of the implemented techniques (via the measurements on the screen) increases willingness to engage in and improve these techniques. Biofeedback is motivating for children and adolescents, because this computer-based approach matches their media behaviour. The final aim is to be able to influence the autonomic nervous system without the help of the biofeedback devices in everyday life. This helps the patients to cope with difficult situations in everyday life without developing physical symptoms.

During their inpatient treatment, most children eventually succeed in positively modulating their sympathogenic activation (measured as muscle tension of the forehead or neck, electrodermal activity, or heart rate variability). In accordance with recent studies (Liedl et al. 2011), we also use biofeedback for the evaluation of treatment, meaning that children will undergo a biofeedback session, for instance, during their 'Stress Day' (Sect. 9.5.3) in order to evaluate the effectiveness of their learned therapeutic strategies. This will strengthen their self-efficacy.

9.4.5 Transcutaneous Electrical Nerve Stimulation (TENS)

TENS has its roots in behavioural medicine. In TENS, a weak alternating current stimulates neuromodulatory stimuli resulting in muscle relaxation, increased blood circulation, and pain inhibition. Electrical stimuli are assumed to stimulate peripheral nerves, muscles, skin and the subcutaneous tissue. This stimulation induces both spinal and central reactions of the nervous system which are thought to result in a segmental spinal pain inhibition.

The amplitude, pulse duration and frequency can be set individually. For chronic pain, 1–60 Hz are recommended, and for acute pain, 60–150 Hz. For smaller children, a device should be chosen that they can easily operate on their own. After a short instruction, most children quickly learn how to use the TENS device and are able to independently place the electrodes. Typically, the devices provide 10–14 different programmes. It is advisable to follow the manufacturers' recommendations for which programme to use, and it should be tested for two to three sessions. To encourage compliance, allow the child try several programmes until he/she has found the most suitable one. TENS may be applied for (Bronfort et al. 2004):

1. Pain due to accidents, circulatory disturbances, scars or musculoskeletal pain
2. Headache (migraine, tension-type headache)
3. Phantom pain

The electrodes are placed as near as possible to the painful area, which is often quite sensitive to touch. It is recommended to use the TENS for two to five sessions a day, each lasting approximately 30 min (>20–<50 min). Many children perceive TENS as beneficial from the very beginning and use it regularly. In most cases, however, there is no long-term effect. TENS can be easily integrated into the therapeutic setting as an additional module. It is particularly helpful, because even slight relaxation and pain reduction will support cognitive therapy. Furthermore, it reduces both fear of pain and pain-related feelings of helplessness.

A promising form of TENS therapy is graded stimuli exposure in children with a pronounced fearfully increased body awareness combined with advanced pain sensitisation. In this case, TENS is not used to achieve relaxation but as an exposure technique to reduce pain sensitisation (see Sect. 9.5).

9.5 Exposure Techniques—Facing the (Fear of) Pain

In pain treatment, we differentiate between in vivo and in sensu exposure. In vivo *exposure* comprises the gradual installation of a daily routine with all its rules and duties irrespective of the pain intensity and mood. The next step of in vivo exposure in the inpatient setting is the so-called 'Stress Day' during which the patient is confronted with strict time pressure while accomplishing various tasks (see Sect. 9.5.3 for a detailed description). For children who are not able to walk very far without crutches or a wheelchair, a graded *in vivo exposure* may be necessary.

In consultation with the physical therapist, the final goal of meeting the demands of everyday life may be subdivided into several consecutive but smaller tasks ('graded exercise'). *In sensu exposure* (*interoceptive exposure*) is included in pain treatment to control pain and increase self-efficacy. Apart from impairments in everyday life, fear of pain due to fearfully increased body awareness is of central importance to all children in maintaining pain symptoms.

9.5.1 In Vivo Exposure—Scientific Background

> 'What? You expect me to go to the city? I'm here to reduce my pain so that **after** that I can walk longer distances again'.

> 'Why should I increase my pain? I want my pain to diminish or vanish forever'.

Some interventions, such as cognitive and distraction or relaxation techniques, are easily explained to the affected child and his/her family. However, it is not obvious to the patient why he/she should expose him/herself to increased pain.

In vivo exposure is based on the assumption that the patient's fear of painful body movements will decrease with direct and graded exposure to feared body movements and confrontation of this fear. Contrary to the fears, patients observe pain reduction rather than their anticipated worsening of pain. This reality check enables changes in dysfunctional thoughts. Confrontation is particularly important for movement-dependent pain. The patient will gradually be able to increase activity, quality of life will improve, and in the long term, the pain will diminish (Bailey et al. 2010). The effectiveness of such a technique has been proven under experimental conditions in adults suffering musculoskeletal pain (Bailey et al. 2010; Leeuw et al. 2008). The evaluated inpatient treatment programmes for children with musculoskeletal pain describe in vivo exposure as a central treatment component which is partially responsible for their success (Sherry et al. 1999; Eccleston and Malleson 2003). In children with other pain locations (e.g. head or abdomen), it is not specifically the fear of painful movements but rather a mixture of general fear of pain and fear-associated perception of somatic signals which leads to the avoidance of activities and an increased pain-related impairment in everyday life.

9.5.2 In Vivo Exposure—Active Coping with Everyday Life

Irrespective of pain location, many children with a chronic pain disorder do not engage with their peers, do not attend school and are physically less active due to their pain—or more specifically their fear of an increase in pain. Consequently, they are easily exhausted, tired and not very resilient. Furthermore, a phase-shift in the circadian cycle and a less restful sleep can be observed in many children. In such a situation, it can be useful for the patient to participate in an active daily structure and to engage in all everyday life activities irrespective of pain intensity (except for untreated acute migraine attack) and mood. This requires highly competent NET staff and considerable time to motivate the child. Sometimes patients do not openly show their aversion to this exhausting new approach, but inform their parents instead, who will often try to achieve a rest for their child. Such a conflict delivers important diagnostic clues, such as family conflicts between autonomy and dependency, or parents supporting ambivalent therapy motivation. In a telephone call, the physician and psychotherapist try to re-establish the parents' cooperation in the treatment.

Lack of cooperation from the parents, even when the treatment concept is repeatedly explained to them, can endanger successful treatment and can result in premature discharge from the hospital. Cases like this point out the necessity of explaining the specific demands of inpatient pain treatment to the parents in advance.

In case of premature discharge, it should always be explicitly pointed out that re-admittance is possible. To this end, we offer another outpatient appointment where the child and the family have the chance to decide upon a second inpatient admission. In such a case, the child and his/her parents have to present their motivation and aims in written form. If sufficient motivation is not given, re-admittance does not make sense after having aborted the treatment due to non-compliance.

For children with a severe musculoskeletal pain disorder who are dependent on crutches or a wheelchair, or who demonstrate extensive resting and avoidance behaviour, the therapeutic approach must be modified. Together with the patient, and in consultation with the physical therapist, we develop a plan for graded exercise. This plan not only determines the final goal (e.g. no need to use crutches anymore for mobility) but also describes the individual steps (e.g. Step 2: to walk without crutches for 1 h and Step 10: to walk without crutches all the time while on the ward; being able to write with the hand; bending down, …). Even these severely impaired children are encouraged to follow active routines and coping strategies, and resting time is confined to a normal amount (1 h at midday) during which the child is encouraged to read, play or listen to music instead of taking a nap.

9.5.3 In Vivo Exposure—Stress Day

If the child succeeds in active coping and in performing the daily routine, the inpatient treatment also includes a Stress Day lasting from about 6:00 a.m. until 7:30 p.m. In the morning, the child receives a plan for the day including a detailed list of all the tasks he/she is expected to do on that day. A Stress Day usually includes doing all routine duties on the ward, planning and organising several tasks, performing meaningful as well as senseless tasks, and engaging in several simple and difficult social situations (for examples, see Chap. 15, worksheet #13). The Stress Day is discussed with the patient and his/her parents in advance. The child receives a certain number of 'time-out cards' which the child may use to pause for 10 min at any chosen time, for instance, to practise a stress or pain reducing technique. The child is allowed to interrupt the Stress Day at any time, so that he/she is always in control of the situation.

The Stress Day is an experiment from behaviour therapy, which may well be combined with the testing of dysfunctional cognitions due to its similarity with the behavioural experiments in cognitive therapy (Sect. 9.3). The Stress Day helps to answer the following questions:

1. How will my body react to severe time pressure?
2. Will my pain actually increase during or after the Stress Day as forecasted by the psychotherapist and the NET?
3. How will I cope with senseless or boring tasks?
4. When will I begin to react stressed or annoyed?
5. How many of the time-out cards do I need?
6. Should the NET notify me if they think I need a time-out?
7. Will I notice somatic stress signals early, or will the pain need to be severe in order to notice stress?
8. Which thoughts or appraisals contribute to my perception of stress on a pre-arranged and structured Stress Day?
9. Will the various techniques practised during a time-out help me?

Prior to the Stress Day, those questions are discussed with the child to evoke curiosity and ambition. The Stress Day should not be conducted prior to the second week of treatment. At this point, the child will already be familiar with several pain coping techniques. The psychotherapist should discuss his/her expectations with the child, for example, ‘I believe that it will be difficult for you to do boring tasks. Thus, I ask you to particularly observe how you and your body will react in these situations. Do you agree? Or do you rather think this won’t be a difficult task for you?’ It is helpful to preschedule both an individual therapeutic session and a biofeedback session for the Stress Day. The individual therapy session serves to discuss any acute difficulties or queries regarding stress or pain coping, while biofeedback will directly show the child the current stress level and give the opportunity to directly observe how well the learned therapeutic techniques work.

On the very next day, the above-mentioned questions help to extensively reflect on the Stress Day. Any implications arising with regard to the child’s future pain treatment are discussed. For instance, a high increase in the pain score and the need for many time-outs show that the child still has difficulties coping with even artificial daily ‘hassles’. Consequently, repetition of the Stress Day might be worthwhile as could be addressing the child’s dysfunctional appraisals.

On the ward, the newly admitted patients get the opportunity to observe how time pressure affects mood and somatic symptoms in their fellow patients. In children with psychiatric comorbidities (i.e. anxiety disorder, adjustment disorder and depressive episode) the Stress Day may be modified (Sect. 10.1).

Although the Stress Day is discussed in detail in advance, problems may arise during its implementation. These are the most frequently experienced problems and possible solutions:

(a) Some children don’t want to show any weaknesses and don’t take time-outs. They rather endure pain that constantly increases in strength, instead of asking for help. Usually, the therapist is able to anticipate this, because often this occurs in patients who are perfectionistic and/or have a social phobia. The therapist should discuss this behaviour in advance and should determine an obligatory time-out. Another possibility is that the child agrees that the NET may prescribe a time-out in case of clear signs of stress. If the patient does not agree with this procedure, this should be discussed in detail during the reflection of the Stress Day and is an important information that needs to be considered when planning for the time after inpatient treatment.

(b) It is possible that children with chronic fatigue and/or depressive symptoms can't cope with the Stress Day. If the therapist anticipates this, it is advisable to start with half a Stress Day (or a few hours in individual cases). Sometimes this cannot be anticipated, because the children feel very confident in advance, but then want to stop the Stress Day. If the NET doesn't succeed in sufficiently motivating the child to go on, the Stress Day should be stopped and discussed in detail. The therapist explains to the child that this is very important for further treatment planning. Often, the treatment emphasis needs to be more about coping with daily hassles and self-management and less about pain.

(c) Children who are easily offended and/or irritated may have problems with senseless tasks and interpret these tasks as a personal attack. Since this trait can be detected beforehand, a plan for coping with these perceived affronts needs to be established and the possibility of misinterpretation should be discussed. Often these children are quite good at self-evaluation and have good ideas for how to cope with a possible crisis. If children are too irritated or too easily offended, senseless tasks should be omitted for the first Stress Day.

9.5.4 In Vivo Exposure—Graded Stimulus Exposure Using TENS

Patients with excessive fearfully increased body awareness and/or prolonged pain chronification experience even the slightest TENS stimulus—not even noticeable in most people—as painful. This finding of neuronal sensitisation is discussed with the child ('pain memory', 'pain gate') to validate his/her perception and to dispel fears of an underlying disease. If the patients understand this education, they mostly ask if this process can be reversed. Once they understand the principle of desensitisation (getting used to (actually) non-painful TENS signals step by step to reduce body awareness to a normal level), they are usually very motivated to use TENS despite a slight pain. The best way is to start with the lowest intensity of the TENS device and gradually increase stimulus intensity. The child uses the lowest possible level for 20–40 min daily until he/she can endure it and not perceive it as unpleasant. Then intensity is increased by one step. Note that progress with regard to the tolerated stimulus intensity may well differ between electrode locations (example: after 1 week of practising, Lisa (15 years) perceived a stimulus level of 5 with the electrode placed on the left side of her neck as just bearable. On the right side of her neck, a stimulus level of 8 was bearable).

9.5.5 In Sensu Exposure—Interoceptive Exposure (Pain Provocation)

The vast majority of children with a pain disorder suffer from head or abdominal pain, while a smaller proportion experience pain associated with movement of the musculoskeletal system. It can therefore be assumed that the Vicious Cycle of Pain and avoidance in these children with head and abdominal pain is not triggered by fear of movement but by the fearful perception of bodily signals (e.g. tension, pressure or proprioceptive signals). Based on this assumption, we developed the pain provocation technique, a form of interoceptive exposure (exposure with feared bodily signals) (Dobe et al. 2009; Hechler et al. 2010; Flack et al. 2018).

Interoceptive Conditioning

Development

Fear of pain is assumed to play an important role in chronic pain maintenance (Asmundson et al. 1999; Vlaeyen and Linton 2000; Crombez et al. 2012). According to the 'Fear-Avoidance Model', fear of pain is developed if perceived bodily sensations are interpreted as threatening and pain elicits hypervigilance (Vlaeyen and Linton 2000; Crombez et al. 2012). This leads to an increase in pain perception and avoidance behaviour, which in turn maintains pain-related disability (Vlaeyen and Linton 2000; Crombez et al. 2012). Children and adolescents avoid everyday activities which are expected to elicit pain. Avoidance behaviour develops due to the anticipation of pain and not as a reaction to pain. The basis for this mechanism is associative learning processes: internal and external stimuli are learned to predict pain and become a conditioned stimulus (CS).

If a patient correctly anticipated pain and he/she developed a mental representation of this association, fear of pain and accompanying passive behaviour (e.g. avoidance behaviour) can elicit a conditioned reaction (CR) (Vlaeyen 2015). This CR serves to predict further pain and decrease the risk of future pain perception by avoiding associated behaviours (Vlaeyen 2015). A CS can be exteroceptive (e.g. auditory), proprioceptive (e.g. changes in balance), and interoceptive (e.g. bodily sensations in muscles, skin and inner organs) (Gatzounis et al. 2012; Vlaeyen 2015; Crombez et al. 2012).

It is assumed that an interoceptive CS needs to appear proximal to the pain location and in temporal relation to the unconditioned stimulus (e.g. pain) (Gruszka et al. 2018). Thus, interoceptive stimuli which occur simultaneously with a pain perception and in the same part of the body as the primary pain location (e.g. slight feeling of pressure on the head for patients with headache) can more easily become conditioned stimuli and elicit a conditioned fear reaction than interoceptive stimuli that occur in another part of the body (De Peuter et al. 2011). As a result of this fear, the children direct their attention to their surroundings and their own bodies (interoception) to check for signals that can predict the occurrence of further pain (Rief and Broadbent 2007; De Peuter et al. 2011).

Interoception becomes maladaptive if it is associated with pain-related disability via conditioning processes (De Peuter et al. 2011). De Peuter et al. (2011) call this form of conditioning 'interoceptive conditioning'. Pain consistently leads to behaviours that aim to stop the pain (e.g. lying down, resting). Non-painful bodily signals that are associated with pain become conditioned to the pain (e.g. slight tension in the abdomen may lead to pain perception; a slight tension in the neck may lead to headache; or bending down or a spine twist may lead to back pain). As a consequence, those affected try to avoid pain by avoiding these intrinsically non-painful bodily signals. The resulting, often complex, avoidance and inactivity further leads to increased impairments in everyday life, muscle loss, chronification of resting behaviour and ongoing confirmation of catastrophising thoughts.

An experimental study at the GPPC systematically investigated whether provoking interoceptive sensations can elicit fear reactions in adolescents with a pain disorder (Flack et al. 2017). The interoceptive sensations were either proximal to the primary pain location (e.g. frowning for patients with headache, tensing the belly for patients with abdominal pain) or distal to it (e.g. patients with headache or abdominal pain had to clench their fists). Self-reported fear and avoidance reactions were assessed with an 'instructed-fear paradigm'. Patients with abdominal pain reported stronger fear and avoidance reactions after provoking proximal interoceptive sensations compared with distal interoceptive sensations. This difference was not found for patients with headache. These results reveal that for patients with abdominal pain, interoceptive sensations in the belly can elicit fear and avoidance reactions (Flack et al. 2017). Against the background of the 'Fear-Avoidance Model', this study provided first evidence for a conditioned fear reaction in patients with abdominal pain (Flack et al. 2017).

Maintenance

The conditioned interoceptive stimuli can elicit fear of pain and avoidance behaviour (De Peuter et al. 2011). Interoceptive stimuli can hardly be avoided, but their frequency and intensity may be reduced by reducing physical activity. This results in an operant conditioning (negative reinforcement) of the pain symptoms: If resting reduces fear and/or pain, then it will likely be continued or repeated. This explains the increasing pain-related disability in everyday life (De Peuter et al. 2011).

A vicious cycle is initiated if restricted activity leads to reduced fitness and normal activity elicits interoceptive stimuli (e.g. an increase in heart rate, sweating or physical exhaustion) which in turn are associated with pain (Asmundson et al. 1999). Pain-related fears, anxiety sensitivity and pain catastrophising intensify this process (De Peuter et al. 2011) (see Sect. 3.3).

Consequences and Further Reinforcement

As a consequence of the described processes, a pain disorder may contribute to a distorted perception ('Somatosensory amplification'; Nakao et al. 2007; Rief and Barsky 2005). This means that somatosensory stimuli, which are usually filtered and not consciously perceived by healthy people, are more easily perceived and interpreted as potentially threatening by patients with a chronic pain disorder.

The classification of these increased bodily perceptions can further be biased, for instance, through certain negative experiences and corresponding expectations, memories or traumatisation (Gonzalez et al. 2011; Rief and Barsky 2005; Rief and Broadbent 2007). For example, if a patient experienced physical attacks on his/her back by his/her father, then pain in the back will automatically be perceived as more threatening in the future. In the worst case, back pain will elicit memories of the trauma ('Flashback') through classical conditioning (see Liedl et al. 2011). This may be one reason for the high comorbidity rates between chronic pain and posttraumatic stress disorders (e.g. Asmundson et al. 2002).

These hypotheses can be confirmed in studies with adults. Gregory et al. (2000) demonstrated that adult patients with head and abdominal pain showed a greater maladaptive perception of interoceptive stimuli. The degree of the distorted perception depends on how much interoceptive stimuli negatively interfere with concentration (Witthöft et al. 2011). Interestingly, this effect was modulated by emotional distress (e.g. stressful life events or fears). These results indicate that a distorted perception and high levels of emotional distress may have a strong impact on the development and maintenance of a pain disorder for children and adolescents.

Research indicates that anxiety sensitivity, somatosensory amplification and emotional distress contribute to the development and maintenance of a chronic pain disorder in children and adolescents.

Summary

In summary, the following processes of interoceptive conditioning can be assumed to underly chronic pain in children and adolescents:

1. When in pain, children with chronic pain develop strong pain-related fears. Consequently, they try to avoid the pain by, for example, reducing physical activity. Conditioned stimuli, such as bodily signals, may then predict pain.
2. The interoceptive perception of these signals is modulated by anxiety sensitivity and elicits fear of pain. Accordingly, children focus on bodily signals that are associated with pain.
3. They perceive bodily signals with more sensitivity—due to a lower threshold of perception—and interpret these stimuli as negative and potentially threatening.
4. On the basis of these processes, fear of pain and pain catastrophising are increased, which in turn increases body awareness and tension.

The consequence is an increase in pain-related disability due to avoidance behaviours, which maintains the pain (Asmundson et al. 1999). Therefore, a reduction in pain-related disability is an important goal of treatment. Apart from the active behavioural interventions for everyday life (in vivo exposure) described above, a normalised and less fearful body awareness with reduced fear of pain seems to be indicated.

The overall goal of interoceptive exposure should be to reduce the association between interoceptive stimuli and fear of pain and to learn new associations. Thus, the interoceptive stimulus should not be followed by a conditioned stimulus (fear of pain), but by positive stimuli (e.g. reduced pain perception after implementing an effective pain coping strategy). These new associations should inhibit previous associations more and more (Craske et al. 2011). How can such an interoceptive exposure be conducted with children and adolescents with a pain disorder? The GPPC has developed a technique of interoceptive exposure (the pain provocation technique) that has been evaluated in a randomised controlled trial (Dobe et al. 2009; Flack et al. 2018—see Chap. 16 for a detailed description of the study).

The Pain Provocation Technique (PPT)

Consistent with other confrontational approaches, the suitability of PPT has to be explored in terms of the child's emotional stability.

Prerequisites

Pain provocation cannot be started before the following four requirements are met.

1. The child is able to reduce the pain by one point on a numerical rating scale of 0–10 by means of a previously learned technique.
2. The child agrees upon a signal to interrupt the exercise if he/she can't increase or decrease the pain on his/her own.
3. A way to proceed in case of interruption should be discussed in advance. In case the child cannot increase the pain, the standard arrangement is that the psychotherapist supports the child in focusing attention on his/her pain and memories by providing affective words (e.g. 'Remember how awful your pain was when [insert situation]'). However, this is rarely the case and usually only observed in children with such high levels of fear of pain that makes them unconsciously focus on non-pain-related topics. A procedure to follow when the child is worried about not being able to decrease the pain on his/her own should also be agreed upon in advance. In such a case, we recommend that the child and the therapist practise one of the already learned distraction techniques together. Simultaneously, the therapist should repeatedly re-establish the reference to reality and surrounding objects (e.g. the therapist could ask: 'How many objects starting with an 'A' do you see in this room?').
4. Finally, before pain provocation is practised for the first time, the child should have expressed an opinion of how he/she would like the therapist to behave during the exercise. For some children, especially traumatised children, it is important that the therapist observes them closely in order to respond quickly, if necessary. Other children prefer that the therapist is involved with other things in the room, or keeps his/her eyes closed to perhaps implement the technique by his/herself.

Procedure

The child (mostly with his/her eyes closed) should focus on that part of his/her body currently, or in the case of recurrent pain, usually, exhibiting the most pain. At the same time, the child should evoke pain-related memories or Black Thoughts (e.g. any painful movements, or thoughts of certain events that are associated with an increased distress level and thus with severe pain, such as a quarrel, time pressure or exam). In some children, concentrating on the pain is enough. For others, just thinking certain Black Thoughts or evoking negative memories associated with pain, is sufficient to provoke pain. Since the goal is to face the pain, it does not matter how the pain is elicited. Having increased the pain by one point (NRS 0–10), the child should say aloud 'STOP' (in order to give feedback to the therapist, who cannot notice the increase in pain, and to make the child understand that he/she can control, or stop his/her thoughts).

Directly afterwards, a trained pain coping strategy (e.g. distraction-ABC, or 'Safe Place') is practised until pain intensity has decreased by one point. Then the child finishes the exercise saying aloud once more 'STOP'. In Chap. 15, we enclose written instructions for the introduction of pain provocation (worksheet #17).

Further Procedure

Practising the technique for the first time usually does not take more than a few minutes. Having finished, the child is asked how exactly he/she succeeded in increasing the pain intensity; if after stating 'STOP' the pain ceased to increase; and how exactly he/she managed to finally reduce the pain intensity to where it was before the exercise.

The child is then asked to repeat the exercise in order to allow him/her to do an alternative procedure. Subsequently, the child may decide on how often he/she will repeat the exercise until he/she feels able to do it as homework on his/her own (usually after practising two to three times). We recommend practising alone three to four times a day.

If the child succeeds in the first step of pain provocation, the next step is to increase pain by *two* points, and bring it down again. Usually, we also implement the following steps: pain increase by two points and pain reduction by three points (+2/−3), and +2/−4.

Successfully learning the method proves to the child that the biopsychosocial model used in the education sessions is not just theory but is indeed reality. Moreover, after introducing this technique, there is usually no need for further clarifications of biopsychosocial associations anymore. This considerably increases the treatment motivation. Furthermore, children indicate that their self-efficacy is significantly increased (e.g. 'I am able to influence the pain after all!' or 'The techniques are really helpful!').

Contraindications

Pain provocation must not be used in children with a comorbid eating disorder, particularly of the anorexia nervosa type, as their increased body awareness enables them to easily increase pain intensity, but impedes subsequent pain reduction. Pain provocation is contraindicated in active/florid psychosis, as these patients' abilities to organise and plan their actions are typically highly impaired. Similar reasons apply for not using this technique with children with a comorbid major depressive episode.

Restricted Scope of Application

In children suffering dissociative symptoms or posttraumatic stress disorder, pain provocation should only be applied by an experienced psychotherapist if the children are sufficiently stable.

9.6 Active Pain Coping on the Ward

> *It is impossible to get up. My pain is so bad, I can't bear it any longer.*
> *—Philipp (13 years)*

We have already reported on the necessity of active pain coping irrespective of pain intensity. We have discussed in depth how to best educate children about the background of chronic pain in order to make them motivated and cooperative. We have also presented useful strategies for pain reduction.

However, for a child with chronic pain in need of inpatient pain treatment, all these techniques are often not enough to enable him/her to cope actively with the pain in everyday life. In particular, children with pronounced passive pain coping and a large number of school absences will have difficulties implementing active pain coping into their 'normal' everyday life at the beginning of inpatient pain treatment.

The NET plays a crucial role in implementing an active daily structure and active pain coping strategies. This means that after the first night on the ward, which may not be too refreshing for many patients, the NET will prompt the child in a polite, understanding, but insistent way to get up out of bed irrespective of his/her severe pain. The child's comments regarding the pain should be taken seriously but left uncommented. The NET may refer to the rules of the ward, or the upcoming appointment with the psychotherapist or physician instead.

> 'Sure, you have severe pain. Otherwise, you wouldn't be here. But, staying in bed didn't help at home. And as you know from your outpatient appointment and the admission session, we are not allowed to make any exceptions to the ward rule. But I can offer to write a short note to your doctor or therapist telling him/her how difficult it is for you to get up, okay?'

The same applies to all prescheduled activities on the ward (meals, group sessions) as well as to the activities arranged by the child him/herself. Regarding sports (swimming, psychomotor activities), the motto is to 'participate at one's best'. This uncompromising but respectful attitude has proven effective. With the help of the NET, most children will successfully join the ward's daily routine even after months of passivity in everyday life at home. The NET will collect all sorts of complaints and behavioural observations and inform the responsible psychotherapist or physician (with the child usually informed of this). This close cooperation between NET, physician and psychotherapist enables most of the children to actively cope with their pain from the very beginning and is essential for successful treatment.

To facilitate the NET's work, the following aspects should be considered:

1. During the outpatient appointment in the pain clinic, before admission, the child and his/her family are informed of the importance of active pain coping, a normal everyday life and the child's obligation to do his/her therapeutic homework. The child and his/her parents are told plainly that the first few days of inpatient treatment will be quite difficult in particular. If it turns out that such an approach seems too rigorous for the child or his/her parents, it might be helpful to discuss their alternatives (which in most cases will be a form of 'Before my child can do that, the pain must decrease'). Sometimes, it may be helpful to meet the family halfway (for an example see Sect. 10.3). However, the principles of active pain coping should never be given up. Only a minority of families feel that the demands of treatment are too high, so that they agree on admission but not on normal everyday life on the ward. In such cases, it is better to abstain from admission and invite the family to contact the clinic when they are more open to the clinic's approach. After having successfully completed their pain treatment, many children report that it was precisely that rigid attitude of the NET and the therapeutic team that gave them security and hope.
2. If, during the stay on the ward, active pain coping is refused by the child, the parents should be informed and instructed on how to support their child. If the parents are not able (or do not want) to motivate their child for active pain coping, it is time to end the inpatient pain treatment, as continuing would result in permanent frustration on the part of both the patient and the NET, and inferior outcomes for the patient.
3. The close cooperation between the NET, physician and psychotherapist on the ward is one of the prerequisites for successful support of the child in active pain coping. The NET is able to support 10–20 children in coping with the demands of everyday life on the ward, provided that all participants cooperate closely (and the child recognises this, that is, he/she knows that the psychotherapist and physician are always well informed about the NET's behavioural observations), all patients are treated equally (suffering the same burden with their active pain coping), and there are no alternatives to active pain coping.
4. The NET should regularly update their knowledge on the treatment of chronic pain.

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Inpatient Pain Treatment: Module 3 (Supplementary Interventions for Comorbid Psychiatric Symptoms)

10

Michael Dobe and Boris Zernikow

> *Whenever I feel severe pain, I automatically remember what "he" has done to me.*
> *—Lena (15 years).*

Contents

Abstract

Due to frequent comorbid psychiatric symptoms in patients with a pain disorder, an adaptation of the pain treatment programme to the patients' needs is often indicated to ensure that the treatment is successful for these children and adolescents. Although this programme is no substitute for the treatment of psychiatric or somatic comorbidities, pain therapeutic interventions as described in Chap. 9 (module 2) often contribute to the amelioration of psychological disorders, as they encourage adaptive changes in cognition, emotion, somatisation,

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M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_10

and attention processes. In the following chapter, we discuss some specific interventions for treating children with comorbid anxiety disorders, depressive episodes, or adjustment disorders with depressive reactions, a limited ability to cope with stress, lack of self-regulation, or social phobia.

10.1 Limited Stress Tolerance: The Special Stress Day

How can you do this to me? You are doing it on purpose.—Melissa (16 years), during her Stress Day, focusing on conflict-solving strategies.

The Stress Day described in Sect. 9.5 must be modified if a comorbid psychological disorder is present. Children need to be familiar with the basic idea of cognitive therapy (ABC-scheme according to Ellis). They also need to be motivated to conduct a protocol of thoughts (C → A → B; see Sect. 9.3) in case of a pain increase, deteriorating mood, an increase in physical tension, or exhaustion.

1. If the patient suffers from pronounced exhaustion combined with little ability to cope with stress (e.g. due to adjustment disorder with depressive reaction or mild depressive episode), the Stress Day may be shortened to some hours, or half a day. The child will have a sense of achievement and will be gradually led to normal stress-coping (graded exposure) without the risk of symptom escalation.
2. In case of substantial social insecurity or even social phobia, it has proven successful to integrate some smaller exposure to social situations into the Stress Day, e.g. making a phone call to a telephone hotline; setting up a travel plan with public transit; talking to a stranger (e.g. a salesperson in a bakery); holding a lecture for the fellow patients; and organising afternoon activities for the group. It is important that the child has consented to this procedure in advance.
3. Analogous to the approach used for social phobia, other specific fears or phobias could be integrated into the Stress Day. For instance, a patient with needle phobia may hold a lecture on injections and demonstrate a real injection. Of course, the child has to consent to this procedure in advance.
4. A different approach is required for a child who tends to react impulsively and/or aggressively when he/she feels that he/she is treated in an unfriendly or unfairly manner. For these children, a Stress Day should be constructed, in which the nursing and educational team (NET) is unfriendly and strictly insisting on completing all tasks. This is an enormous challenge for such a child and he/she will experience very intense stress, physical tension, aggression, or pain during such a Stress Day. Psychotherapists and the other team members should be aware that such a Stress Day could escalate, if not well prepared. As a preventive measure, the child should inform the other patients on the ward that he/she explicitly asked for an unfriendly version of the Stress Day. The affected child should be able to stop the unfriendly version of the Stress Day anytime and switch to a

‘normal’ Stress Day. The NET should also repeatedly make this clear to the patient. On the other hand, if the NET has the impression that the child feels extremely offended, they may interrupt the Stress Day for a brief discussion and reflection of the situation with the child.

5. For children who previously experienced bullying or substantial disappointment regarding their social relationships, a good option is to confront the child with tasks and scenarios in which he/she has to do something for the NET, or other children. This form of the Stress Day should also be discussed in detail in advance with the child and everyone on the ward. It is important that the patient sees the Stress Day as a chance for some changes in dysfunctional patterns and that it does not strengthen the patient’s distrust towards a presumably hostile world.

Although the implementation of such Stress Days is very challenging, a successful Stress Day is very useful for the patients to experience a feeling of success and change behavioural patterns associated with pain chronification.

10.2 Trauma Therapeutic Interventions and Methods for Stabilisation

It’s over now.—Moritz (14 years), after having finished a trauma exposure.

Not every stressful life event is a critical life event, and not every critical life event is a traumatic experience for the patient. It is more and more recognised that the term ‘traumatisation’ clearly defined in adults cannot readily be transferred to children or adolescents (e.g. van der Kolk and Courtois 2005). In the child, both the current developmental age and the developmental age at the time of the stressful event are important factors for the understanding of the child’s processing of a stressful, emotional experience. A situation may be experienced as traumatic by a child but only very stressful and not traumatic by an adult. The foreseeable loss of a grandmother after a long and severe disease may become a traumatic experience to the child under unfavourable circumstances, for instance if the grandmother was the only close attachment figure. The same may be the case when a family court judge asks a 10-year-old boy in the absence of his parents for his opinion on his parents’ extreme conflicts, and with which parent he would like to live in the future. Depending on how severe the parents’ custody conflict is and what incidents have happened between the parents so far, such a questioning may be experienced by the child as a threat to his existence, and (re)trigger traumatisation.

A significant proportion of children with a pain disorder suffer from very stressful memories (visual, auditory, or kinaesthetic). These memories may have their origin in surgery; an accident; a death; sudden, severe psychological disorder or physical illness of a beloved attachment figure; the experience of domestic violence; ambiguous, unacceptable parental behaviour (i.e. the father standing up menacingly in front of his child, making him/her fear physical violence although it is not acted out); sexual abuse; alcohol excesses of a parent; extreme bullying; or a conflict-loaded parental separation.

Particularly if therapy-resistant chronic pain is caused by sports or traffic accidents, processing patterns that are in at least one aspect suggestive of traumatisation, play an important role. Some of these patterns are: hyperarousal combined with high physical tension; substantial problems with concentrating; and pronounced avoidance behaviour. It is well known that even experiencing or witnessing domestic violence (not necessarily as the victim) is predictive for the development of chronic abdominal pain (Sansone et al. 2006). In a study by Seng et al. (2005) with children aged 9–17 years, posttraumatic stress disorder (PTSD) was a risk factor for the development of chronic abdominal pain (odds ratios: simple PTSD = 4.5; complex PTSD = 14.9). Young Casey et al. (2008) demonstrated that past traumatisation significantly influences whether acute back pain becomes chronic. Traumatic life events and chronic pain seem to mutually maintain and reinforce each other (Asmundson et al. 2002; Liedl et al. 2011). This is likely to be mediated by interoceptive conditioning (see Sect. 9.5). Thus, simultaneous treatment of traumatic symptoms and chronic pain may be useful (Asmundson et al. 2002; Liedl et al. 2011).

Many affected children fulfil the diagnostic criteria of the common diagnostic manuals of PTSD. But there are also many patients who suffer severely from their past experiences and subsequent consequences without fulfilling all PTSD criteria. Often, these experiences occur in the context of constant problematic family situations. While they do not fulfil the criteria of a full-blown PTSD, they may meet the criteria of an adjustment disorder or a non-specific trauma disorder.

According to our experience, it is best that all concurrently present pain and trauma disorders be addressed at the same time. This is true irrespective of the possible existence of any causal connection between the two disorders. In the education sessions, it is important to point out that stressful or traumatic life events are associated with pain perception, and that they mutually maintain and reinforce each other. The following examples illustrate what this means in everyday life.

1. Justin (17 years, pain disorder associated with both psychological factors and a general medical condition, back pain) developed chronic back pain after a severe swimming accident (causing incomplete paraplegia and dependency on a wheelchair), and eventually, very painful surgery. Remembering the surgery increased his pain perception by two points within seconds, with concomitant pronounced vegetative symptoms and difficulties in concentrating.
2. Judith (16 years, CRPS type I, left foot) told us that whenever she painfully mobilised her left foot for some time, she became very exhausted, then suddenly very sad and hopeless, which triggered intrusive memories of a traumatic sexual assault that happened 3 years before. When she entered pain treatment, Judith had never told anybody about this sexual abuse due to her fear of the offender.
3. Mohamed (14 years, pain disorder with both psychological factors and a general medical condition, headache) reported that since being involved in a severe traffic accident 2 years ago, he suffered severe constant headache (the person who

caused the accident had died at the scene). Certain traffic scenes make his severe headache even worse, while pain peaks also trigger memories of the traffic accident.
4. Whenever Patricia (14 years, somatoform pain disorder) had back pain (for instance after physical exercise) she suffered stressful memories from her childhood, which was dominated by family violence. In one of her memories, her drunken father throws her so violently against the wall that her whole back hurts afterwards.

Pain treatment for these children is made more difficult by the fact that passive pain coping has so far been a solution to coping with stressful memories. Engaging in active pain coping means incurring an increased risk of stressful memories. This may increase the emotional burden.

In principle, many techniques presented in Chap. 9 are suited to reducing the emotional burden caused by traumatic memories (particularly the imaginative ('Safe Place' in particular), distraction and mindfulness-based techniques). Further trauma-specific stabilising techniques are the 'Safe' exercise and distancing techniques such as the 'Screen-technique'. Sufficient emotional stability and inner distancing are indispensable for successful pain treatment.

Trauma exposure or processing stressful life events are not necessary prerequisites for a successful start to pain treatment (although both are indicated in a subsequent outpatient psychotherapy). This approach will take the psychological pressure off children for whom trauma exposure is contraindicated in the foreseeable future (e.g. instable environment, high emotional burden, or contact with an offender cannot be avoided at the moment).

Special training and experience in trauma therapy are necessary for responsible and helpful training of stabilising techniques. If the initial stabilisation of the patient is guaranteed, pain treatment can be successful; it may contribute to further reducing the emotional burden and impairment of everyday life. However, only the subsequent successful treatment of the trauma disorder will prevent reactivation of pain symptoms. An untreated trauma disorder will result in severe physical tension due to the concomitantly disturbed regulation of emotions and stress. Often difficulties with concentration and sleep also arise. Together, these symptoms increase the risk of reactivating and maintaining the pain disorder.

Two different kinds of stabilisation techniques can be distinguished: those that reinforce positive feelings or the access of inner resources to create an inner balance for the stressful memories (associative techniques), and those that reduce the emotional distress of the negative memories (dissociative techniques). A well-known associative strategy is the 'Safe Place'. In the following, we shortly describe two well-known and helpful dissociative strategies that are usually taught in trauma therapy training.

1. The *'Safe' exercise* will teach the child to lock stressful or traumatic memories into an imagined safe (alternatively: room, cupboard, box, place, …) in order to be less burdened by those intrusive memories in everyday life. A rational

dissociative ability (e.g. the ability to 'lock' thoughts, emotions, or memories) is used as a resource (for survival) and not regarded as problematic behaviour. There should be enough time to 'develop' the 'Safe', mostly more than one therapeutic session. The child's spontaneous ideas should be allowed even if this will change the 'Safe' several times. With gradually increasing stressful memories, the child may test step by step if the technique works. The more sensory channels (i.e. visual, auditory, haptic) are involved, the more precise the various steps that are practised (locking, re-opening, taking out and putting back the memory) and the earlier the child visually realises the safe (e.g. painting, collage, photograph), the more he/she will benefit from the exercise.

2. The imaginative distancing techniques (also named 'screening' techniques) follow a different approach. The best-known variant is the '*Screen-technique*'. With this technique, the emotional burden of mainly visual intrusions, is reduced by having the child transfer his/her stressful images or films onto a TV screen (big-screen, monitor, DVD-player, smartphone, etc.) installed in an imaginary room. Thus, the child can watch these intrusions 'from a distance'. With the help of an imaginary remote-control (alternatively: helper; magic abilities; …), the child may try to modify speed, play mode (fast-forward or -backward), colour mode (black and white, colour), or tone (loud/quiet, distorted). The film may be switched on and off, the child may insert breaks or create still-pictures for particularly stressful situations. There is no limit to creativity (e.g. press the 'comic' button and all voices change to Donald Duck character). As with the 'Safe' exercise, stepwise installation is recommended, starting with the less stressful 'films' and using as many sensory channels as possible. In complex traumatised children, it has proven helpful to instruct them to use the various buttons of the remote-control so that they can keep their emotional burden (and thus their hyperarousal) in a medium range. In that context, avoiding extremely stressful memories is interpreted as a sign of active self-defence which helps the child to control his/her hyperarousal (constructive avoiding).

Apart from training the child in stabilisation techniques, the therapist should explore if the child has any dysfunctional cognitions associated with the trauma, such as 'It's my fault', 'I could/should have prevented it', or 'It happened to me because I deserved it. And that is why awful things will happen to me again and again'. These cognitions ('trauma logic') must be addressed in therapy since their concomitant inner tension helps maintain both trauma and pain symptoms.

In addition to the standard pain education, we recommend using disorder-specific manuals for trauma education. This education will inform the child and the parents that generating dysfunctional cognitions is quite a normal process for which the child is not to blame. These cognitions of guilt need to be reduced, as soon as the child has received sufficient information about the trauma disorder, because these cognitions are a constant reminder of the traumatic event and maintain the trauma disorder. This process usually takes months. At the very beginning, the therapist has to make clear to the child that he/she is not even theoretically to blame and why not.

The therapist should provide evidence for his/her reasoning that is plausible for the child. Until the next session, the child is asked to write down these arguments why he/she is not to blame (he/she does *not* need to believe these arguments yet). In the next step, the therapist discusses and refutes counterarguments (e.g. 'I am to blame because I didn't run away!'; 'I didn't defend myself when he touched me!'; 'If I wasn't so difficult, my mother would not have attempted suicide!'; 'It must have something to do with me, otherwise it would not have happened to me!'). The child is asked to write this down, too. As soon as the child feels slightly confused (e.g. 'Actually, I know that I am not to blame, but I feel guilty'.), the therapist explains that it is normal in this phase of confusion that victims are still used to believing that they are to blame, although they know it is not true. In this phase, it is helpful for the child to record situations in which such thoughts arise and to discuss, refute or alleviate them with the help of the counterarguments.

Once the child is stabilised and the family setting provides enough support and safety, it may be adequate to schedule a trauma exposure task concurrently with inpatient pain treatment. In addition to classical trauma exposure (e.g. cognitive trauma therapy according to Ehlers, eye movement desensitisation reprocessing (EMDR)), pain provocation may be used for interoceptive stimulus exposure (Sect. 9.5) in case of close interoceptive conditioning of trauma and pain stimuli (for example, after surgery or traffic accidents).

Case Report: Miriam (15 Years), CRPS Type I, Left Foot and PTSD

> 'Half a year before admission to pain treatment, Miriam had a severe traffic accident in which she and her family came close to death. Every day she recalled the cries, the smell of scorched cables, and some scenes from the hospital. Whenever she saw or heard an ambulance, she experienced a very stressful inner tension. Sitting in a car had become a strong emotional burden for her, so she tried to avoid doing so. Her severe pain due to CRPS resulted in pronounced helplessness and increased her inner tension which itself triggered her bad memories. Experiencing such helplessness frequently reminded Miriam of a stressful event in her childhood (attempted sexual abuse by a stranger). With the help of the 'Safe' and mindfulness-based exercises she was able to be well stabilised. Concurrently, she engaged in active pain coping, graded exposure for CRPS, and a total of three trauma exposures (EMDR). This combination resulted in a very successful processing of the accident. At the end of her stay, she was able to sit in a car again, which made her so happy and motivated that she decided to start outpatient psychotherapy, with the focus on trauma therapy, in order to work on the sexual abuse'.

Pain provocation is a technique with lower emotional burden (see Sect. 9.5 and Chap. 15, worksheet #17). Children with stressful memories are instructed to focus on both the pain location and the stressful memory. The aim is to enhance self-efficacy and active coping by first increasing, then decreasing both pain intensity and emotional burden (Dobe et al. 2009; Flack et al. 2018). The interrelationship between the perception of physical (pain) stimuli and the memory of stressful events may be reduced by this interoceptive stimulus exposure. This technique can only be implemented if the child is both sufficiently stabilised (e.g. with the help of the

'Safe Place' or the 'Safe') and he/she is able to successfully use pain coping techniques. With the help of pain provocation, the child will have the positive experience that he/she is in control of the amount of emotional burden to him/herself and will experience increased self-efficacy (Dobe et al. 2009; Flack et al. 2018). Pain provocation is contraindicated for complex traumatised children (e.g. long-standing abuse experiences or multiple experiences of family violence) and traumatised children who are not yet sufficiently stabilised and feel helpless with regard to their flashbacks. For these children, pain provocation may reactivate the trauma. Again, treating traumatised children requires high-level expertise.

After performing pain provocation, children are often surprised at the close relationship between stressful memories and pain stimuli (interoceptive conditioning). This experience supports the education and makes the patients cooperate with even more motivation. Pain provocation cannot replace trauma therapy. It is an additional technique to stabilise the child and can be a good preparation for subsequent trauma-specific therapy.

10.3 Passivity and Avoidance: Setting Up a Daily Routine

For various reasons, everyday life for many of the children with chronic pain is characterised by passivity and avoidance. Successful pain treatment is always based on active pain coping in everyday life. A prerequisite of active pain coping is that the child knows what he/she can do. This is by no means trivial, for example, if the child only has a few friends due to low social competence, has not undertaken much activity for a long period of time, is afflicted by sad or fearful thoughts or does not leave the room due to a dysphoric-tense mood within the family. Some of these children find it difficult to name any activity they enjoy. They will benefit from making a 'list of pleasant activities' (Chap. 15, worksheet #14). Other children, however, have so much difficulty organising their daily routine that even with a structured inpatient life on the ward, they need the close support of the NET. What does this close support look like?

Every morning, the child is handed a piece of paper outlining the schedule of the day. Fixed common activities like the five meals, morning and evening rounds, 'beef rounds' as well as the visiting hours or the rest period in the evening are not listed. But the child's daily scheduled duties on the ward are included on the sheet. It is the child's responsibility to stick to the schedule. If there are any problems in keeping the schedule, the NET informs the responsible physician or psychotherapist. If during the course of treatment, it becomes obvious that the child has severe problems organising his/her everyday life, he/she will be guided in making a schedule including all variable and fixed appointments. In addition, any active pain coping strategies that could be practised during the breaks should be noted on the schedule.

In pain treatment, inadequate organisation of everyday life should not be tolerated. Active pain coping is supported by encouraging the child to strive for autonomy (learn to follow a daily routine), and to take responsibility (rules and duties on the ward, e.g. organise leisure time activities or common cooking sessions). A good 'side effect' is the enhancement of the child's self-esteem; the child will recognise that by working in a structured way, he/she is able to get many more tasks done than expected. The following case report illustrates the implementation of an active daily structure as part of inpatient pain treatment.

Case Report: Jana (16 Years), Pain Disorder with Multiple Pain Localisations

After a painful school accident and severe adverse effects of analgesic treatment, Jana increasingly developed pain in all major joints, as well as back pain. This started about 4 years before admission to our ward. At times, Jana complained about headache, too. After 2 years, her pain had become so severe that she was using a wheelchair for more than a year, and was unable to attend school. With the help of physical therapy, she was able to walk with crutches, and was attending a school supporting students who were physically handicapped when she presented at the German Paediatric Pain Centre (GPPC). Due to her permanent fatigue, Jana usually attended classes while lying down. Several stays in a paediatric rheumatology clinic, invasive pain-therapeutic procedures and the use of various analgesics were so far unsuccessful. Previous therapeutic attempts recommended the implementation of passive pain coping strategies, and Jana and her family followed these recommendations. Before her disease, Jana had been a happy girl. When she was a child, she liked to do some sports. She presented at our paediatric outpatient pain clinic following the advice of her paediatrician. At their first outpatient appointment, the ambivalence of Jana and her family towards the demands of an inpatient stay (active pain coping irrespective of the current pain intensity or emotional well-being) became evident. During the talk, we came to the agreement that Jana should write down her aims for her inpatient stay and declare that she would consent to our therapeutic approach before admission. Her parents were asked to give their written consent for cooperation. Due to Jana's extraordinary impairment, it seemed impossible to start with an age-appropriate activity plan from the beginning. Thus, we agreed on gradually increasing activity in her everyday life on the ward. Shortly after Jana and her parents had put our requests into practice, Jana was admitted, walking with crutches and using wrist orthoses. The admission session was used to explain the treatment plan to Jana and her parents. During that talk, it became obvious that Jana suffered from comorbid depression and pronounced social phobia, which had already been observed in the outpatient evaluation.

Our procedure. We agreed on graded exercise therapy. The number of breaks (in which Jana could also lie down) was gradually reduced. Those breaks were operationalised using time-out cards with a value of 30 min each. In consideration of her previously very low activity level (just a few hours a day), we agreed on a total of 6 time-outs of 30 min each during the first step of the treatment plan. Jana was allowed to use these whenever she wanted. Jana had to set up a daily schedule and pick some activities from her 'list of pleasant activities' to practise in her leisure time. During the course of treatment, Jana gradually became more active (attending the clinic's school; participating in swimming, sports or pedagogic leisure time activities), but at the end of her stay, she still needed three time-out cards a day. Contrary to her fears, active pain coping did not increase her pain. Though she was frequently exhausted, this helped her to fall asleep more easily, and sometimes she woke up in the morning feeling more refreshed than usual. Parallel to graded exercise, the time Jana was allowed to use her crutches was curtailed until she finally only needed the crutches when performing longer activities outside of the ward. Due to her depressive symptoms, Jana needed a lot of encouragement and support from the NET, which she received in the daily positive evening reflections and by being complimented for every success, small though it might have been.

10.4 Treatment of Anxiety Disorders in the Context of Pain Treatment

I'll never do it—Anna (14 years), while planning the last, most difficult step (anxiety hierarchy) with her psychotherapist.

Many children do not just suffer a pain disorder but also fear. In some of the children, the fears preceded the pain disorder and enhanced pain chronification while other children developed their fears during the course of pain chronification. In any case, at the time of first therapeutic contact, the child will present with both a pain and an anxiety disorder that maintain and reinforce each other. We strongly recommend treating these disorders simultaneously.

10.4.1 Integration of the NET

Even in an *inpatient* pain treatment setting, it is impossible to practise all important fear exposure exercises during individual psychotherapeutic sessions. And since those fears frequently refer to social situations or interactions, the close integration of the NET into treatment planning is essential.

How is the treatment of pain and fears best combined in an inpatient setting, integrating the NET in a way that will not confuse or overburden the child?

A detailed education session on pain, fears, and their interaction is essential at the beginning of treatment. Since pain and fears have similar symptoms and mutually maintain each other, the education on fear is easily integrated into the vicious cycle of pain. Not only in pain but also with anxiety and fears, important factors are increased body awareness, negative cognitions, and increased physical tension interpreted as a warning signal. During the education on the vicious cycle (Sect. 8.2), the child will learn how pain and fears maintain and reinforce each other via Black Thoughts, increased body awareness and muscle tension.

Independent of the type and degree of the fears, these three interventions have proven useful for the NET.

1. Most children with fear lack self-confidence and do not take risks. They need encouragement and a sense of achievement to believe in themselves and to face their fears. A structured approach for addressing this, is the 'Note Box' (Sect. 10.5). Simply, take a carton with a slot that fits folded notes. The child may

make his/her own Note Box, and with some effort, some children will create real works of art. The Note Box is stored in the room of the NET. Each time a member of the NET, a physician, or a therapist observes something positive about the child or his/her behaviour (it may also be positive characteristics, a special outer appearance, or a nice habit), they write a note, fold it and put it into the Note Box. During a daily evening ritual, the box is emptied and a member of the NET reads the various notes to the child. At first, many children are very sceptical about this intervention ('You write this only because you are instructed to do so'), but during the course of treatment, they will realise that the notes of different people are often congruent, and they begin to accept them as meaningful and honest. It is important that new notes are added every day and that the child's role is as a passive listener in the evening (discussions about the truthfulness of the notes are not a component of the activity). Particularly, children with comorbid depressive thoughts will reject these positive observations in the beginning. Nevertheless, consistent repetition will over time have a positive effect. Dysfunctional cognitions likewise did not develop overnight, but slowly through perceptions of devaluation. Children aged 14 years and older often regard a Note Box as childish. The following intervention might suit them better.

2. Older children and adolescents prefer direct and personal feedback to anonymous feedback. Giving compliments and expressing appreciation by direct contact is an interaction strategy suitable for this age. The positive evening reflection is a structured form of direct verbal feedback. As with the Note Box, the various observations and judgements are collected and expressed verbally. The patient is invited to just listen to the feedback and not react to it immediately. In this setting, any discussion on how truthful the comments are will not help, and the NET should react to any discussion with sentences such as 'But that's just the view of him/her' or 'He/she just likes that characteristic of you'. This intervention may well be continued in an outpatient setting, perhaps by the patient's parents.
3. Biofeedback therapy is an essential module when simultaneously treating pain and anxiety disorders (Sect. 9.4). This is also conducted by the NET. As with pain treatment, it is an important experience for the child with an anxiety disorder to understand how his/her body is reacting to fears, and how these physical processes may be modified by learned techniques. We use biofeedback therapy before (e.g. when starting graded exercise) or during (e.g. during a Stress Day) exposure in order to help the patients learn to positively influence their tension and anxiety under more realistic circumstances. Most of the patients are fascinated by the technique, since apart from validating the education (they experience how certain thoughts, memories or appraisals directly provoke somatic reactions), it gives them hope that they are able to better control their stressful somatic symptoms on their own.

10.4.2 Treatment of a Pain Disorder Combined with Specific Fears

If the fears relate to real situations that can be operationalised, it is helpful to use graded exposure therapy. The situations are practised together with the child's contact person of the NET. First, the child sets up a list of situations with gradually increasing fear together with the psychotherapist (graded exercise). The list should only include situations that can be practised frequently enough during the stay on the ward or during the Stress Tests. If this is not possible (i.e. fear of class tests; fear of certain persons; fear of certain situations at school or in a certain sports club; fear related to the specific family situation), a situation on the ward can be modified in such a way that it triggers a similar anxiety reaction. Before conducting the exercise, the child is asked to indicate the degree of tension (0 = no tension; 10 = maximal tension) which is compared to the impression of the NET member. The exercise is then repeated until the tension *before* implementation is no higher than 2–3/10. Only then treatment continues with the next step. This procedure prevents that the children 'race through' all exercises with high tension only to get it over and done with. This type of avoidance behaviour would only increase anxiety. The graded exposure plan is clearly visible in the room of the NET, so that every shift is well informed about the current status.

The following example illustrates our approach using graded exposure.

Case Report: Joris (13 Years), Chronic Abdominal Pain and Social Insecurity

Background. On admission, the parents report that Joris is very shy and that he would 'take his time to feel comfortable'. During his stay on the ward, it quickly became obvious that Joris was not just shy but also had distinctive fears (and increased abdominal pain) facing new social situations. After comprehensive education, he came to understand the relationship between, and the mutual reinforcement of, fear and pain. The findings and diagnostic results were discussed with his parents.

Procedure on the ward. We not only presented the procedure indicated to treat anxiety (inpatient treatment: graded exposure; alteration of the dysfunctional fear-maintaining cognitions; increasing self-esteem; subsequently: outpatient psychotherapy) but also outlined the adverse effects of a successful treatment of the anxiety disorder (increased need for autonomy; increased readiness for discussion. For a detailed discussion of this intervention, see Chap. 11—Integrating the family system). During a family session, Joris' parents agreed to the treatment plan and its possible adverse effects. In addition to changing his dysfunctional thoughts (Sect. 9.3), Joris developed the following graded exposure exercise together with the NET and his therapist:

Step 1: to ask a nurse to hand Joris a sheet of paper.

…

Step 4: to ask a nurse to help him with a certain task.

…

Step 6: to introduce a newly admitted child to his/her duties on the ward and to take the role of a mentor in case of any questions.

…

Step 8: to ask all children aged >10 years what they like about him, and record the answers.

…

Step 10: to present a poster (‘That’s me’ poster) giving all important information on him, his hobbies, his strengths and weaknesses, and to answer any upcoming questions (total duration, 10 min).

At the same time, Joris created his personal ‘Note Box’. Before and after any particularly difficult situation on the ward, the NET discussed the situation with Joris and elaborated on suggestions as to how to behave more favourably. With three biofeedback sessions per week, Joris could evaluate the effectiveness of the cognitive and imaginative strategies in reducing his anxiety-triggered physical reactions.

The family’s approach. According to our experience, fears rarely develop without a family model. Joris’ family was no different in that regard. During her childhood, his mother had suffered considerable social anxiety. Although his father denied any fears, he denoted himself a ‘careful person’. The parents had the notion that sometimes the environment is dangerous (‘You never know what will happen’) and somehow unfair (‘Those using their elbows will succeed. All others will have to stand back’). During conflicts, they mostly used avoidance strategies (from avoiding any dispute up to using excuses to allow for social withdrawal). They did not believe that their son could solve any conflict or problem on his own and tried to help him whenever possible. They reared Joris with a laissez-faire attitude that missed clear-cut consequences. During the family sessions, we had detailed discussions on the anxiety-focused treatment of their son and any advantages, or disadvantages of their son’s behaviour. Finally, the parents agreed not to relieve their son of his commitments, to set up clear rules, and make demands of their son irrespective of his current intensity of pain or anxiety. Furthermore, they were open to doing subsequent outpatient psychotherapy in which they would aim to change their own behaviour.

Course of treatment. Joris’ outpatient psychotherapist informed us that continuing psychotherapy was no longer necessary. Due to the consistent cooperation of his parents during inpatient treatment, Joris reported much less anxiety and pain. Both Joris and his parents gradually changed their lives. Twelve months later, Joris lived a normal life without pain or increased fears. After 24 months, we were informed that Joris planned to go abroad for one year.

10.4.3 Treatment of a Pain Disorder Combined with Panic Attacks

Every now and then, we treat patients with pain disorders and recurrent panic attacks. A panic disorder has a strong negative impact on daily life and quality of life, making normal pain treatment difficult. In each patient with a panic disorder, a potential traumatic background needs to be carefully explored. The following approach is suitable for children with a combined pain and panic disorder in whom the panic disorder is less severe, a traumatic background is improbable, and a subsequent outpatient psychotherapy is warranted.

The treatment starts with a detailed education on both disorders. Regarding its development and maintenance, panic disorder resembles pain disorder more than all other reported comorbidities. Like a pain disorder, panic disorders arise from the interaction of increased interoceptive perception, its dysfunctional appraisal and the resulting physiological processes (shortness of breath or fainting; hyperventilation; extreme internal and external tension). Unlike pain disorders, the dysfunctional appraisals in panic disorder are of a more existential quality ('I am dying'), resulting in more pronounced fear and physiological processes. Due to the similarities, it is possible to directly transfer some aspects of pain treatment to the treatment of panic disorders. In both treatments, body-related dysfunctional thoughts are of importance. For panic disorders, there is often a biographical reference that makes the children believe that body signals indicate a life-threatening or even deadly disease (e.g. the father's or the beloved grandmother's heart attack). The dysfunctional thoughts may well be treated together with the dysfunctional thoughts related to pain (Sect. 9.3).

Techniques for interoceptive exposure are successfully used in the treatment of panic disorders and help to reduce fearfully increased body awareness. One form of interoceptive exposure is the pain provocation technique. For panic disorders, patients provoke an increase in fear-associated bodily signals by intentional hyperventilation (straw breathing, spinning around very fast, shaking one's head). Finally, physical symptoms are reduced with the help of certain breathing exercises (i.e. intentionally extending expiration in order to interrupt hyperventilation) or imaginative strategies. The first implementation should be supervised by the therapist; further implementation may be supported by the NET. Some children only agree to graded exposure. In this case, the provoked degree of anxiety (or rather shortness of breath) is determined beforehand. When the child has become more confident in influencing bodily symptoms and anxiety, the provocation is gradually increased.

10.4.4 Treatment of a Pain Disorder Combined with a Generalised Anxiety Disorder

Children with generalised anxieties and worries benefit the most from a combination of cognitive methods and techniques of fear exposure. Presumably, generalised anxieties and worries are maintained by mental avoidance techniques. Methods to interrupt or avoid dysfunctional thoughts should be avoided (i.e. distraction techniques and cognitive strategies such as positive self-instructions are contraindicated). Instead, mental avoidance should be interrupted by, for example, thinking the worst case through (for some children, it is best to absurdly exaggerate the worst case) and perform a reality check. As a sort of behavioural experiment to verify certain fearful thoughts, it may be helpful to install a graded exercise representatively focusing on only one of the child's many specific fears. Installation of the graded exercise can be realised as described for specific fears (see above). The child should further be instructed and reinforced by the psychotherapist as well as by the NET to face other specific situations he/she is afraid of during therapy sessions and on the ward.

To this end, observation sheets proved helpful to check and discuss the management of fears in common situations on the ward. In addition, a 'Stamp Booklet' can be given to the child, in which he/she collects stamps each time he/she successfully copes with a fear. These stamps can later be exchanged for rewards either on the ward, or stipulated by the parents. Older children record the procedure with a protocol of thoughts (see Sect. 9.3).

10.4.5 Treatment of a Pain Disorder Combined with Social Phobia

Treating children with comorbid social phobia is a special challenge in pain treatment. Basically, children with social phobia fear being devalued for their behaviour or appearance by other people and as a result feel ashamed. They develop a pronounced fear of shame and avoid social situations in which devaluation is possible. This avoidance behaviour can reach bizarre dimensions or be completely hidden behind a façade. No matter what the avoidance behaviour looks like, it is accompanied by extremely high physical tension and a clear activation of the sympathetic nervous system in all social situations that are interpreted as threatening. As many affected children are also ashamed of visible signs of nervousness and tension, they make extreme efforts to control their facial expressions and gestures. This implies that a patient who seems tense but otherwise normal upon first contact, may suffer quite a lot under his/her social phobia. The challenge in an inpatient setting is to establish a therapeutic relationship of trust in a short time. Patients with a social phobia will do all they can to behave and respond in a way that they are liked by the therapist and the NET. However, they often show a delayed or inappropriate reaction which may seem disingenuous, because they think through all possible responses and behaviours to find the 'right' one. Of course, this causes high tension which reinforces the pain. Thus, successful pain treatment is impossible unless the symptoms of social phobia can be reduced. Unfortunately, at the beginning of the treatment, many children with social phobia try to rationalise, minimise or devalue the exploration of dysfunctional cognitions, because they believe that every 'weakness' is a potential source of devaluation. This should not be misinterpreted as a lack of treatment motivation. It is an expression of these children's inner turmoil. The best way to further explore social phobia is to provide an appreciative feedback of all observations (behaviour, personal impressions in the sessions) with hypothetical questions concerning social phobia.

An example could be: 'We have noticed that you are rather shy and don't like to be addressed. Is this observation pure coincidence or is it true? (…) I feel that you try hard not to make a bad impression. Has this something to do with me or do you always behave like this? (…) I don't know you too well, but many children with chronic pain are very shy and care a lot about what others think of them. They don't want to make mistakes and want to be perfect. Do you have such thoughts, too?'

It is important to proceed both appreciatively and logically, because the patients will feel very vulnerable when faced with such direct questions. They need to feel accepted to make corrective experiences. It is useful to discuss the vicious cycle of social phobia with the child and to clarify how social fears, with associated high tension and self-critical cognitions, reinforce the pain.

A combined pain and anxiety treatment can only be started when the child is ready to report his/her dysfunctional cognitions. Techniques or strategies should not on any terms be implemented before that. It is the nature of social phobia to constantly fear devaluation and criticism, which leads to extreme self-criticism reflecting the anticipated feared devaluation. Affected children are in a constant mode of critical self-observation and self-devaluation. If these children start using distraction techniques, they will internally comment on this implementation negatively. Frequently, this will increase the pain; at best, the pain will not change.

Once the affected children are ready to record their cognitions and to change these cognitions and fears (within their abilities), treatment should start with mindfulness-based and imaginative strategies. Distraction strategies are contraindicated. The children should be encouraged to make corrective experiences with regard to their dysfunctional cognitions. Suitable options for this are graded exposure (see example above), combined with a protocol of thoughts and therapeutic debriefing to conduct a reality check regarding the dysfunctional cognitions. Graded exposure should be implemented within the child's abilities and should only slowly be increased. Sometimes, children with social phobia try to appear better and more courageous than they really are to please the therapist. If the graded exposure exercise is too difficult, (physical) symptoms could increase before its implementation. Alternatively, children dissociate during the graded exercise and somehow manage it, because their fear of being devalued by the therapist is even higher than the fear of the exercise. Therefore, it should be asked several times whether the patients think they can manage the next step. Furthermore, checking for bodily symptoms of anxiety needs to be reduced. Due to the complexity of the treatment and its slow progress, we recommend using additional treatment manuals, informing the NET about the background of social phobia (to create an understanding of the sometimes-bizarre avoidance strategies) and gathering supervision (at least initially). Apart from graded exposure, behavioural experiments (see case report below) are suitable to check the truthfulness of negative cognitions.

According to our experience, the therapeutic relationship is of great importance for the success of the inpatient pain treatment for these patients. The therapist should be perceived as an ally who, on the one hand, values them and takes them seriously despite their supposed weaknesses and who, on the other hand, is insistent in emphasising that only graded exposure with feared situations will help them find their way back into normal life.

The following case report illustrates the procedure.

Case Report: Jenny (16 Years), Pain Disorder (T = Therapist; C = Child)

T. Hi Jenny. Great that you brought your diary of thoughts with you again. Did you notice something?

C. Yes, I did. I noticed more and more Black Thoughts in other situations. For instance, yesterday morning I was in a bad mood when I had to go to school.

T. Why was that?

C. Well, I overslept and there was no time to put on my make-up. My hair was a mess and I was pressured for time.

T. How did you feel at that moment?

C. I was tense and insecure.

T. What was on your mind?

C. Impossible to go to school like that. The others will laugh at me.

T. What would it mean to you to go to school, your hair being a mess and having no make-up on? What would that say about your person?

C. Well, that I am scruffy and too lazy to take care of myself in the morning.

T. What is the worst thing that could happen to you then?

C. The worst thing would be if all the others would point at me and laugh and avoid talking to me the whole day.

T. I understand. And what would be the best case to happen?

C. All this going unnoticed.

T. What do you think will probably happen if you go to school not made up?

C. Well, my friends may wonder and ask if I overslept. But maybe they will think badly of me and won't tell me.

T. How convinced are you about your thought 'If I leave not being made up then the others will think I am scruffy and lazy'?

C. About 80%.

T. Should we test your thinking?

C. What do you propose?

T. I would like to do an experiment with you. We ponder what you might feel in detail, what could happen if you go to school with your hair being a mess and with no make-up. We do it like scientists: You will perform the experiment and observe if your fears come true.

C. Oh my God, I will need a lot of courage to do this. I can't do it!

T. Alternatively you could first make a survey on the ward of what others think about people without make-up. Should we plan such a survey?

C. That sounds better. Maybe afterwards I will do the experiment.

Jenny did the survey and found out that nobody thinks a person without make-up scruffy and lazy. Afterwards, she dared to show up on the ward without make-up. Nobody was laughing at her, and only a few people noticed the difference. While discussing the experiment with her psychotherapist, she was able to reflect and change her dysfunctional thoughts. This encouraged her to conduct the experiment in her school at home. That time, she was clearly less tense than during the first experiment. Her conclusion was: 'People do like me even if I am not always perfect. And anyway, I don't care about those who dislike me'. During the course of treatment, Jenny's inner tension decreased, making it easier for her to cope with her headache.

10.4.6 Integrating the Family System

For long-term reductions in their child's anxiety, the parents must be comprehensively informed about the anxiety disorder early in the course of treatment, as well as the graded exercise to be integrated into everyday life. In many cases, the parents involuntarily contribute to their child's symptomatology due to their own fears, anxiety disorders, or family burden (e.g. conflict-ridden separation of the parents). Sometimes, parents help their child to avoid a challenging task by completing it for him/her. In the last years, paediatricians and psychotherapists have observed with some concern the growing phenomenon of so-called 'helicopter parents'. These parents try to control their children's lives, solve their problems and conflicts, and try to ensure their children a perfect life. As a consequence, children often withdraw (into media worlds) and become more and more dependent ('Mum's gonna do that') and passive. As they do not learn to endure or solve conflicts, they feel easily insulted and do not cope well with criticism. These children cannot develop self-confidence and frequently suffer diffuse fears with increasing age. If this type of anxiety-maintaining parental behaviour does not stop, it is extremely difficult for the child to control and reduce his/her fears and pain. If parents, however, have learnt during the education session the necessity of strengthening their child, and discovering their own resources, they become invaluable co-therapists, supporting their child in the implementation of graded exposure exercises, or in courageous behaviour in everyday life. Thus, both child and parents will benefit from the therapeutic process. With therapy, the child experiences success in (more or less voluntarily) dealing with fears and no longer perceives his/her parents as helpless but as strong instead. The parents experience themselves as strong and powerful and able to expect something from their child while simultaneously supporting him/her.

10.5 Cognitive Restructuring in the Presence of Comorbid Depressive Symptoms

Many studies have demonstrated an increased comorbidity of chronic pain and depressive symptoms (for a meta-analysis, see Pinquart and Shen 2011). From a clinical perspective, depressive symptoms often do not indicate the presence of a depressive episode but are part of an adjustment disorder with depressive reaction, which makes a difference to treatment. Dysfunctional thoughts in children with depressive comorbidity are fundamentally different in some aspects from those of children exclusively suffering a pain disorder.

Examples of depressive dysfunctional thoughts

1. 'I'm too stupid to defend myself against the pain'.
2. 'I am worthless'.
3. 'The whole world is against me'.
4. 'Why always me? No matter what I do I will be unlucky anyway'.
5. 'I hate myself and my body'.

6. ‘I have to be perfect to be valuable’.
7. ‘Everything will get worse, because I can’t do anything’.
8. ‘I’m so ugly’.
9. ‘I deserve the pain. It’s my own fault’.

If depressive symptomatology is suspected, it may be helpful to directly query the patient about his/her thoughts (‘What did you think facing those things?’). The respective topics could be school, friends, oneself, or the family. The psychotherapist may also prompt some thoughts (Do you know thoughts like ‘I am hardly worth anything’; ‘I have to do everything right’; or ‘I’m sure something horrible will happen to me’). If such thoughts arise more frequently, the therapist should address this in pain treatment. In principle, the interventions and cognitive strategies discussed in Sect. 9.3 can be transferred to the treatment of depressive symptoms. Children with depression are usually good at naming their thoughts, because they circle around the same thoughts each day. Unlike with the pain disorder, changes in negative appraisals can only be achieved very slowly. After the education about depression, the treatment mostly can directly start with a protocol of thoughts and the cognitive interventions suitable for the child. For children with severe depression, a daily structure needs to be installed first. This structure needs to be followed irrespective of fatigue, pain and negative thoughts.

Frustrating social experiences (e.g. repeated teasing; devaluation) or interactions (e.g. being rarely praised by the parents) play an important role in the development of depressive symptoms. We feel that positive interactions coupled with encouragement and praise should be implemented into the psychotherapy and at home (and into the daily life on the ward). To this end, you can use the following interventions:

- *Note Box*: We use this positive feedback technique in younger children with depressive symptoms (Sect. 10.4). In these children, it is helpful if they have access to the box at any time to read the positive notes.
- *Positive evening reflection*: A joint evening reflection of the day between an adolescent with depressive symptoms and the NET can be very helpful for older children (Sect. 10.4). The child’s contact person of the NET reports his/her positive observations of the patient during the day. Additionally, keeping a diary of success can be arranged, so that the adolescent becomes more independent of the feedback of others. This way, the patients write down positive experiences during the day. However, this intervention is only suitable for children who are able to identify their own resources. During the Stress Tests (see Sect. 11.6), we ask the parents to continue this exercise, so that they also learn to praise and strengthen their child. Parents can best be trained to provide positive feedback with specific examples. This intervention is not indicated if the parents demonstrate resistance even after repeated education (‘I can’t whitewash everything!’), because the parents’ negative or even hostile attitude towards the child will reinforce the depressive symptoms. Sometimes, the therapist can motivate the parents by giving examples from their daily life (‘Imagine a workplace where the boss only pays

attention to mistakes, never praises anyone and complains about trivialities. The boss of another workplace criticises his/her staff but also praises them for their efforts. He/she often smiles and gives the staff the feeling that everything will work out. However, the pay is a bit lower than at the first workplace. Where would you rather make an application and why?').

- *Reinforcement schedules*: Particularly for children aged less than 12 years, it might be helpful to use schedules of reinforcement to support newly learned behaviour (e.g. distraction during episodes of pain) as well as the use of Colourful Thoughts. With this technique, the desired behaviour is rewarded by stamps. Having gained a certain number of stamps, the child is allowed to get something he/she desires. Especially if the child does not have much positive time (fun leisure time) with his/her parents, we try to increase that time with the help of a reinforcement schedule (e.g. for a certain number of entries, the child can 'buy' 30 extra minutes of play time together with his/her mother). Sometimes even older children or adolescents benefit from such a reinforcement schedule. In patients with depressive symptoms, the use of reinforcement schedules should always be considered. An inadequate implementation of the described interventions may reinforce the depressive thoughts of the children. This needs to be discussed in the education for the parents: 'Please let us know if you are not able to implement the interventions as discussed at home. Otherwise, your child will think that positive feedback is not important enough for you, which will confirm his/her depressive cognitions'.

The successful implementation of cognitive strategies requires quite some time. In order to avoid any frustration, the patient and his/her parents should be informed in advance that it will take a while until the patient feels the changes and believes in them. Thus, in these children, outpatient psychotherapy is often indicated after the inpatient stay.

10.6 Social Competence Training

Many children with chronic pain have difficulties with social interactions. During the course of their pain disorder, they often withdraw from social activities (school, sports club, and neighbourhood). This may be a consequence of the pain disorder. Children with chronic pain expect the generally supportive behaviour of peers much more often than healthy ones (Forgeron et al. 2011). In most cases, their expectations are not fulfilled, they are disappointed and feel misunderstood or hurt and gradually retreat. Pain is often regarded as a bad excuse for school absence by classmates and teachers. Sometimes, the affected children are bullied and excluded. Finally, during the course of the disease, many children with chronic pain have learnt that complaining of pain enables the avoidance of disliked activities. This is a consequence of the pain disorder and not its cause.

On the other hand, some parents report that their child did not have many friends, tended to withdraw socially and had problems coping with peers even before the pain disorder. Presumably, a pain disorder makes it even more difficult for these children to learn age-appropriate social competencies because now they see their pain as the main obstruction to making social contacts, which were associated with fear in the first place.

All this demonstrates that a pain disorder has an unfavourable impact on age-appropriate social development or social competence. If many of these socially incompetent children meet during inpatient pain treatment with its daily structure aiming at active pain coping, social conflicts sometimes are inevitable. To allow for these group dynamic processes on the ward, each week, two group therapy sessions are offered in order to train social competence. Once a week, there is a 'beef round' where the children may discuss social conflicts and develop, or train conflict-solving strategies. Since patients at the GPPC are not a cohort but admitted consecutively, it is not possible to offer step-wise social competence training. Instead, current topics are categorised according to the various underlying social problems and the group develops solutions which may be trained doing role plays.

Typical issues are dealing with bullying, asserting one's own needs, setting limits, making friends, providing critical feedback. To strengthen group cohesion, further therapeutic group plays are implemented, such as 'drawing others', 'charade of feelings', 'the Oscar of the ward' and mutual positive feedback (on small cards).

The psychotherapists not involved in that group session are given brief written feedback on relevant behavioural observations. This allows them to continue working on problems or resources in the individual therapeutic sessions, or family sessions. Often, the group therapy sessions inspire the NET to do certain interventions (e.g. to function as mediator in conflicts between adolescents; to arrange an extra appointment for a positive evening reflection; to support certain patients in coping with social conflicts).

There are daily morning, as well as evening rounds, led by the NET in which the children may express their current mood or well-being (Table 7.1, Sect. 7.3). The NET writes down their impressions and hands them over to the next shift, and to the physician/psychotherapist. If needed, the following interventions may be requested by the primary psychotherapist:

1. Preliminary discussion and reflection on problematic social situations with the NET. The aim of this intervention is that the NET supports the child to learn to distinguish between favourable and unfavourable social interaction strategies (*favourable*: to ask someone for something; to enforce a wish in an appropriate way; learning to say 'no'; to apologise; to bring up the issue of someone's disturbing behaviour instead of reacting with social retreat. *Unfavourable*: Avoiding social contacts; lamenting the injustice of others; feeling like a victim). The therapist is informed in case the NET's discussion of a problematic situation leads to further misunderstandings. The situation is then discussed again with the patient, the member of the NET and the therapist. Sometimes it is inevitable that the NET or a therapist moderates the patients' discussion of conflicts on the ward.

2. Setting up and implementing a graded exposure exercise (Sect. 10.4) addressing the patient's specific social fears.

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Inpatient Pain Treatment: Module 4 (Integrating the Family System)

11

Michael Dobe and Boris Zernikow

> *Why did nobody explain that to us before?*
> *—Mr. S. (44 years) after the first family session*

Contents

Abstract

In this chapter, we describe the most important aspects that need to be considered for adequately integrating the family system into treatment. First, we present important contents of family sessions, such as pain education, reducing feelings of guilt and family conflicts and stress factors. Then we discuss Stress Tests and

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M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_11

the possibility for parents to observe their child on the ward. Finally, we present recommendations for the family on how to cope with relatives, friends and teachers as well as recommendations for therapists on how to work with families with a migration background.

Many parents are not sufficiently informed about the biopsychosocial background of chronic pain and are stuck in their striving for 'the one' physical cause of pain. Their understanding of chronic pain is similar to that of the majority of medical practitioners. Insufficiently treated pain disorders in children lead to increased impairments of the child's life. But additionally, it affects the parents (particularly mothers) by increasing their emotional burden which can result in depressive symptoms (Jordan et al. 2007), and the risk of developing a pain disorder themselves (Lommel et al. 2011).

We feel that it is essential for successful pain treatment to value the parents who are often suspicious or resigned, and meet them with understanding. We do not ignore the fact that parental anxiety and tendency towards passive coping strategies contribute to the development and maintenance of their child's pain disorder. However, parents certainly do not do this on purpose.

In light of the complex mutually dependent processes involved, it would be both unfair and unwise to hold the parents responsible for their child's pain disorder, more so as the parents explicitly seek help for their child.

We *explicitly* promote a helpful future-oriented therapeutic attitude: based on their current knowledge and abilities, parents always strive for the best for their child. Sometimes albeit rarely, it becomes evident during the course of treatment that the family's abilities are quite limited due to psychiatric disorders or somatic diseases of one or even both main attachment figures (particularly parents with a borderline or a narcissistic personality disorder are able to prevent any treatment success due to their extremely problematic interaction strategies). Under such conditions, interdisciplinary pain treatment as described in this manual reaches its limits. Sometimes, the only possible solution left is cooperation with the youth welfare office (see Sect. 11.5 'the tip of the iceberg').

Fortunately, after comprehensive education, most family systems are very motivated and able to change their behaviour with the ultimate goal of helping their child with a pain disorder.

11.1 The Admission Session

At the beginning of inpatient paediatric pain treatment, there is a detailed admission session scheduled with the patient, his/her family, the physician, and the paediatric nurse. The findings and impressions from the outpatient evaluation serve as a basis for preparing this session. The aims are as follows:

1. To determine previous treatments and their effectiveness.
    (a) previous diagnostic efforts
    (b) previous outpatient or inpatient treatment (hospital stays; surgery; invasive pain treatment)
    (c) previous and current medication (duration of treatment; dose; adverse effects)
2. To determine the disease model.
    (a) of the parents
    (b) of the child
    (c) of the patient's relatives
3. To determine any pain modulating factors (strengths, resources or skills of the child or his/her family; other factors that evoke fear, anxiety, sadness or desperation).
4. It is then helpful to summarise again the most important aspects of inpatient pain treatment, previously described during the outpatient appointment (active pain coping irrespective of pain intensity; one therapeutic family session per week starting with an education session, then discussion of all aspects relevant to everyday life; three to four individual psychotherapeutic sessions a week for the patient; mandatory therapeutic homework; etc.). Based on that information we explore the child's and the parents' aims. Sometimes, unrealistic goals are specified ('The pain has to go away so that my child can enjoy life again!') or parents do not want to or lack the time to join family sessions. In these cases, prerequisites for inpatient admission have to be emphasised again. Being 'free from pain' is not and cannot be the aim of an inpatient pain treatment, because it supports the Third Thought Trap (see Chap. 4) and may prevent treatment success. Parents who only want their child to be 'repaired' do not wish to be integrated into the treatment (or at least not too much). This may also effectively prevent treatment success. These parents need to understand that successful pain treatment is not possible without the parents' education, the preparation and reflection of Stress Tests in family sessions and the discussion of possibilities to support the child in his/her everyday life. If parents insist on their point of view, failure of the treatment is very probable, even if physicians and therapists try their best. In this case, the child should not be admitted, because treatment failure would reinforce pain chronification and harm the child. Finally, an admission is contraindicated, because costs associated with the treatment are so high that it should not be started if treatment failure is anticipated. This should be explained to the parents.
5. At the end of the admission session, we construct a genogram including the grandparent generation of the patient, depicting the age, profession, psychological disorders or severe somatic diseases (particularly pain disorders) of the family members and their interrelationships. The child should help set up the genogram, reinforcing the belief: 'You and your opinion are important'. The genogram is transferred onto a flip chart together with a summary of diagnoses, resources, the most important test results and a photograph of the patient. The genogram may later be complemented and serves as a memory aid for the team

Fig. 11.1 Example genogram

during the multiprofessional ward rounds. Figure 11.1 displays an example of a genogram including all essential information. During the ward round, the genogram helps to generate important hypotheses with respect to pain-maintaining family structures, as illustrated by the following examples.

(a) All female members of the maternal side of the family suffer pain. What is the significance of this to the child with respect to the disease model or future perspectives? How do these relatives cope with pain? What does the child think regarding healing or causes of his/her pain disorder, if all female relatives suffer chronic pain for a long time?
(b) The mother describes the father's family as being very achievement oriented. The father is rarely at home. The genogram shows that there are many relationships in the father's family system that were broken off. What does that mean to the child? Does the child fear that a decrease in performance or an increase in autonomy will result in less approval or even more devaluation by his/her father?
(c) The genogram displays that there are lots of conflicts between the parents, but also between the generations. Does the child assume that he/she is responsible for these conflicts? Does he/she hide important stress factors in order to not increase the parents' burden? Is the child worried that the parents may separate? Does the child put his/her own age-appropriate needs last, because he/she needs to function as a partner substitute by an offended parent? Is the child the mediator between the parents when they do not talk to each other anymore?

Finally, some formalities are settled (e.g. Is the child allowed to leave the ward on his/her own to visit a store? etc.) and an appointment for the first family session is scheduled. Only in exceptional cases, for instance, in children with separation anxiety, should the team, the child and his/her parents agree on fixed telephone talks (Sect. 14.1).

11.2 Education, Normalisation, Appreciation and the Reduction of Feelings of Guilt

Before the first family session takes place, some individual therapy sessions are scheduled. This has several advantages. First, it allows the child to get ahead in knowledge compared to his/her parents, so that the child can be the 'expert' in the first family session explaining important associations. Another advantage is that the child already learns about some basics of pain treatment. In addition, factors that modulate the pain may already be identified during these individual sessions. Finally, this schedule allows us to prepare the family session together with the child. The child will decide whether his/her parents need a theoretically, or rather a practically oriented education. Which behavioural changes would the child like to see in his/her parents? Which difficulties will arise from the implementation of certain therapeutic strategies at home? Does the child feel guilty for the family's burden resulting from his/her pain? Does he/she worry about or blame him/herself for other developments or problems in the family?

The first family session is very important. It is the key to getting the family's compliance with the planned procedure. An insufficiently prepared first family session may seriously endanger further successful pain treatment. Thus, we recommend investing enough time into the preparation of the session during the child's individual therapy sessions. The family session is led by the therapist and not by the physician. In the first family session, essential information on family resources, conflicts, and the family's attitudes towards active as well as passive pain coping strategies should be collected. Taboo issues and those covered by confidentiality need to be discussed in advance. If the child's and his/her parents' disease model is known, the therapist can draw conclusions on which of the Three Thought Traps they might face.

The child should be explicitly assured that he/she can speak up at anytime during the family session in order to correct the therapist's statement. We encourage the children to get highly engaged in the family session and even to explain certain educational topics to their parents themselves.

After welcoming the family, the first family session should *start* with a brief summary of the previous course of treatment and the agenda of the session. Parental efforts and deprivations should explicitly be appreciated. Approval and appreciation of the parents' efforts will be an important basis for the upcoming and sometimes challenging changes in the family system. At the same time, this approach minimises room for the question 'who is to blame for the pain disorder', resulting in a good overall ambience and increased readiness to learn. Most parents expect that previous therapies and therapists will be disparaged and the parents' efforts judged as insufficient or even causal factors of the pain. A (for the parents) surprisingly great appreciation makes them curious and attracts their attention, increasing the odds for a successful first family session before the therapists have even started to convey any educational content. The child should be complimented on his/her motivation to cooperate. Hinting to the parents that 'It would be favourable if you as parents would catch up with the knowledge of your child', the education can start.

In principle, the same rules apply for the education of the parents as for the child's education. First, the parents are asked whether they have any questions. It is beneficial, if the child starts explaining what he/she has understood so far. The therapist and physician should encourage the parents to participate in the education with questions or critical considerations ('Is this undertandable for you?'; 'Many parents have further questions to this. Do you have any questions?'; 'It is crucial for the success of the pain treatment that we agree on an explanatory model for your child's chronic pain. Please don't hesitate to indicate all aspects that you don't agree with or which you don't understand'). Mostly, parents feel valued and well-informed with this approach. Unfortunately, this is not always the case. According to our experience, three problematic situations can be distinguished:

(a) Family systems with parents with chronic pain.
(b) Family systems with parents with a somatic fixation.
(c) Family systems with parents with severe psychiatric disorders.

In the following, we describe adaptations to the above-mentioned approach for these.

11.2.1 Family Systems with Parents with Chronic Pain

There are special cases of family systems where one or both of the parents suffer from pain themselves. They may have undergone pain treatment and are familiar with many aspects from the education. Usually these parents will be aware of their problems and motivated for treatment. Nevertheless, some parents with chronic pain are stuck in the Second or Third Thought Trap (Sect. 4.1), did not experience any success in their own treatment so far, and thus are sceptical about the biopsychosocial model of chronic pain. If the explicit inclusion of these parents in treatment, and the intensified education (described in Sect. 11.3) does not change their view of chronic pain, sustained success in treatment is nearly impossible.

It is common in parents with chronic pain to have difficulties in instructing their child in active pain coping while being in pain themselves. They easily understand the emotional state of their child, but the ability to put oneself in another person's position based on empathy and love means more harm than good for active pain coping. Her child expressing or showing pain will remind a mother with chronic pain of her own pain, enhancing her pain perception, and vice versa. Obviously, this has to do with our ability to feel empathy, which presumably is mediated by mirror neurons (Goubert et al. 2006; Singer et al. 2004). The more love a parent feels for his/her child, the greater the empathy will be. Thus, in fact, love may hurt. Most affected parents and children can agree with these assumptions. Supposedly, the process outlined here cannot directly be altered, but it is our experience that it is of great help to those parents and their child if their perception is validated. But, contrary to empathy and pain perception, pain behaviour can be changed. If a parent does not demonstrate pain behaviour, the child's pain will not increase, because he/she does not realise his/her parent's pain. Of course, parents do not want to involuntarily increase their child's pain by displaying pain behaviour. Therefore, parents can easily be motivated to reduce their pain behaviour without insulting or blaming them. Needless to say, this also applies for the children.

11.2.2 Education for Parents with a ('Hidden') Somatic Fixation

For various reasons, parents with a somatic fixation are not satisfied with the education on the biopsychosocial aetiology of a pain disorder. Some parents just fear an awful underlying disease. Others reject the psychosocial components, because they are associated with feelings of guilt ('This means I did something wrong!'). Other parents believe that their child's pain and burden are not taken seriously with a biopsychosocial approach ('My child wants to change something, but she CAN'T change anything due to the pain!—If everything was psychological, she could change it'). Many parents with such an attitude appear brash or even verbally aggressive. Since this behaviour is based on concerns, it is comprehensible. Some parents are more cautious or shy and do not want the physician and therapist to have a bad impression, if they express their somatic worry. We call this a 'hidden somatic fixation'. When the child has a long medical history of clinical diagnostics and various physicians, but the parents only hesitantly and cautiously raise their questions during the education, a possible somatic fixation should be directly addressed (→ e.g.: 'You indicate there are no questions left. However, many parents secretly fear that there is a so-far undetected serious underlying disease that is responsible for the pain. What about you? Are there any doubts left?').

Once identified, the therapist and physician should address the underlying fears and worries with understanding and appreciation. It is useful that the psychotherapist leads the session. The physician should take the parents' fears seriously, but dispel them step by step by explaining anatomical facts (a book about anatomy may be helpful here). If the parents rather display dysfunctional cognitions of guilt, it is the psychotherapist's function to change these thoughts. In any case, the 'simultaneous interview' (Jacobson et al. 1991) of physician AND psychotherapist is crucial for the success of these family sessions.

11.2.3 Education with Parents with Severe Psychiatric Disorders

Basically, these parents have the same fears and worries as parents with a somatic fixation. But, due to the problematic personality structure, an education based on content and appreciation can hardly be successful. Furthermore, often family interactions are dysfunctional which leads to constantly high tension and makes successful pain treatment impossible. According to our experience, parents with a borderline or narcissistic personality disorder are particularly difficult. It is crucial for treatment success that the parents cooperate. However, parents with such a personality disorder are very unlikely to cooperate unless the therapist is able to establish a complementary relationship that addresses the parents' unfulfilled basic needs. Only then are these parents able to think about behavioural changes. And still, long-term changes are unlikely without psychotherapeutic support for the parents. Additionally, the inpatient setting does not provide enough time for a long-term therapeutic relationship. It is beyond the scope of this manual to present the various approaches for dealing with these parents.

If a relationship can be established, the further procedure is similar to that described for parents with a somatic fixation. This procedure will enable an understanding of chronic pain and a slight improvement of the overall situation in most cases. For a longer term positive effect of the pain treatment for the children, an outpatient psychotherapy is usually indicated for both parents and children.

If the problems cannot be solved despite considerable efforts, a social worker should be consulted to see if the physical and emotional development of the child is endangered (in accordance with the laws of the respective state) (Sect. 11.5). The youth welfare office should be included if the parents involuntarily contribute to pain chronification and thus prevent treatment success.

At the end of the first family session, its content is summarised and the parents are asked to write down any questions left in order to discuss them during the next session. They are advised of the parents' guide 'How to stop chronic pain in children' (Dobe and Zernikow 2014) and the educational films (available at our website: https://www.deutsches-kinderschmerzzentrum.de/en/doctors-and-therapists/questionnaires-and-diaries/pain-diaries/). Quite often, the parents tell us that it was not until they had read the guide, with its many case reports, that they developed some understanding of the biopsychosocial model of the development and maintenance of chronic pain. The next family talk is scheduled for one week later. Some families need clear arrangements regarding phone contact with the physician or psychotherapist between sessions, particularly if they tend to catastrophise or have a somatic fixation.

11.3 Reducing the Family's Attention Towards Pain and Improving Active Pain Coping

Mostly I lie down and my mum massages my belly.—Jessy (13 years).

One aim of inpatient pain treatment is to help parents support their children in active pain coping and to reduce attention towards pain.

11.3.1 Reducing the Family's Attention Towards Pain

Contrary to the assumption that children with pain enjoy the increased family attention paid to their pain, most children find it annoying that they are constantly asked about their pain. Not only the child's relatives, but also concerned and engaged teachers or peers remind the child of his/her pain symptoms by their well-meaning questions. The child, on the other hand, finds it difficult to set boundaries to the questioning. This questioning is a normal behaviour and an expression of healthy social relationships in other illnesses. Sometimes children suffer from social isolation as with time, friends and neighbours withdraw and classmates do not ask anymore (Forgeron et al. 2011).

In a child with chronic pain, the increased questions inevitably contribute to maintaining or even to reinforcing the pain problem.

We have observed a wide range of family attention—from the concerned mother who asks about her child's pain ten times a day, to the father with chronic pain, who records the pain-sensitive areas of his child's back with a marker. No matter who focuses on the child's pain—it will unintentionally reinforce the child's pain perception. In order to answer the question 'Does it still hurt?' or 'Do you still feel pain?', the child has to focus on his/her body and his/her pain location. In the least favourable case, the child has just been distracted, and the query will confront him/her with the pain again.

These questions reflect helplessness and a dysfunctional interaction. A simple and humorous intervention is the *1 € rule (for the sake of simplicity, we will use the term 1€, but it can easily be adapted to any currency).*

The 1 € Rule

The education on the interrelationship between parental questions and an increase in pain often does not lead to a behavioural change. Now it's time for the *1 € rule* ('bibliotherapy': parents will find information on that method and its background in the parents' guide 'How to stop chronic pain in children' (Dobe and Zernikow 2014).

In the family session, we agree that whenever a family member asks the child about his/her pain, he/she is obliged to immediately give 1 € to the child. Children love this rule. Every time someone asks about the pain now, the child will primarily think of the money gained, and not of his/her pain. Parents need to understand that it is no longer negative if they unintentionally ask about the pain, because from now on, their child will joyfully put out his/her hand. This intervention also emphasises that asking about the pain induces pain, giving the child some sort of right to claim appropriate compensation. It is useful to clarify in a previous individual therapy session whether the parents easily feel offended. In these cases, it should be pointed out in the family session that the previous behaviour was normal and comprehensible (and no one is to blame), but it was not helpful. The 1 € rule may be extended at will. There are some parents who want to spare their child, so they take all possibly demanding activities from him/her (e.g. carrying things; tidying up; setting the table). If even comprehensive education does not modify this behaviour, a compensation of 2 € or even 5 € should be discussed. In order not to offend the parents' feelings (which is definitely not the purpose of the intervention), we make it clear that introducing that rule is not meant as a criticism of the parents' previous behaviour, and that in acute pain, asking one's child about pain is absolutely normal and adequate behaviour. (In German hospitals, pain therapists have been trying for years to establish regular post-surgery pain assessments, and the hospitals only get certified if their acute pain patients are regularly assessed for pain.) Since nature did not prepare us for the special case of chronic pain, however, most parents behave as if this was acute pain. Unfortunately, this behaviour will contribute to the maintenance of chronic pain.

Parents often argue that they would like to know how their child is doing. From a therapeutic point of view, it is explicitly desired that parents keep asking the child about his/her well-being; however, not concerning the pain, but rather concerning his/her mood. The parents are also invited to express what they perceive about their child's current state. During the long-standing course of a pain disorder, the perception of negative thoughts and pain may become closely associated, and instead of a negative emotion, the child perceives nothing but an increase in pain and is unable to differentiate between the two qualities. Here, parents may help, addressing any negative or positive emotion (but not pain) they notice.

The parents should always be instructed to explain the 1 € rule to their relatives and all the child's other attachment figures. The child should be prepared that the odds are that he/she will not make as much money as hoped for, since the parents will usually learn from the intervention quite fast. The record-holder of the last few years, a highly gifted 15-year-old girl, did not make more than 60 € before her parents completely stopped asking about her pain.

11.3.2 Praise and Active Pain Coping

Praise is another option for parents to support their child in active pain coping. Many children with chronic pain have low self-esteem and feel guilty about many of the family's problems. Everyday family life is determined by worries, doctor's visits, and the permanent effort to understand the patient's feelings and state of health. Praising the child for any active pain coping effort or for other positive behaviour is less common. It is important to explicitly highlight this aspect and illustrate it with examples from life on the ward or within the family.

In doing so, we see various parental reactions. While some parents are keen to notice more precisely the achievements of their child, others have difficulties in recognising positive aspects. For instance, Mrs. G. was very happy to see that her daughter Julia could gradually use her painful foot more and more, although she still needed crutches. Soon after that, the crutches were no longer necessary. Mrs. H., on the other hand, was bothered that progress in treatment was slow (likewise for a sore foot), and she was worried that at such a pace, her daughter Mia would need years to recover and might therefore not pass her grade in school this year. In the course of treatment, Mia repeatedly experienced setbacks because of lacking motivation and fear of the future.

By praising and complimenting their child, parents are able to provide motivation—but, fuelling fears and worries will discourage the child.

Therefore, we ask the parents to notice and approve progress—small as it may be, and to record it on the Weekend Observation Sheets (Sect. 11.6, and Chap. 15, worksheet #18).

Parents may also be asked to write down their child's progress or positive behaviour in a 'Success Diary'. This intervention takes considerable therapeutic competence because parents are easily offended. Particularly, parents not used to praising their child feel guilty and tend to have depressive thoughts and behaviour. We do not recommend focusing on this problematic parental behaviour; otherwise treatment resistance will occur easily, counteracting the treatment aim. A psychotherapist focusing on problems is a wrong model for the parents. The majority of patients want their parents to feel good during the family sessions (and not 'to wear them down', as an adolescent girl called it). A successful family session in which problems are raised, but laughter and some ease also occur will motivate both parents and children.

11.3.3 Reducing and Preventing Passive Pain Coping

Although passive pain coping is dysfunctional, it is important to point out that it is comprehensible at the beginning of the family session. It is quite normal to go to bed when feeling ill, tired, or exhausted. It is understandable that parents and children make no difference between chronic pain and acute diseases and act accordingly. Rest and passivity—although useful for an ill or injured child—result in further chronification in chronic pain. Passive behaviour is enhanced by parental worries, and passive pain coping increases pain (e.g. Lipani and Walker 2006; Walker et al. 2007; Simons et al. 2008; Dobe et al. 2011).

During the family session, we have to inform the parents that especially passive coping strategies (e.g. sleeping, lying down, and avoiding movement) will, in the long run, prevent successful pain treatment.

Active pain coping does not mean that the patient should permanently be in action—everyone needs a break once in a while. However, the difference between a normal break and rest or pain-related passivity is not obvious to many patients and their parents. A normal break is independent of the presence of pain, while pain-related rest or passivity means avoiding any effort associated with pain.

Problems in coping with stress and fears further contribute to the maintenance of pain. Most parents are convinced that their child cannot do certain activities anymore due to his/her pain. They erroneously suppose that if pain is reduced, or even stopped, this will automatically lead to normalisation of behaviour. Unfortunately, this is a fallacy. After long-lasting pain-related school absence and social withdrawal, the child will react with clearly increased physical tension when trying to go to school again. Generally, negative cognitions will arise (‘I don’t get it anymore’; ‘Being in this state, I will never score high on the class test’; ‘Lara is staring at me, she’s probably thinking I intentionally missed school. She doesn’t really know what pain is like’; ‘Damn, I can’t concentrate anymore’). If the adolescent is not prepared for this situation, there is a huge risk that the pain will be reactivated or increased. Even before starting school again, pain may increase. This phenomenon of acquired stress intolerance should be discussed in the family session *before* the first Stress Test. Due to the mechanisms mentioned above, passive therapeutic interventions (e.g. massage, acupuncture, homeopathic medicine, heating pads, or cool packs) are scientifically proven to have *no* lasting impact on chronic pain. Instead, they will reinforce the pain in the long run, because they prevent active pain coping. These passive interventions suggest that medical applications, products and devices are necessary and that an active life is only possible if pain relief has been achieved by external factors. Sentences, such as ‘Gee, your back is tense as if you were 70 years old; first, we have to release these tensions’ or information on ‘energetic imbalances’ in the body may further strengthen the Second Thought Trap and unsettle the child and his/her family.

In the following example (Niklas, more than 50% of school days missed during the last semester; second family session in Niklas’ second week on the ward), the patient’s family already understood the education, and will now discuss the importance of active pain coping.

Case Report: Niklas (13 Years), Pain Disorder with Abdominal Pain

> Well, Niklas, we explained to you and your parents how chronic abdominal pain develops and how chronification happens. What does it specifically mean now knowing that any type of passive pain coping or avoidance contributes to a further increase in pain? I guess deep in your heart you already know the answer: to do everything despite the pain, even things one doesn’t like to do. Obviously, you have already tried all this, and we know that severe pain is a severe impairment. But, as you already experienced on the ward, active coping in everyday life despite the pain is awkward but not impossible. You already learned some helpful strategies for how to cope with pain. At the beginning of your inpatient stay, you didn’t know these strategies and had to cope with daily life anyway, like all the other patients. And you did it! You can be very proud of yourself! As you noticed, it became easier for you each day irrespective of whether or not you used those techniques. Your body got used to everyday activities, and now is reacting with less distress and less painful physical tension. You think less about how to cope with everyday life. Now the task is to use that knowledge, your regained power and the learned techniques in everyday life. Often these strategies will help you better cope with difficult situations in your daily routine. But sometimes the techniques may not help that much yet, for instance, if you didn’t sleep well and wake up in the morning totally exhausted, wondering how to manage and pass the math exam in such a condition. Then it is important to go on in spite of your pain in order to help your pain centre learn that pain is not an alarm signal anymore and that it has lost its impact on you, your life and behaviour. If you succeed in doing so, there is the chance of lasting recovery from your pain disorder. Addressing the parents: It wouldn’t be fair to leave that job to your child alone. Your child needs you to be strong parents. Niklas must be able to rely on you to support him with his active pain coping efforts, particularly in situations when it is difficult for him. Most parents have secretly thought about this, but have hesi-

> tated, because they didn't want to be bad parents. Do you commit to support Niklas in active pain coping? Niklas, are you confident that your parents are able to help you? Addressing the parents: You should understand that supporting Niklas in active pain coping irrespective of pain intensity *doesn't* mean that you are bad parents. In such a moment, you may not focus on your child's current worries and pain, but think about his future instead. If we succeed in enabling your child to perform more active pain coping on the ward even when he is in severe pain, we are sure you will also succeed.

Now it is time to discuss how far Niklas should go with his efforts *before* he can ask his parents for support. It is very helpful to define the circumstances under which the parents should act without the approval of their child. We have had good experiences with changing the family systemic context variables before and during particularly problematic interactions. For instance, if it is difficult for the mother, who is suffering from a pain and anxiety disorder herself, to prompt her son to actively cope with his pain during obviously painful episodes, it is a great relief for mother and child if the slightly impatient father (who is pressed for time) feels responsible for family processes in the morning. If this is not possible (e.g. single parent; severe psychological or psychosocial stress factors) and the parent cannot be sufficiently empowered, substantial family stress factors require another approach outlined in Sect. 11.5 (Coping with stress factors within the family).

11.4 Coping with Conflicts Between Autonomy and Dependence

Frequently in outpatient or inpatient pain treatment, it becomes obvious that apart from the pain, there are some conflicts of autonomy and dependence between the child and his/her parents.

On the one hand, this could mean that the child is striving for more freedom and a voice, i.e. autonomy, against his/her parent's will. This is quite a normal process in human life. It only becomes problematic if this conflict is carried out adamantly, resulting in dysfunctional thoughts and physical tension which reinforce pain. This leads to conditioning of family conflicts, increased tension and increased pain and can culminate in mutual accusations (→ 'It is obvious! As soon as you should do something, your pain returns'). During these conflicts, many parents do not recognise the child's pain and instead suspect him/her of purposely putting pressure on them (→ First Thought Trap). Of course, the child and his/her family suffer in this situation, but it makes successful pain treatment extremely difficult. The child will be worried that successful pain treatment comprising psychological approaches will strengthen his/her parents' position that the pain is 'mental', 'in his/her head', or 'imagined'. This is not completely wrong (but also not completely true). The best solution is to focus on the current problem and to point out during the education that the conflicts are associated with increased tension which reinforces pain. Obviously, both parents and child cannot cope with the situation. A pain-focused approach avoids the discussion about 'the chicken and the egg' at the beginning of the treatment. At the beginning of treatment, it is not always possible to determine whether the pain disorder may have been preceded by oppositional behaviour (e.g. conduct disorder) that is accompanied by pronounced truancy and/or refusal of performance, and by increased media consumption and reduced activity. We rarely observe such symptoms in our patients.

On the other hand, there will also be developments in the opposite direction. During the course of the pain disorder the child has spent more time with his/her parents (mostly the mother) and retreated into the secure family environment. Many parents have a bad feeling about this, but are unsure how to change the situation to be more age-appropriate—just talking about it is insufficient. Some parents and children enjoy the development towards an increase in parental care and dependency—if only there wasn't any pain. At worst, parents and the child ally against the cold and hostile world in which teachers, classmates, physicians, or other people are responsible for the unjust or inappropriate treatment of the child's pain condition. Generally, the child will be lacking motivation to try autonomous behaviour and will not undertake anything without the parents.

Irrespective of the specific nature of the conflict, the more the family interaction is dominated by conflict, the more obstructive it will be for success in pain treatment. Regardless of the different positions, seen from a more abstract point of view, the recommended therapeutic approach is quite similar:

1. The first step is to normalise the development of the conflict ('Presumably you all know about families with similar conflicts?') and to find out what was previously undertaken to solve the conflict ('Obviously all of you suffer from this situation. You've probably tried to find a solution. What exactly did you try so far?'). Then the efforts of the family are appreciated ('I can well understand that you are all frustrated. It is quite impressive that you are still willing to cooperate to find a solution in spite of all that mutual hurting in the past. You have explained your conflict quite openly which shows that you are still interested in a solution').
2. The next step is to identify the family's interaction patterns which have a functional or dysfunctional impact on the family's general well-being and the child's pain. To this end, the technique of 'circular questioning' is very useful ('Mrs. G., what do you think your child is thinking about the fact that you are seldom complimented by your husband but blamed instead?'). In a next step, techniques aiming at more respectful interactions (e.g. optional time-outs during a discussion which is getting worse) and more autonomous behaviour on the part of the child (e.g. giving the child the chance to resolve conflicts on his/her own) should be introduced.
3. Desired behaviour is reinforced with a reward meeting the needs of the driving force in the conflict. The reward may be cuddling with the mother after the child has faced a difficult situation on his/her own. Or it might be a reinforcement schedule which provides the desired freedom once unloved housework is done or

> the child has demonstrated respectful behaviour. If each family member is willing to make a compromise, the technique will work and none of the family members will feel cheated. The aim of all these interventions is to erase the association between pain perception and family interaction.

Family conflicts are not the (one and only) cause of the pain disorder. The pain is not purely of psychological origin (told to the child) nor caused by wrong upbringing (told to the parents). To avoid polarisation in the family session, we recommend discussing the upcoming family session with the child in advance.

The child is a valuable ally in the family session if he/she can be sure that the goal is a win-win situation for him/her and his/her parents. Usually the child knows exactly what his/her parents are thinking and how they will react to various interventions. This knowledge should be used to prepare the family sessions.

Sometimes, one parent equates his/her biography and symptoms (mostly due to unprocessed life events) with the child's situation (→ 'That is exactly the way it was for me!—Nobody believed me either. No physician or therapist has ever helped me!'). In these special cases, parents prevent an active pain coping. Sometimes these parents are assumed to suffer from 'Münchhausen syndrome by proxy'. This is a rare but extremely severe mental disorder of a parent, in which the parent invents or fabricates symptoms or illnesses in the child to receive attention and appreciation through the accompanying treatment. In nearly all cases, we could exclude this disorder, because the parents were worried and their behaviour was not aimed at receiving attention, but at protecting the child. Protecting the child is not in line with the Münchhausen syndrome by proxy. There are only few treatment options for these extremely worried parents. One option is to patiently discuss the differences between the parent's own and the child's symptoms. The parents' fear, which underlies their behaviour, should be discussed respectfully and without prejudice. Another option is to encourage the child's autonomy (this is only possible from the age of 14 and requires that the child is a bit annoyed about the ongoing investigations and treatments).

11.5 Coping with Stress Factors Within the Family ('The Tip of the Iceberg')

'You were born to help me, not to impose on me' (just one of several things 16-year-old Dana has heard from her mother and experienced as stressful, apart from experiencing physical family violence).

The family conflicts depicted in Sect. 11.4 may make pain treatment difficult but not impossible. The migraine of the single mother that makes it impossible for her to look after her children 4 days a month, or the drug abuse of the father with a pain disorder who can still attend work regularly are problems that can be solved.

However, for a few children, pain is only 'the tip of the iceberg', and during the course of treatment, a severely disturbed family interaction becomes obvious. These disturbances may be so severe that the child's well-being is endangered (e.g. severe physical violence and/or sexual abuse within the family) requiring immediate action (the exact procedures depend on the laws of the respective state). Table 11.1 depicts the graded procedure we follow.

Table 11.1 Simplified description of the background and approach dependent on the degree of family burden and danger to the child's wellbeing

Degree of severity	Background	Approach
Grade 1	The family stress factors (e.g. physical or psychological disorder of one or both parents; death of a beloved relative; permanent conflicts between the parents) result in substantial emotional burden for the child and his/her parents. But these stress factors do not endanger the further development of the child because the family is ready to work together on a solution	Addressing the possibility that the child may feel guilty allows the parents to explain to their child that he/she is not responsible for the family conflicts. The various unfavourable circumstances may be openly discussed and thus are not tabooed. If the emotional burden is so high that there is need for further outpatient psychotherapy for the child (or his/her parents), such a treatment will be initiated. Supportive measures of the youth welfare office may be helpful. If the parents do not understand how dangerous the situation is, the youth welfare office needs to be contacted
Grade 2	The family stress factors (e.g. conflicts as given in grade 1, but also violence; verbally or physically escalating parental conflicts; at least one parent suffering from a severe psychiatric disorder (e.g. personality disorder); long-lasting home care of a terminally ill relative; brother or sister with a conduct disorder and aggressive behaviour towards family members) are substantial and usually already resulted in a psychological disorder of the child (i.e. adjustment disorder with depressed mood)	During the family session the parents take all the responsibility off the child. Facing the emotional symptoms of their child, the parents or guardian agree on cooperation and further efforts in order to avert the imminent risk to the child's development. If the parents do not understand how dangerous the situation is, the youth welfare office needs to be contacted. The child's well-being is endangered
Grade 3	The stress factors within the family have a severe negative impact on the child and have already resulted in a psychological disorder. It turns out that the family resources are insufficient to prevent an imminent risk to the further development of the child.	Apart from ongoing outpatient psychotherapy, there is the necessity of outpatient family support, or (rarely) inpatient measures of the youth welfare service (Procedure dependent on the laws of the respective state). Parents or guardian of the child agree to cooperate. If the parents do not understand how dangerous the situation is, the youth welfare office needs to be contacted. The child's well-being is endangered

Table 11.1 (continued)

Degree of severity	Background	Approach
Grade 4	There are severe stressful factors within the family, having resulted in a chronic psychological disorder of the child as well as an endangerment of the child's well-being. Often the child is so desperate that he/she has at least considered committing suicide	Approach is depending on the willingness (and resources) of the parents or guardian for cooperation with the outpatient and transient inpatient support of the youth welfare service and the outpatient psychotherapist. In most cases, there is a fair chance that family stress factors can be reduced to an acceptable level so that the child is able to cope with them
Grade 5	There is the strong suspicion of severe domestic violence (physical and/or sexual) or structural or psychological neglect. Hence, the well-being of the child is clearly endangered	Because the parents or guardian do not understand how dangerous the situation is, or do not have sufficient resources to initiate a lasting change, the child has to be admitted to an inpatient institution of the youth welfare service as soon as possible (examples: Linda, age 15 years—CRPS type I: continual sexual abuse by her father. When this issue is brought up in a family session, the mother accuses her daughter of lying; Karl, age 14 years—pain disorder with headache, depressive episode: his single mother is unable to look after her child or provide for his basic needs; Yvi, age 17 years—pain disorder with abdominal pain, complex posttraumatic stress disorder due to repeated sexual abuse by different partners of her mother: her mother has a borderline disorder and conflicts with her always escalate to physical violence and mutual destructive insults)

The classification into five grades of severity reflects just one possibility of facing the different types of extraordinary stress factors within the family. Being an oversimplification, it may still give orientation to set up a preliminary treatment *concept* which may be optimised later.

Having no plan and thus being helpless are the main obstacles when establishing suitable support for children and families in need.

At the German Paediatric Pain Centre (GPPC), the social worker participates regularly in the ward rounds. With cases of grade 2 or up, he/she becomes more and more involved in the pain treatment, doing the tasks outlined above (for detailed information on the role of the social worker, see Sect. 12.6). We feel that with the collaboration of the physician, psychotherapist, social worker, and patient, most affected parents or persons with custody of the child can be motivated to closely cooperate with us and the youth welfare institutions.

One technique to get the family's cooperation within a problematic family constellation or with the family's taboo topics is to set up a genogram on a flip-chart (Sect. 11.1). The genogram is taken into the family session in order to elucidate striking behavioural patterns repeatedly found in each generation (e.g. on the paternal side, breaking of relationships is only seen with male family members—the (male) patient and his father have increasing verbal conflicts). Sometimes it may be advantageous to use the genogram to introduce topics tabooed by the family without having to explicitly name them (e.g. the alcohol abuse of the father is headlined (variant: overwritten) with the bright red letters 'TABOO').

Independent of the genogram, the own 'bad feeling' needs to be addressed and justified with the existing facts early in treatment. For older adolescents, the therapist needs to ask for his/her consent to discuss the provided information with the family. This may be a difficult process, because the affected adolescents mostly fear to discuss tabooed family conflicts, problems or burdens. These concerns and fears should specifically be addressed in the family session ('Do we have to worry that you reproach your child and exercise pressure, as soon as we have left the room?'). It is helpful to directly ask the attachment figures what they think about the worries or accusations and how they want to cope with them. It is important for the child that the therapist confirms the truthfulness of the statements with his/her own observations and the existing facts, to protect the child and to direct possible verbal attacks and devaluations to the physicians and therapist (as adults).

Case Report: Rena (12 Years), Complex Regional Pain Syndrome Type 1

After 3 weeks of inpatient treatment, Rena hesitantly reported of violent confrontations with her impulsive mother several times a week. The mother frequently changed partners and some of them were strange and looked at her strangely. She thought that she was to blame for everything, because she causes problems and everything she does was wrong. Earlier in the course of pain treatment, it was obvious that Rena was intimidated and scared in the presence of her mother and regressed verbally. The mother permanently devalued her child and contradicted herself. The responsible physician and therapist had the feeling that the mother could 'explode' at any time. The child reported that the mother sometimes threw objects at her in a rage and once hit the foot that was now affected from CRPS. Because the mother minimised the obvious conflicts, the team decided to address all problems with the mother in a family session, against Rena's will. First, the mother listened to the observations in silence, but then suddenly jumped up, screamed at the team and ran out of the room. After a longer break, the session was continued and the mother was told that she had the possibility to inform the youth welfare office together with the team and to ask for educational support. The mother almost seemed relieved when she reported in tears about the conflicts and the excessive demands. She said she would contact her previous psychotherapist and ask to continue her therapy. The youth welfare office was engaged and found a new home for Rena (since then she stayed on the pain ward; overall, approximately seven weeks). She made enormous progress in the following months. The mother resumed her psychotherapy. One year later, Rena was able to walk normally and without pain, she reconciliated with her mother and returned to her mother's home (with ongoing outpatient psychotherapy and support from the youth welfare office).

Unfortunately, many factors have to positively interact in order to enable such a positive course of treatment despite enormous psychosocial stress factors. In Rena's case, the youth welfare office very quickly drew their own conclusions that confirmed our impression. The foster family followed our recommended graded exposure exercise plans carefully, the outpatient psychotherapist consulted our institution to plan further procedures and the follow-up visits were accompanied by an educational assistant.

Rena's case demonstrates that even under unfavourable conditions, even severe pain disorders with pronounced comorbidity can be healed. However, this requires team-oriented thinking, multiprofessionality and many individual therapy sessions for establishing a relationship and trust. We know many 'Renas'. Many of them can receive help, if the physicians and therapists do not look away, but listen, try to understand and face the conflicts. Severe pain disorders are no product of chance but an expression of massive emotional burden which needs to be treated in order to treat the pain.

11.6 Stress Tests and Parent's Observation on the Ward

So far, we have discussed various aspects of including the family within the scope of family sessions. Most parents are much interested and increasingly engaged in the implementation of these techniques and interventions. But many difficulties do not become obvious until they try to transfer theory into practice. This is the reason why it is indispensable that *during inpatient treatment*, the patient passes two Stress Tests at home, each of 1- or 2-days' duration and including attending class at his/her home school, if possible. The patient and his/her parents independently record successes and failures. These Stress Tests are very helpful to figure out the family's actual resources and obstacles to assist with long-term implementation of active pain coping or other interventions discussed with the family. Furthermore, for most parents, observations on the ward are helpful in learning how to deal with their child in pain.

11.6.1 Stress Tests

The aim of a Stress Test is to give the child and his/her family the opportunity to examine how well the various techniques and strategies can be implemented into the family's everyday life. Thus, it does not make sense to start with a Stress Test on the first of the three weekends of the stay. Only the second and third weekends are suitable for a Stress Test. A Stress Test is a regular part of the inpatient pain treatment programme, and will be omitted only in rare exceptions (e.g. acute risk to the child's well-being, an acute infectious disease within the family, start of withdrawal from opiate addiction). The Stress Test should include attending school at home. A family

Stress Test takes 2 days, sometimes three. If the home is far away from our clinic, the beginning of the Stress Test is scheduled for the same day as the family session (mostly on Thursday or Friday afternoon), so that the child can go home with the family. The goals for the family are set in detail during the preceding family session (for example: participating in family life irrespective of back pain; meeting friends; meeting the demands of housework (e.g. vacuuming); implementing the 1€ rule; practising the techniques; parents should support active pain coping; positive evening reflection with the mother).

The nursing and educational team (NET) records the aims of the Stress Test on the Weekend Observation Sheet (Chap. 15, worksheet #18). The NET reminds the child and the parents to *separately* document the degree of success at the end of the Stress Test. The reflection of the Stress Test should be very appreciative, and the NET will try to get the parents' support. Reprimanding parents is definitely not advisable, as parents are important co-therapists in the implementation of interventions. Since building trust is the NET's responsibility, all members of the NET need comprehensive training.

The child's ratings of the success of the Stress Test frequently differ from those of the parents. These different views are very helpful for the psychotherapist.

The NET should inform the family in advance that these differences are likely to occur. Any ideas or wishes for future therapeutic work may be recorded in the column 'wishes'. Finally, the parents are instructed to immediately call the ward if any substantial problems arise in the implementation of the discussed interventions (e.g. impossibility of attending school; child is refusing to implement the graded exposure exercise). Sometimes this phone call helps to avoid the premature interruption of the Stress Test (for instance, the helpless mother is coached in sending her son to school despite pain in the morning). At the scheduled (or, sometimes, premature) end of the Stress Test, the documentation sheet should be handed to the NET in person. The NET always makes a record of their subjective impressions when the sheet is handed back.

After the Stress Test is finished, the documentation sheet—supplemented by the subjective impressions of the NET and verbal expressions of the child or his/her parents—is handed over to the physician or psychotherapist in charge. Any modification of the procedure in individual and family sessions required as a result of the experiences in the Stress Test will be discussed with the patient in his/her upcoming individual session.

Any problems or failures during the Stress Test are an important indicator of obstacles for the long-term implementation of therapeutic interventions and should <u>never</u> be neglected.

11.6.2 Parent's Observation on the Ward

In case of substantial difficulties in the implementation of active pain coping strategies, an observation of everyday life on the ward for one or both parents may be a very useful addition to the Stress Test. Ideally, such an observation would start at

7:00 a.m. and last until 8:00 p.m. A shorter duration is possible, but should be an exception. The indicated time frame will allow for sufficient opportunities for the parent to observe his/her child in active pain coping on the ward. Observation is especially useful on a child's 'Stress Day' (see Sect. 9.5.3).

From the medical history, the admission session, the individual sessions, and the previous course of treatment, it is clear in most cases what the aims of observation should be. These are discussed between the NET, physician and psychotherapist, and recorded by the NET on the parent's observation sheet (Chap. 15, worksheets #19 and #20). Most often, the focus will be on training skills and striving for security in the implementation of active pain coping strategies at home. Often, the parents are unsure about what to expect from their child, and have feelings of guilt. Often, they say, 'If I had known what my child could accomplish in spite of the pain, I would have intervened much earlier'. Sometimes observation focuses on the modification of dysfunctional interactions between the child and his/her parents. In this case, the aims may be to compliment the child, to recognise even small progress, or to implement pleasant shared activities (i.e. spending time together in a relaxation room, or playing a game).

At the end of the observation day, the NET and the parent reflect on the experiences of the day (Chap. 15, worksheet #20). This discussion should focus on the degree to which the preset aims were met. The completed worksheet is given to the physician or psychotherapist in charge. It will form the basis of the upcoming family session.

Finally, we want to point out a special but rare aspect of observations that will not be seen in the agreement of aims: generating hypotheses on the harmful extent of dysfunctional family interaction. Sometimes this is helpful to estimate whether support of the youth welfare service is needed after discharge and if so, to what extent.

1. Mrs. F. is very unkempt when she arrives at 8:00 a.m. to start her observation, as agreed upon. For the following 3 h, she lies on her daughter's bed and is very indignant when asked for collaboration by the NET.
2. Instead of playing with his daughter, Mr. P. prefers to play table tennis with another male patient. He shows no interest in stopping until he is summoned by the NET to do so.
3. Even in the artificial environment of inpatient pain treatment and supported by the NET, Mrs. H. is unable to enforce her will on her son. She doesn't stick to the aims jointly agreed to. The child's strong oppositional behaviour is only observed when his mother is present and not seen in everyday life on the ward.

11.7 How the Family Is Advised to Cope with Relatives, Friends and Teachers

Children and their parents report, sometimes with amusement, but more often annoyed or feeling burdened, that they get a lot of advice on how to handle their child's pain. Pain is a universal experience, and everyone has had their own experiences that he/she wants to share with the child and the parents, often unsolicited and accompanied by reproaches. The ‘counsellor’ even expects to be appreciated for his/her hardly helpful advice! This may provoke interactive distress for the parents and the child.

Before their inpatient treatment, the children have usually tried various therapeutic interventions, e.g. acupuncture, homeopathy, osteopathy, diets, massage, physical therapy, dental corrections, transcranial magnet-stimulation or analgesics.

All advice is based on the assumption that ‘The child suffers pain because …’. This assumption allows for *mono*causality only. These explanations usually stem from one of the Three Thought Traps (see Sect. 4.1). Our parent’s guide ‘How to stop chronic pain in children’ (Dobe and Zernikow 2014) presents detailed suggestions for how to get the parents enthusiastic about a view comprising all three dimensions of pain chronification. This explanation is also understood by relatives, family friends or teachers.

In the following paragraphs, the main ideas of the parent’s guide will be summarised.

11.7.1 How to Cope with Relatives and Adult Family Friends?

While abundant well-meant advice is just annoying, it is time for the parents to intervene and protect their child from advice, if relatives talk about their own pain or the child’s chronic pain in a catastrophising way. We recommend that the parents either educate the adviser on chronic pain, or if this seems insufficient, at least temporarily discontinue the discussion or contact. Alternatively, adolescents may be supported in telling the relative or friend of their own wishes and needs, when parents consent to this approach.

Example: Asking a Relative or Friend of the Family Not to Question/Enquire About the Pain Anymore

> Up to now we didn’t tell you what we are going to tell you now because our child loves you and doesn’t want to hurt you. She definitely doesn’t want to be questioned about the pain anymore, and she doesn’t like to talk about it, because this will remind her of the pain and lead to increased pain perception. She has decided to undertake an inpatient pain treatment to do something about her pain. I know this will be difficult for you—as it is for us. The physicians recommended to give her 1 € each time you or we still ask about her pain. I hope you will understand. You would do her a great favour. (Add the following sentence only if really necessary: If you cannot stop talking about pain, we have discussed that the next step should be to temporarily discontinue your contact with her. But this is the last thing we want. If you are not willing to stop talking about the pain, however, we will have to take that step to protect our child).

Fortunately, most relatives or friends will understand. Rarely some of the relatives (mostly the grandparents) ask to attend the family session in order to get more information on the background of what they consider a somewhat strange procedure and that their grandchild is so enthusiastic about. If their previous efforts are appreciated, in most cases, they are ready to collaborate. Often, the 'fact sheet for relatives' from the parent's guide 'How to stop chronic pain in children' (Dobe and Zernikow 2014) proves helpful to get a better understanding of the issue.

11.7.2 How to Cope with Teachers?

Most parents of children with chronic pain in need of inpatient pain treatment report having had to argue with their child's teacher about days missed from school. Some parents complain about teachers not trying to understand their child's problems and needs. They often report that their child is exposed to substantial social burden due to the lack of understanding of both teachers and classmates.

The teacher's statements should be evaluated carefully. Even if the teacher is acting incorrectly, this normally reflects certain aspects of the child's social behaviour.

How is the child dealing with false accusations or unfair judgements? How does he/she react to teasing? How does he/she behave towards his/her classmates? Does he/she always insist on understanding for his/her problems, or is he/she able to understand his/her peers' or teachers' view (Forgeron et al. 2011)? Most teachers are good at recognising anxious behaviour or avoidance. If during a parent–teacher meeting a teacher says that in his/her view the child's headache is an excuse to avoid a class test, then this information should be regarded as valuable. Of course, with regard to chronic pain, teachers, like most other people, are prone to getting stuck in one of the Thought Traps, especially the First Thought Trap (Logan et al. 2007).

Our experience with schools, their principals or teachers is more often good than bad. Generally, the teacher's view is helpful: *the child must go to school*. In accordance with most teachers, we do not recommend any type of home schooling, as lessons at home will support a strategy of avoidance and enhance pain. This again will result in social deficits and impair the child's ability to cope with distress and daily hassles. Finally, we want to point out that pain itself cannot prevent behaviour and thus cannot prevent school attendance. We know many terminally ill children who knew they were going to die, but absolutely wanted to maintain normal attendance at school in the last weeks and months of their lives despite very severe tumour pain that could not be treated sufficiently with pain medication. Furthermore, there are many children with pain disorders who manage their everyday lives despite pain, although it is very strenuous for them. It can be expected that massive school absence over several months will have reasons additional to a pain disorder alone. Home schooling will effectively prevent long-term treatment success. In patients with a severe impairment (e.g. comorbid social phobia and/or depression and/or posttraumatic stress disorder), it may be helpful to arrange a plan for reintegration into school with the teachers over several weeks that gradually enables the child to normally attend school in the end.

During the first Stress Test or the first day at school after a (mostly) long school absence, patients typically face the question 'What's your disease?' Over the years, we have found a quite simple answer that totally ignores the background of the pain disorder but protects the child. If there is good reason not to explain the pain disorder in detail to classmates and teachers (as will be in almost all cases), this might be a helpful answer:

Example: Explanation of the Pain Disorder to Classmates and Teachers

> Finally, I found a pain clinic that succeeded in diagnosing my disease. The official name is much too complicated to remember, so you just have to know that it is a type of pain-disease. They taught me how to cope with it. You would help me by not asking about my pain anymore, but approaching me as normally as possible. This would be the very best for me.

That explanation is good for most children. As is the case with relatives, the ‘fact sheet for teachers’ from the parent’s guide ‘How to stop chronic pain in children’ (Dobe and Zernikow 2014) has proven helpful. However, it should only be handed over to teachers really interested in the child and his/her pain disorder. In case the teacher asks to talk with the physician or psychotherapist, one should discuss with the child and his/her parents *in advance and in detail* what information should be given to the teacher. We proactively offer to talk to the school counsellor or the principal in the case when the school is questioning whether to exclude the child from classes and the parents see no way of dealing with this themselves.

11.8 Pain Treatment in Families with a Migration Background

A person has a migration background if he/she moved from abroad or was born in this country but at least one of his/her parents is a foreigner. In Germany, according to the Federal Statistical Office, now, more than 80% of the children and adolescents with migration background under the age of 20 years are second- or third-generation migrants who were born in Germany. There are many children with migration background. Almost 30% of all children between 5 and 20 years fulfil the above-mentioned criteria. Most children with migration background come from Turkey (14.2%) or Russia (9.4%). Despite the high percentage of children with migration background, only one study has examined pain in these children in Germany (KiGGS study; Ellert et al. 2007). According to this study, children with migration background report significantly more headache during the last 3 months compared to children without migration background. This is consistent with the results of the only other European study on this issue (Bugdayci et al. 2005).

Studies with adults demonstrate that German physicians perceive pain expressions of Turkish migrants as exaggerated compared to those of other adults. Adults from North America or Northern Europe seem to express their pain less emphatically than adults from more southern origins (Greenwald 1991). One study conducted at the GPPC revealed that children with migration background reported higher pain intensities than children without migration background when presenting to the outpatient clinic due to chronic pain. According to our clinical experience, children with migration background tend to show their pain more openly. One should accept these differences as culture specific and let the affected families know that they are taken seriously.

In general, quality and intensity of pain expressions should not have an impact on treatment planning.

In some families with a migration background, at least one of the parents may have difficulties with the native language or does not speak the native language at all. In this case, the children often act as interpreters. This is unfavourable for pain treatment aiming at behavioural changes in the family's everyday life. It is not suitable that an affected child should translate complex relationships for his/her parents, who are often somatically fixated. In rare cases, neither of the parents speaks the native language at all. If only one of the parents speaks the native language, there is the risk that he/she will translate only those parts of the discussion to his/her partner that he/she understands and that fit into his/her world view. The only suitable approach is to ask for a professional interpreter in order to establish some understanding of chronic pain in the family without overstraining the child or the parents. Apart from its sometimes-substantial costs, such an intervention is not without problems. Involving a neutral interpreter might make (mostly) the father feel reproached, his language competence devalued. One should know that in families with migration background, it is quite difficult to discuss family conflicts or the child's stressful problems with a stranger, the interpreter, present.

A culturally different distribution of gender roles may be a challenge for pain treatment; for instance, if an adolescent girl opposes the traditional role model, provoking substantial family conflicts. Such a situation is especially difficult since parents are often not ready to discuss these problems or they deny them. Here, pain treatment is charged with social problems that cannot always be satisfactorily resolved. We endeavour to discuss any consequences regarding the patient's life openly. However, a satisfactory solution cannot always be found, but at least some kind of approximation can be attempted. It is good for therapy if continual (pain) psychotherapy following the inpatient treatment can be done by a psychotherapist with the same cultural roots as the family. If the family conflicts are severe, the only solution is to contact the responsible youth welfare office (Sect. 11.5).

Many traditional cultures in which the individual's independence of action is subject to a fatalistic or religious interpretation, lack an understanding of underlying psychological concepts. In this case, it may be helpful to just briefly justify some therapeutic interventions and instead focus on precise instructions for how to do the exercise. It is our experience, irrespective of culture-specific or religious characteristics, lasting changes in family behaviour towards active pain coping are more improbable with language barriers between our team and the family (lack of understanding) and with families who prefer maintaining their cultural or religious standards over individual well-being (rigidity of thinking).

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Inpatient Pain Treatment: Module 5 (Pharmacological Treatment, Physical Therapy and Other Optional Interventions)

12

Michael Dobe, Boris Zernikow, Michael Frosch,
and Monique Ribeiro

Contents

M. Dobe · B. Zernikow (✉) · M. Frosch
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de; M.Frosch@kinderklinik-datteln.de

M. Ribeiro
Department of Psychiatry, Department of Anesthesiology, Perioperative and Pain Medicine – Harvard Medical School, Boston Children's Hospital, Boston, MA, USA
e-mail: Monique.Ribeiro@childrens.harvard.edu

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_12

Abstract

In this chapter, we present interventions implemented in the context of the interdisciplinary pain treatment for specific patient populations or in socially challenging situations. First, we discuss pharmacological treatment options and physical therapy including graded exercise. Then, the basic concepts of integrating art and music therapy, or the support of a social worker are briefly presented.

Having a tight and concise treatment team working closely with children and families is an essential factor of interdisciplinary pain treatment. Communication amongst team members is key in providing a unifying explanation and treatment model, therefore preventing splitting that may lead to unnecessary overmedicalisation. There is the old saying, ‘Too many cooks spoil the broth’, which is also true in pain treatment. According to their developmental state, children need clear-cut structures and defined contacts, which are reliably accessible.

Therapeutic alliance is known to have a highly effective impact on successful pain treatment. Our concept of an intensive interdisciplinary pain treatment with designated contact persons as ‘team captains’ meets this requirement. Other therapeutic options, such as consultation with a psychopharmacologist or a child and adolescent psychiatrist (if a pharmacological treatment seems beneficial), physical therapy and social work involvement, massage therapy, music or art therapy, should also be available when indicated. It goes without saying that in musculoskeletal pain, physical therapy is a crucial treatment component.

12.1 Pharmacological Treatment

This section presents the most often used analgesics, their mechanisms of action, and profile of adverse effects. While there are no EMA (European Medicines Agency) or FDA (U.S. Food and Drug Administration) approved medications or specific guidelines for pharmacological treatment of paediatric functional chronic pain in the absence of a ‘tissue destruction’ (like in cancer, rare conditions like epidermolysis bullosa or inflammatory diseases like juvenile idiopathic arthritis), medications are often used symptomatically in this population, especially in early stages, prior to the realisation that a comprehensive, multimodal approach is necessary.

There is a lack of adequate, randomised controlled trials studying pharmacological options for paediatric chronic pain and often, adult data is projected to treat comparable disease processes in children and adolescents. However, this can be problematic, as adults and children may differ in the way they metabolise and respond to medications, as the developing brain might be more susceptible to side effects, and the trajectory of paediatric and adult chronic pain is frequently very different. Chronic paediatric pain is a dynamic process comprised of biological processes (such as central sensitisation), psychological factors (pain appraisal, psychological comorbidities), and social–cultural constructs (family response to pain, level of disability). The existence of co-morbid conditions, particularly psychiatric co-morbidities such as anxiety, depression, and somatic symptom disorders; should also be taken into consideration when deciding which agents might be appropriate.

Finally, matching the pathophysiology of a pain condition with the mechanism of action of a drug is extremely important to make an informed decision regarding medication treatment. In our view, pharmacological treatment of pain symptoms should target pain syndromes that are proven to be responsive to analgesics such as pain due to inflammation or structural disease. Target setting and patient contracts are also important parts of prescribing a medication. This would avoid unnecessary polypharmacy as it is often seen in this population as well as the risk of overmedicalisation in detriment of the clinically effective multi-modal approach.

It is important to point out though that addressing psychiatric co-morbidities that may pose a barrier to care as well as amplify pain responses may be a valuable intervention and a target for pharmacotherapy when well indicated and monitored.

As part of the evaluation of our inpatient pain treatment programme, we analysed changes in medication use (Hechler et al. 2009) (Table 12.1). On admission, one-third of the 119 patients did not use any analgesic and did not start taking analgesics during therapy. Another third of the patients were on analgesics at the beginning, but discontinued taking medications. Presumably, in those 39 patients, there had never been any indication for analgesics. In the last third of the patients, medication-based analgesia was initiated (mostly in previously undiagnosed migraine) or continued during the inpatient stay because there was a clear indication to do so.

The results of another study comprising 2249 paediatric pain patients presenting in a 5-year period at our outpatient pain clinic were similar. Ninety percent of the patients had taken analgesics in the past, while 76% had taken analgesics during the 3 months preceding first presentation. In only 57% of the patients taking drugs did pain therapists rate drug-based analgesia as indicated and recommend continuation. In other words, *43% of the patients were on analgesics without any benefit* (Zernikow et al. 2012b).

Table 12.1 Drug usage 3 months after discharge from the GPPC

***N* = 119**	***N* (%)**	**NSAIDs**	**Other non-opioids**	**Triptans**	**Opioids**	**Co-analgesics**
No previous analgesic	40 (34)	–	–	–	–	–
Analgesic discontinued	39 (33)	16	18	1	3	1
Analgesic continued	32 (27)	21	2	9	0	0
Analgesic newly started	8 (7)	6	1	1	0	0

NSAID nonsteroidal anti-inflammatory drugs

12.1.1 Opioids

Opioids are amongst the most potent pain relievers. However, its narrow safety profile, addiction potential, and limited effectiveness in chronic, non-cancer pain syndromes in adults raise questions about its utility in conditions such as backache or joint arthrosis (Stein et al. 2010; Noble et al. 2010). A 'brainman' film explains this issue in less than 3 min (https://www.youtube.com/watch?v=MI1myFQPdCE). The United States currently experiences an opioid epidemic, with almost 42,000 deaths related to opioid overdoses in 2016 and this been especially challenging in the children and adolescents population. A Cochrane review on opioids for chronic non-cancer pain in children and adolescents could not detect a single randomised controlled trial to include (Cooper et al. 2017a, b). As such, opioids play only a minor role in multimodal pain therapy of children and adolescents with chronic pain and for most patients, they should be discontinued in the course of treatment.

Mechanism of Action

The analgesic effect of opioids is mediated via opioid receptors present in high density in the CNS. In humans, endogenous opioid peptides (encephalines and endorphins) can activate those receptors and inhibit nociceptive afferents. Morphine and other exogenous opioid analgesics also bind to those receptors, mimicking the effect of endogenous opioids. The analgesic effect of opioids is mediated by several mechanisms like:

1. Inhibition of the conduction of ascending nociceptive signals at the spinal level.
2. Dampening of the limbic system reduces affective pain processing and emotional responses to pain (patient perceives the pain as less threatening).
3. Activation of descending pain-inhibiting tracts.

Opioid receptors are categorised into several subclasses. The opioid's pattern of receptor activation explains the individual profile of therapeutic and adverse effects. The *μ_1-receptor* is exclusively found presynaptically. Its activation results in a decrease of Ca++ influx into the cell and a reduced release of neurotransmitters responsible for pain signal conduction. Thus, activation of the *μ_1-receptor* has a predominantly analgesic effect. The *μ_2-receptor* is mainly found postsynaptically. Its activation results in an increased probability that K+ channels will open with subsequent hyperpolarisation. Activation of the *μ_2-receptor* leads to decreased pCO_2 reactivity and may cause respiratory depression. Activation of intestinal *μ_2-receptor* in turn leads to prolonged intestinal passage, increasing the risk of constipation.

Adverse Effects

Gastro-intestinal side effects, such as constipation, nausea, and vomiting, due to activation of the *μ-receptor* and reduction of propulsive peristalsis happens in about 10% of the patients and can be especially problematic for those already struggling with abdominal pain. Delayed bladder emptying and urinary retention may happen in a small percentage of patients.

From a central nervous system standpoint, decrease in respiratory rate is seen in normal analgesic doses and may reach the point of severe respiratory depression, somnolence, coma or death, especially with rapid titration. Interestingly, the risk is much less if the opioid dose is titrated to actual pain level and effect given the body's ability to adapt to even the highest doses. The same tolerance process is responsible for the need for dose escalation in some cases.

While anxiolysis and muscle relaxation are often seen with opioid use, mood changes such as depression, mania, and irritability, particularly in young patients, are also possible and need to be monitored closely. Due to both physiological and psychological dependence, there is a considerable habit-forming potential and addiction risk with opioid therapy. This risk is especially significant if fast-acting preparations are used (immediate release droplets, fast intravenous injection, etc.) since the fast flooding in the CNS has strong psychotomimetic effects. The risk is lower with slow release preparations, due to their delay in effect. Special note should be paid to its use in the adolescent population due to the notion that the adolescent brain is likely biologically prone to being hyper-responsive to immediate rewards, therefore increasing the risk for addiction. Physical dependency is *always* observed in long-term opioid therapy, since the body habituates itself to external opioids and will react with symptoms of withdrawal if the opioid is suddenly stopped. Any opioid therapy lasting more than a week must be tapered.

Contraindications

Contraindications and interactions of the various opioids are not necessarily identical (for details, see the individual drug sheet). Due to their risk of addiction, most of the opioids are subject to regulatory restrictions on their availability and accessibility that differ from country to country and should only be prescribed by providers with the adequate structure to monitor for side effects, and the risk of diversion and misuse. Patients with a history of addiction are especially endangered.

12.1.2 Nonsteroidal Anti-inflammatory Drugs (NSAIDs)

Nonsteroidal anti-inflammatory medications like ibuprofen are commonly used for musculoskeletal pain and often the first-line treatment for inflammatory conditions such as Juvenile Idiopathic Arthritis. They also play a role in the abortive treatment of migraine headaches.

Mechanism of Action

NSAIDs reduce pain and inflammation by blocking the conversion of arachidonic acid into prostaglandins via inhibition of cyclooxygenase (COX) I and II enzymes. Ciclooxygenase I is involved in the synthesis of prostaglandins in many systems in the body (to include the kidneys—having a role in renal filtration, mucous secretion in the GI tract, and platelet aggregation). As such, its blockage is largely responsible for many of the side effects observed with NSAIDs, particularly when non-selective agents such as Ibuprofen and Naproxen are used. As such, selective COX II NSAIDs such as Celecoxib, Etoricoxib and Meloxicam might be better tolerated regarding GI side effects—but they are not licensed for the use in children and adolescents in Europe.

Acetaminophen, an over the counter analgesic with antipyretic properties, has a mechanism of action that is not completely understood, but thought to be related to central cyclooxygenase inhibition and modulation of descending serotoninergic pathways. Special attention should be paid to its lethality potential in accidental and intentional overdoses (AAP 2001).

Adverse Effects

The non-selective inhibition of prostaglandin synthesis results in an altered composition of the protective mucus layer of the stomach's mucous membrane, increased exposure of the GI tract to acid secretions and vulnerability to irritation, discomfort, progressing to gastritis and ulceration, especially with prolonged use and higher doses. The role of prostaglandins in platelet aggregation can increase risk of bleeding, especially combined with other medications that have the same potential, such as SSRIs. Due to its effect on renal perfusion, renal insufficiency might be a contraindication for NSAIDs—this is true for the selective COX2 inhibitors as well because they show similar renal side effects like the non-selective ones! While sporadic use of NSAIDs has an important role in the abortive treatment of migraine headaches, frequent use (more than 2–3 times a week) can be associated with risk of rebound headaches or even medication overuse headache.

12.1.3 Anticonvulsants

Anticonvulsants have been used to treat a number of adult chronic pain conditions such as post-herpetic neuralgia, diabetic neuropathy, so-called fibromyalgia and migraines. The data in children, however, are, at best, mixed with some studies demonstrating no significant differences between them and placebo, but with higher rates of adverse events in the medication group (Powers et al. 2017).

Calcium Channel Blockers (Gabapentin and Pregabalin)

Indications

Both medications are effective in treating diabetic and post-herpetic neuralgia, which typically affect the adult population. Phantom limb pain is another known indication for these agents. While they are also commonly used in so-called fibromyalgia treatment, a placebo-controlled trial in the so-called 'juvenile fibromyalgia' did not demonstrate similar benefits.

Mechanism of Action

Both Gabapentin and Pregabalin act by modulating calcium channels, which appear to become dysregulated and overactive in impaired peripheral nerves during chronic pain conditions. They have membrane stabilising properties, preventing spontaneous depolarisation of the affected fibres and, therefore, pain. Gabapentin also inhibits glutamate mediated signal transmission which is part of its analgesic mechanism.

Adverse Effects

The most frequent adverse effects for both Gabapentin and Pregabalin are dizziness, drowsiness, ataxia and fatigue. Headaches, nausea, vomiting, weight gain, changes in sleep, and CNS signs like blurred vision, nystagmus, and paraesthesias are also possible. From a behavioural standpoint, special attention should be paid to the possibility of mood changes, emotional lability, depression, anxiety, abnormal thinking and suicidal thoughts. Rarely, blood dyscrasias such as leucopenia and thrombocytopenia might also be present.

Interactions

Gabapentin is primarily renally excreted and should be adjusted in the setting of renal failure. The simultaneous intake of antacids based on calcium or magnesium may influence the bioavailability of gabapentin. Pregabalin shows less interaction with other drugs compared to gabapentin, which makes it more suitable for a combination therapy.

Topiramate

In daily practice, Topiramate (and Amitriptyline) has often been prescribed for migraine prevention. A recent RCT had to be concluded early for futility after a planned interim analysis had proven that both drugs worked no better than placebo (Powers et al. 2017).

Mechanism of Action

Topiramate blocks voltage-dependent sodium and calcium channels. It also inhibits the excitatory glutamate pathway while enhancing the inhibitory effect of GABA.

Adverse Effects

Weight loss, difficulties with concentration, fatigue, and somnolence are common side effects of topiramate. Metabolic changes such as metabolic acidosis, hypocitraturia, hypercalciuria, and elevated urine pH increase the risk of calcium oxalate and calcium phosphate stone formation leading to nephrolithiasis.

Interactions

Salicylates and acetazolamide might enhance toxic effects of topiramate and vice versa through inhibition of carbon anhydrase and combination therapy should be avoided.

12.1.4 Antidepressants

Antidepressants, especially Tricyclic Antidepressants (TCAs), are commonly used in the paediatric chronic pain population especially in the USA. There are clear cultural differences in using TCAs in paediatric pain patients, with US American colleagues believing that they may have some role in symptom control, quality of life, and mood and anxiety improvements. In the European care settings, antidepressants are extremely seldom prescribed. As antidepressants carry warnings from the American medication regulatory agencies regarding the increased risk for suicidal ideation, their use should be recommended only after careful diagnostic evaluation (to assess not only the accurate diagnosis, but also the presence of psychiatric comorbidities) and should be monitored appropriately, ideally with the input of a mental health provider. Amitriptyline is approved by the EMA for the treatment of depression and for long-term analgesia in chronic pain in children and adolescents. Due to its proved effectiveness in the prophylaxis of migraine in *adults*, amitriptyline is used with this indication in children, too; despite the fact that in children and adolescents it proved ineffective for prophylaxis. In a large randomised study, amitriptyline and topiramate displayed no superiority to placebo for the prophylaxis of migraine (Powers et al. 2017). A recent Cochrane review on antidepressants for chronic non-cancer pain in children and adolescents could detect only four RCTs with a total of 272 participants (6–18 years of age) (Cooper et al. 2017a, b). The Cochrane group rated the overall quality of the evidence as very low.

Selective Serotonin Reuptake Inhibitors (SSRIs)

SSRIs are the first-line pharmacologic treatment for management of anxiety and depressive disorders in children and adolescents in the context of a multimodal therapy. TCAs have no proven evidence for the pharmacological treatment of depression in this population. Compared to TCAs, SSRis have a better safety profile and lower adverse effect rate. Fluoxetine, Escitalopram, Sertraline, and Fluvoxamine are FDA-approved for management of anxiety and/or depressive symptoms in the paediatric population. A recent und huge meta-analysis on the efficacy and safety of SSRIs and Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs) for common psychiatric disorders among children and adolescents found only small benefits of these drugs, a huge placebo effect, and severe side effects of SSRIs/SNRIs compared to placebo (Locher et al. 2017). SSRIs are not FDA-approved for the treatment of paediatric pain conditions. In Germany and many European countries, only Fluvoxamine is approved for the treatment of obsessive-compulsive disorder in children eight years or older. All other SSRIs are not approved either for chronic pain or for psychiatric conditions in the paediatric population.

A meta-analysis on *adult* patients with irritable bowel syndrome demonstrated that both SSRIs and TCAs resulted in very small but significant improvements compared to placebo, with SSRIs showing greater global function benefits, whereas TCAs led to greater decrease in symptom scores (Ruepert et al. 2011). According to this Cochrane review, there was a beneficial effect for antidepressants over placebo for improvement of abdominal pain. This analysis was based on eight studies with 517 patients. The relative risk reduction was 1.49 with a 95% confidence interval that reached nearly the 1.0 (95% CI 1.05–2.12; $P = 0.03$). The number needed to treat was calculated as being 5.

In the paediatric population, however, the results are mixed for functional abdominal pain syndromes. While initial small, open-label studies showed benefit of SSRI Citalopram for patients with co-morbid anxiety and abdominal pain, further studies failed to replicate that (Campo et al. 2004; Talley et al. 2008; Roohafza et al. 2014). Fluoxetine showed mixed results in small trial and was found to be helpful in the so-called 'juvenile fibromyalgia syndrome' population, but not helpful for chronic headaches.

While we do not recommend these medications as a first-line treatment for paediatric chronic pain patients due to the scarce evidence showing benefit, it is important to point out that the presence of psychiatric comorbidities that can alter pain perception and ability to engage in treatment is prevalent in this population and, therefore, SSRIs might be often prescribed for these reasons. As such, it is important to the pain clinician to be familiar with this class of medications.

Selective Serotonin and Norepinephrine Reuptake Inhibitors (SNRIs)

Duloxetine, Venlafaxine, and Minalcipram are SNRIs and used in chronic pain, mainly in adults. Minalcipram and Duloxetine are FDA-approved for the treatment of so-called fibromyalgia in adults. Duloxetine and Venlafaxine are also FDA-approved for the treatment of major depressive disorder and generalised anxiety disorder in adults. There are some data to suggest that SNRIs may result in improvements in somatic pain as well as mental health symptoms in a combination of their antidepressant and analgesic action in adults. For all three of these agents, the data for paediatric chronic pain patients are limited to case reports and, therefore, they are not first-line treatment, although Venlafaxine or Duloxetine could be considered if the primary symptoms being addressed are anxiety or depression that have failed at least two trials of SSRIs.

Mechanism of Action

SNRIs exert their therapeutic effect by binding to serotonin and norepinephrine re-uptake transporters and preventing the re-uptake and subsequent degradation of these neurotransmitters. In doing so, they restore the levels of serotonin and norepinephrine in the synaptic cleft. While Duloxetine and Minalcipram have their dual action (serotonin and norepinephrine) at initial doses, Venlafaxine is thought to have that action in doses above 150 mg daily.

Adverse Effects

Central Nervous System adverse effects such as dizziness, drowsiness, and insomnia may occur in 10–15% of patients. GI symptoms such as anorexia, nausea and dry mouth, and cardiovascular effects such as hypo- or hypertension, and tachycardia may happen. Tremors, paraesthesias, akathysia, and ataxia are observed at times. Tremors, agitation, confusion, depression, mania, and hallucinations may be seen at a very small percentage of the cases. Hyponatremia is a rare, but concerning side effect.

Venlafaxine specifically has a well-defined discontinuation syndrome that can cause dizziness, fatigue, headaches and nausea. Other common discontinuation symptoms include agitation, anxiety, chills, dysphoria, myalgias and paraesthesias. Therefore, patients should be specifically cautioned against abrupt discontinuation and should be titrated and tapered slowly for that reason.

Interactions

Combination Therapy with SSRIs or TCAs increases the risk for serotonin syndrome and cardiovascular events and, therefore, if not avoidable, should be cautiously monitored.

Tricyclic Antidepressants

Tricyclic Antidepressants (TCAs) such as Amitriptyline and Nortriptyline are FDA-approved treatments for anxiety and depressive disorders in the adult population. Once SSRIs were developed, the former became a second-line treatment due to the latter being equivalent in terms of efficacy, better tolerated, and having a superior safety profile. TCAs are frequently used in lower doses than those required for anxiety and depression treatment in chronic pain syndromes in the adult population. Fibromyalgia and migraine prophylaxis are often indications for their use in adults. There is a lack of randomised-controlled studies evaluating the effectiveness of TCAs in paediatric chronic pain syndromes and one placebo-controlled trial with children and adolescents with chronic migraine did not demonstrate significant differences in reduction in headache frequency or headache-related disability in childhood and adolescent migraine with Amitriptyline or placebo. Despite limited and inadequate evidence, low doses of TCAs are at times used in this population, especially in the setting of co-morbid sleep disorders. In our view, given limited evidence and risk benefit profile, TCAs should not be used routinely as a treatment for paediatric chronic pain syndromes, although there might be a small role for its use in combination with cognitive behaviour therapy, especially in the presence of co-morbid sleep difficulties.

Mechanism of Action

In the CNS, amitriptyline unselectively inhibits monoamine (serotonin, and norepinephrine primarily) reuptake from the synaptic gap into the presynaptic neuron, leading to an increased neurotransmitter concentration in the synaptic gap.

Adverse Effects

The most frequent adverse effects of Amitriptyline are neurologic (i.e. headaches, dizziness, tremors, drowsiness), cardiovascular (i.e. palpitations, tachycardia, orthostatic hypotension, and ECG changes such as AV block or other conduction defects), gastrointestinal (i.e. dry mouth, constipation, nausea), weight gain, blurred vision/disturbed accommodation, or increased sweating. Other central nervous adverse effects are paraesthesia, ataxia, or tiredness. From a cognition standpoint, cognitive slowing and difficulties with concentration are also possible.

Interactions

The combination of Amitriptyline and MAO inhibitors may lead to the life-threatening serotonin syndrome. If Amitriptyline is used in conjunction with other drugs affecting QTc interval (i.e. macrolides), there is a risk of prolonged QTc interval with dysrhythmia, torsades de pointes, or sinus tachycardia.

12.1.5 Triptans

The chemical structure of triptans is similar to serotonin, and their action is mediated by the activation of serotonin receptors. Triptans are approved for the abortive treatment of migraine and cluster headaches. They can be administered orally, intranasally or subcutaneously. Of the seven different triptans available, sumatriptan, zolmitriptan, rizatriptan, and almotriptan (12–17 years) and the combination of sumatriptan and naproxen sodium (12–17 years) are approved by the FDA for children and/or adolescents. Nasal sumatriptan and zolmitriptan are approved in children older than 12 years of age in Europe.

Mechanism of Action

Like serotonin, triptans are agonists at both the 5-HT 1B and 5-HT 1D receptor. Activation of these receptors has many effects. Pain signal transduction in the trigeminal nerve terminals and in the dorsal horn, and the secretion of pro-inflammatory peptides (i.e. substance P, calcitonin gene-related peptide) is reduced, inhibiting the spreading of pain stimuli along the thalamus and the cortex. Triptans are also agonists at the 5-HT 1F receptor. Activation of that receptor subtype reduces the secretion of certain vaso-inactive peptides.

Adverse Effects

Adverse effects of triptans are weakness, dizziness, and paraesthesias, sensations of warmth or heat, and nausea. Sometimes, a transitory increase in arterial blood pressure is observed and this effect is mediated by the activation of 5-HT 1B/1D receptors of the cardiovascular system. Seldom reported are dysrhythmias, disturbed blood circulation, or musculoskeletal effects. After the intranasal use of Sumatriptan or Zolmitriptan, up to 25% of the children report a bitter taste.

Interactions

If combined with ergot alkaloids migraine medications (i.e. ergotamine), there is an increased risk of coronary spasms and cardiovascular events. Hence, such a combination is contraindicated. Triptans may interact with antidepressants from the selective serotonin and norepinephrine reuptake inhibitor family (SNRI) like duloxetine or venlafaxine. Monoamine oxidase inhibitors slow down triptan metabolism. Under certain circumstances, serotonin may accumulate in the nervous system to a critical level with potentially life-threatening consequences. This serotonin syndrome may present with restlessness, hallucinations, loss of coordination, tachycardia, fluctuating arterial blood pressure, increased body temperature, increased reflexes, nausea, vomiting, and diarrhoea.

Contraindications

Triptans are contraindicated in arterial hypertension or vascular diseases, especially in the presence of coronary artery disease.

12.2 Interventional Treatments

In paediatric chronic pain treatment, invasive procedures are rarely used. Some centres do perform invasive pain treatment in children with a complex regional pain syndrome (CRPS) (for a review see Zernikow et al. 2015). Singular sympathetic blocks, epidural catheters and continuous sympathetic blocks are applied most often. Spinal cord stimulation and pain-directed surgeries were also reported. The latest publications report the use of peripheral perineural local anaesthetic infusions with or without a multimodal treatment approach to facilitate rehabilitation for selected paediatric CRPS patients (Donado et al. 2017; Dadure et al. 2005).

Invasive procedures are often applied when conventional treatments do not result in quick improvements or fail completely. We are faced with a growing number of children in whom invasive treatments have been trialled and failed. It is our impression that invasive procedures do more harm than good in this patient population.

Usually physical therapy as part of a multimodal interdisciplinary intensive treatment works well, but it may take some time until improvements become obvious. In our experience, non-invasive multimodal treatment makes no headway as long as severe psychological issues are not addressed sufficiently—and this might take time. This process cannot be accelerated by invasive anaesthesiology techniques.

Severe psychological problems are present in almost all CRPS patients and they are more prevalent in children with relapsing courses. Critical life events are often elicited in children and adolescents with CRPS (Wager et al. 2015). If children receive a body-oriented treatment only—like invasive treatment—there is a real risk of a symptom shift and onset of psychiatric diseases such as eating disorders, self-mutilation, and suicide (Sherry et al. 1999).

12.3 Physical Therapy in the Context of Pain Treatment for Children and Adolescents

12.3.1 Basic Information

In the treatment of chronic pain disorders, physical activity and exercise are beneficial for improving active pain inhibition. Exercise strongly affects body awareness and self-perception, which is frequently impaired in chronic pain disorders. Improving physical activity and exercise may positively affect body awareness, active pain inhibition on the neurobiological level, and psychosocial factors. This is not only true for musculoskeletal pain, but also applies to other forms of pain.

However, contrary to chronic headache or abdominal pain, chronic musculoskeletal pain is often accompanied by functional disability of the affected region of the body and impaired movement. This may manifest as restricted joint mobility, less physical strength, endurance and coordination. The associated rest can then lead to reduced muscle mass and the risk of contractures. Pain avoidance through rest may further increase musculoskeletal problems and initiate a vicious cycle. Then, even slight stress will elicit pain and the patients will have the impression that they are no longer able to tolerate any stress anymore, which will continue and extend the avoidance behaviours. The role of physical therapy is to break this vicious cycle and to reverse the negative association between movement, stress and pain perception. Therefore, in the context of active pain treatment of children and adolescents, physical therapy primarily uses concepts and interventions of *medical training therapy (MTT)*. MTT combines motor skills, such as endurance, mobility and coordination, with the economic use of strength. The aim is to restore and improve physiological movement patterns with regard to physiological functions, psychological and social resources, as well as activity and participation. Thus, similar to the pain treatment, physical therapy takes an interdisciplinary approach. In the medium and long term, MTT can contribute to pain reduction and an optimal implementation of strength, mobility, endurance and coordination through the activation and improvement of physiological functions (Scharrer et al. 2012).

12.3.2 Prerequisites, Planning, and Focus of MTT in Pain Treatment

It is important that the patients actively cooperate and are motivated, so that the physical therapy can be effective for children and adolescents with chronic pain and that movements and other contents of MTT can be maintained. Therefore, physical therapy should be preceded by an education about the underlying disease model and the physiological mechanisms, particularly in the case of chronic musculoskeletal pain with functional impairments. In this context it is helpful to explain why slight stress was temporarily perceived as painful and why it is important to overcome this experience. This education aims to convey security, so that there is no need to fear danger or damage when resuming movement and stress during MTT (Scharrer et al. 2012). Often, numerous contradictory medical or therapeutic examinations make consultation of previous physicians necessary (e.g. orthopaedist, rheumatology or traumatology) to agree on the treatment concept and on the use of MTT.

The treatment plan of MTT with regard to focus, intensity, and interval is strongly individualised, particularly for musculoskeletal pain. This plan is determined by various factors, such as the functional status of the motor system, limitations in mobility, the number of pain locations, and individual factors (e.g. previous experience, fear of movement). There are four forms of MTT in pain treatment that can be combined or implemented separately: endurance training, strength training, coordination training, and mobility training.

Endurance Training

Endurance training is characterised by repeated and initially small exercise units for increasing activity of 'normal' movement patterns (walking, climbing stairs, or running easily, with the harmonious and coordinated use of the whole motor system). The aim is to optimise motion sequences and gradually increase stress according to an individual plan of stress and improvement (Thompson et al. 2010). As already mentioned, individual goals are useful, such as an increasingly longer walking distance or endurance. Through physiological movement patterns and individual increases, the patient may experience that increasing stress does not constantly increase the pain. Regular exercise leads to physiological adaptation and a reduction of the pain perception and pain intensity. Apart from adaptation, the repeated training of MTT leads to more economic movements, that is, the same motoric performance is achieved with less effort and leads to less exhaustion. In MTT, endurance training is mostly implemented as aerobic training. Specifically, various forms of the endurance training may be used:

- Predominantly aerobic and infrequently anaerobic training.
- Activating different parts of the muscles; either big parts of the motor system (swimming, jogging, and biking) or local applications (training the movement of a leg or joint or a muscle group).
- Different kinds of stress, such as interval training, or continuous running, or unstructured training (e.g. different games).
- Basic endurance training or specific training of individual functions.

In pain treatment, all these interventions can be part of an individual treatment plan. The individual selection is oriented towards the stress intensity, the underlying disease, limitations in mobility, pain locations, and complications in the motor system and the individual goals (Mujika 2012).

Strength Training

Strength training within the MTT is implemented less in patients with chronic pain disorders than endurance or coordination training. It may be important for local limitations in mobility of a limb (e.g. after injury or with CRPS). The aim of strength training with MTT is to increase muscle strength to contribute to safe and controlled movement in leisure time, school and sports and to reduce stress of the motor system. Mostly exercises aimed at improving muscle strength are implemented apart from, or subordinate to, endurance and coordination training in pain treatment.

Coordination Training

The coordination training aims to improve the security of movement, motion sequence, and movement transitions in order to coordinate the stability of the position and the freedom of movement. This comprises exercises for balance security in different positions (sitting, standing, walking, and grasping), for postural stability of torso, shoulder and hip, and for changing positions. This is particularly important for musculoskeletal pain concerning the whole motor system with limited mobility, for pain including the spine, or for pronounced chronic dysfunctions or contractures of a limb (Hodges and Richardson 1999). Safe coordination is a prerequisite for a harmonious, goal-oriented, and economic movement of individual extremities or complex motion sequences, such as walking, climbing stairs, running, or sports activities.

Mobility Training

Mobility training is primarily used for children and adolescents with limited mobility of small and large joints due to pain or other diseases (Kallerud and Gleeson 2013). We distinguish between the promotion of passive movement by the therapist and the active movement of the patient him/herself. For small limitations of mobility and lack of allodynia, active movement should be enhanced with therapeutic guidance right from the start of mobility training. For complex limitations of mobility, combined muscular atrophy and contractures, or allodynia, passive movement by the therapist may be indicated at first. The aim is to improve the range of motion to a point where active movement of the patient becomes possible.

Since the primary issue in children with chronic pain is increasing their activation and decreasing the amount of passive behaviour (‘I will do’ instead of ‘You take away my pain’), massages send the wrong signal. This is not the place to describe the various active physical therapeutic techniques and interventions in detail. Instead, we want to focus how to optimise the cooperation between physical therapist (independent of his/her sub-specialisation), patient, physician, and psychotherapist. We believe the following four aspects are most important.

1. In order to ensure good communication between the physical therapist and the staff on the ward, the physical therapist should attend the ward rounds—at least during the time when his/her patients are discussed. This will allow him/her to get some idea of the underlying biological, psychological, or social aspects of the pain disorder and to better understand the aspects contributing to the development of the limited functioning and mobility. Problems concerning the patient’s motivation or sudden regression or progress may be explained in the overall context of treatment. Any divergent observations of staff and physical therapist may be directly discussed. The physical therapist helps the staff to understand which movements the child is actually able to do, and to what degree, or which movements are still severely impaired. Together, physical therapeutic exercises are set up that can be practised on the ward once or several times a day in a graded exercise plan.

Case Report

A boy with CRPS type I in his right foot had to re-learn to walk. After many small steps of progress, the task was now to set the foot on the ground and to gradually do so without crutches. It was the child’s wish to keep one of the crutches for now. But this wish had to be rejected after consultation with the physical therapist who was right in pointing out that putting stress to one side of the back muscles counteracts the targeted functional improvement.

2. It is beneficial to separate professionally led physical therapy from practice during the daily routine guided by the NET. Graded exercise on the ward simulates everyday life quite well, and any motivational problems may be easily addressed and solved since the NET knows the child better than the physical therapist. Frequently the patients talk about fearful or stressful issues particularly during times of increased tension, such as graded exercise with its inevitable increase in pain. Then, it is important for the patient to be emotionally supported by the members of the NET who are trained in communication and daily contact with patients. The NET can also pass that information on to the physician or psychotherapist in charge.
3. We would like to point out another obvious, but very important, aspect. From their daily work, physical therapists are accustomed to discussing the background underlying the active exercises. Usually this is helpful. However, *under no circumstances* should the physical therapist offer the child monocausal hypotheses to his/her disease, be it blockades, muscular imbalances, muscular tension, trigger points, etc. Most children (and their parents) are stuck in the Second Thought Trap and tearfully tell their parents about the physical therapist's 'latest discoveries': 'The physical therapist said, 'Such a crooked spine must hurt'. Of course, all consulting professions should be cautious with any monocausal model.

Any observation made by the physical therapist is an important contribution to pain treatment. It should not be directly communicated to the child, but to the staff during the ward round.

In children with chronic musculoskeletal pain, physical therapy is an indispensable component of inpatient pain treatment. The individual benefit of active physical therapeutic interventions embedded into an interdisciplinary treatment programme (*not* as a solitary exercise) has been scientifically proven (Ayling Campos et al. 2011). For best treatment success and to ensure a satisfying working environment, both the clear-cut division of the different responsibilities and the establishment of defined communication structures have proven invaluable.

12.4 Graded Exercise for Desensitisation and Movement in the Context of Complex Musculoskeletal Pain Disorders (e.g. Complex Regional Pain Syndrome (CRPS))

CRPS is a chronic disease which is characterised by chronic pain of the affected region (mostly an extremity, a hand or a foot) and the triad of sensory abnormalities, motor, and trophic disturbances. In most cases, the pain is associated with an acral allodynia. Affected patients avoid even minimal stimuli, such as brief skin contact, contact with water or temperature fluctuations, because this elicits discomfort and an increase in pain intensity. This in turn reinforces the trophic disturbances and impairs the vascular supply of the region. At the same time, patients often avoid any active movement and adopt an extreme misalignment (particularly in the foot; pes equinus position with maximal flexion), which bears the risk of a fixed contracture.

For affected children and adolescents, a non-invasive interdisciplinary pain treatment is indicated (Zernikow et al. 2012a). Apart from medical and psychological education, as well as psychological treatment, functional treatment methods play an important role. The principles of physical therapy can be applied to CRPS with the help of MTT. But, at the beginning of treatment, enhancing active movement may be impossible due to the extreme misalignment and contracture. Furthermore, allodynia may impair or even prevent passive movement by the physical therapist.

In these cases, initially, desensitisation is indicated to reduce touch sensitivity. This includes the gradual increase of sensory stimuli regarding quality, intensity, duration, and regional extension, which should be implemented by the patient him/herself. The collaborative objective in consultation with the patient should be to increase the stimuli every two days. This increase aims at improving tolerance of various sensory stimuli and striving for desensitisation. Table 12.2 illustrates a plan of graded exercise for desensitisation. During inpatient treatment, the graded exercise is planned and adapted in mutual agreement of physician, patient, and NET. It is implemented by the patient him/herself under supervision of the NET at least twice a day. In case the motor function of hand or foot is severely impaired, desensitisation is combined with *mirror therapy* from the start of treatment. In *mirror therapy*, while watching the active motor exercises of the unaffected, ‘healthy’ side of the body in the mirror, the contralateral extremity is thought to be stimulated for active movement via associated neural tracts in the motor cortex. If passive or active movement is not yet possible in physical therapy due to allodynia, coordination training and mobility training of adjacent joints and muscles should be implemented. This may prevent further complications of the motor system and ‘prepare’ it for further mobility training. As soon as the patient is able to tolerate that his/her foot or hand is touched, gradual desensitisation is combined with graded exercise for movement. After passive mobilisation, the goal of this graded exercise is to enhance active movement of the patient and introduce physiological activities in everyday life including grasping, standing, and walking. A case report illustrates the combination of functional therapy with graded exercise for desensitisation and movement, and mirror therapy and transition into daily life.

Case Report

A 10-year-old boy who experienced a distension of ligament during football training developed pain in the right ankle. The pain persisted even when the swelling was reduced. The boy had not been able to fully stress the foot while standing or walking for four months and had been using crutches for 12 weeks. He was further unable to wear a shoe on the affected foot. The average pain intensity constantly was about 5–6/10 throughout the whole day. At the beginning of treatment, the boy did not stress the right foot at all and only walked with

Table 12.2 Schedule for desensitisation and graded exposure for movement, as well as mirror work of a 10-year-old boy with CRPS during treatment days 1–25 of the inpatient interdisciplinary pain treatment

Grade of exposure	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
Treatment day	1 + 2	3 + 4	5 + 6	7 + 8	9 + 10	11 + 12	13–15	16 + 17	18 + 19	20 + 21	22 + 23	24 + 25
In the morning												
Pressing scale × times, x kg for x s	3 × 4 kg for 2 s	3 × 5 kg for 5 s	3 × 6 kg for 5 s	3 × 6 kg for 10 s	3 × 8 kg for 10 s	3 × 10 kg for 15 s	3 × 12 kg for 15 s	3 × 15 kg for 15 s	4 × 16 kg for 15 s	4 × 18 kg for 15 s	3 × 5 kg for 5 s	3 × 6 kg for 5 s
Place right foot in lukewarm water for x s	10	15	2 × 15	3 × 15	5 × 15	5 × 20	6 × 20	3 × 60	180 (continuously)			
Kicking a ball										3×	6×	12×
Mirror work												
Tap your foot on the floor (1 min)												
Rotate your foot inwards and outwards (1 min)												

Circle/ rotate your foot (1 min)												
Move your foot up and down (2 min)												
In the evening												
Same exercises as in the morning												
Active mobility training												
Walk without crutches										6 Steps	8 Steps	12 Steps

The exposure to sensory stimuli is gradually increased in 12 grades. Active exercise of the affected region is added in the last grades. The mirror work is continuously implemented and not interrupted crutches. There was a muscle hypotrophy in the right leg compared with the unaffected side. The foot displayed moderate flexion and every attempt of active movement was restricted by flexion, extension, supination and pronation. No further structural lesions of bones, cartilage, muscles, joints, or ligamentous apparatus were evident.

Table 12.2 demonstrates the graded exercise for desensitisation and movement and the mirror therapy during the inpatient pain treatment. The functional treatment is accompanied by physical therapy. At the beginning of treatment, coordination training and mobility training of the torso and hip musculature, and the knee is initiated. From grade 4 onwards (day 7 of treatment), passive movement of the right foot is accepted by the patient and can be implemented for 15–20 min each day (including regular breaks). From grade 7 onwards (day 13 of treatment), active motor exercises can be implemented. Coordination exercises without crutches and first steps are introduced from grade 10 onwards (day 20 of treatment).

At the end of the four weeks of treatment, the boy is able to walk a few steps in the room several times a day without crutches and with harmonious movement without breaks for relief. The therapist and the boy agree on a graded exercise plan for the subsequent 2 weeks with the goal of walking freely in the following four to 6 weeks. This agreement is complemented by a professional outpatient MTT with coordination, mobility, and endurance training 2–3 times a week.

At the follow-up meeting six weeks after discharge, the boy is free of pain. At that time, he has been able to walk freely without crutches for three weeks. With high motivation to restart sports again, he resumes swimming, riding, and football training (running exercises).

12.5 Art Therapy and Music Therapy

Art therapy or music therapy may have added benefits in certain cases. First of all, both methods are used as supplemental techniques in children with pain disorders who are interested in nonverbal expression. Both methods encourage the children to express themselves concerning certain issues (family situation, emotions, etc.) by means of different media. The idea is that those methods make it easier for the child to feel and talk about difficult emotional issues and to make them accessible to the child. The instrumental communication during music therapy allows the child to nonverbally practise listening to other people and follow their play, and then to focus him/herself, his/her feelings and personality, with an active component of relaxation. Art therapy encourages the child through activities (such as painting his/her pain, a Pain Fighter, or a ‘Safe Place’) to actively engage in pain coping using his/her artistic abilities. The resulting paintings may be used in individual therapy sessions to practise imaginative techniques (Sect. 9.2).

12.6 Social Workers

As with physical therapy, certain patients may benefit from including a social worker as part of their team if there are psychosocial issues that may be impacting treatment progression. Social workers are engaged in about 5–10% of our inpatients’ treatments (see Sect. 11.5 for an overview of our gradual procedure). The specific approach of the social worker on the ward, in the family sessions, or in the support after discharge is very much dependent on each individual case. For many patients, it was very helpful that they had the opportunity (hidden behind confidentiality) to receive information on possible outpatient, day care, or inpatient options through the youth welfare service. Based on that information, they were able to plan the further interventions together with their psychotherapist. Most parents strongly benefit from the participation of social workers in family sessions if issues pertaining the youth welfare service are discussed. Parents perceive social workers as very supportive, because they get concrete and reliable answers to their questions. Just making formal application for help care benefits overburdens many of these families, and it is a relief for the child and his/her family to know that there is someone available to support them, not only during, but also after their stay on the ward. Social workers may offer support with applications, or in responding to a rejection letter. If the child and his/her family give us written permission to release us from professional confidentiality, we may contact the responsible youth welfare service (by phone or in writing) and accelerate the processing of their application. In selected cases, the social worker will offer to accompany the child and/or the family to the responsible youth welfare office. A social worker or the child's psychotherapist will always be present in the initial discussion regarding necessary supports through the youth welfare service.

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Inpatient Pain Treatment: Module 6 (Planning the Time After Discharge)

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Michael Dobe and Boris Zernikow

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Abstract

Planning the time after discharge is crucial to long-term treatment success. Therefore, we discuss the importance of relapse prevention and a treatment plan in the following chapter. We further present a procedure for the special case of readmission.

At the end of the patient's stay, it is the physician's or primary psychotherapist's responsibility to set up a treatment plan together with the patient and his/her parents for the time after discharge. This plan is based on the previous course of treatment. In the case of complex mental or psychosocial comorbidity, we recommend beginning to discuss this plan in the middle of the stay in order to allow the child to think about his/her own aims and wishes regarding the time following discharge.

M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_13

13.1 Relapse Prevention

At the end of his/her stay, the child usually knows which interventions were helpful, which ones he/she would like to continue, and if there is need for family support for the further implementation of these interventions. As the final family session is scheduled after the last individual therapy session, the psychotherapist discusses family interventions with the child, which from the child's point of view might help avoid a relapse (e.g. the child's wish for a psychotherapeutic treatment of his/her parent with a pain disorder). In addition to the discussion of the treatment plan (Sect. 13.2), the following three interventions have proven helpful for relapse prevention:

1. Again, the child and his/her family are explicitly referred to the fact, already taught in our education sessions, that a pain disorder means increased pain sensitisation. This implies that the child will have a higher risk of experiencing more pain (and fatigue) during a common cold or injury than children without a pain disorder. Due to the patient's medical history, distinct pain sensitisation and concomitant fatigue are to be expected during the months following discharge. Increased pain perception (e.g. when attending school again) should *never* result in a relapse to passive pain coping strategies. An increase in stress, as a result of increased internal and external tension, will lead to an increase in pain perception. After school absence for weeks or even months, high pain intensities can be expected for the first normal school days (see Sect. 4.2). These are normal associations that cannot be prevented by psychological pain coping strategies alone (comparable to first work days after a long recovery from an injury). Anticipating any possible increase in symptoms and having a detailed action plan (e.g. taking time-outs to practise the techniques at first) will help the child and his/her family to master the time after discharge.
2. Many children are very exhausted from the incessant burden during the previous years, and seem to be more prone to infections. Often patients catch a feverish (viral) infection after discharge. Of course, fever is a somatic alarm signal demanding rest and perhaps a visit to the child's general practitioner. If indicated and prescribed by the physician, analgesics are allowed during these infections. A feverish infection will often lead to a combination of severe pain, pronounced passivity and fatigue. This carries the increased risk of reactivating former behavioural patterns. It is agreed in the discharge session that after the second day without fever, all regular activities should be performed *irrespective* of pain intensity or fatigue. If this agreement is not followed (generally, two days absent from school if fever has disappeared), the parents will call the German Paediatric Pain Centre (GPPC) and an appointment in the outpatient clinic will be arranged in order to support the family in the implementation of what was learned in the inpatient treatment.
3. It should be decided which member of the family will contact our outpatient pain clinic, and for which specific problems. The threshold for calling the clinic should be set high to make it clear that not every difficulty arising from everyday life automatically has to result in a plea for professional help. Difficulties getting up or a bad mood in the morning are normal in the first weeks after the inpatient stay and do not require consultation by telephone (this may also be a permanent

state independent of pain). But if the patient has an infection, the fever has disappeared for two days, and he/she refuses to go to school, the pain ward and the primary psychotherapist should be informed. The follow-up visit in the outpatient clinic should be scheduled sooner than originally planned, if necessary, in order to address these issues early on.

13.2 Treatment Plan

During the discharge session, we determine *who* is responsible *for what, when and where* regarding the implementation of outpatient or inpatient therapeutic interventions. This information is recorded in the patient's chart as well as in the discharge letter. We also record which strategies and interventions (e.g. outpatient psychotherapy, continuation of physical therapy, TENS) the child has chosen to implement until the follow-up visit 3 months after discharge. Adherence to these recommendations is usually high, except for initiating outpatient psychotherapy (Barth et al. 2016). It should be explicitly discussed to what degree the parents will participate in the implementation of the interventions. In the discharge session, we frequently point out that the parents have the difficult task of doing *nothing* to allow the child to partake in active strategies themselves. Of course, this is more difficult for them than actively doing something for their child's relief. Thus, we compliment the parents for trying to abstain from action and ask them to forgive themselves if they do not always succeed. At the GPPC, the child's primary psychotherapist is always present when the patient returns for follow-up.

13.3 Special Case: Readmission

Sometimes, the patient may relapse after discharge. When this occurs, an appointment in the outpatient clinic should be scheduled to discuss the possible reasons for this relapse in order to evaluate whether a second inpatient treatment with a modified focus might contribute to a solution. A readmission with the same content and focus usually makes no sense (e.g. 'to repeat the techniques' or as parents sometimes wish: 'to refresh what was learned'). Instead, family factors need to be identified that prevented the success of the pain treatment. Were important factors missed or ignored during the first stay? Is there still a somatic fixation? Readmission with several Stress Days makes sense, if, for example, 15-year-old Kjell has more difficulties dealing with stress in school and social life than he admitted during the first stay and he is still severely impaired. Readmission is not indicated if the parents report that their 14-year-old daughter Ellen is withdrawing more and more, avoids social contact and is always in a depressed mood. Then, an inpatient treatment in a child and adolescents psychiatry ward may instead be indicated.

Before readmission, it is essential to have an outpatient appointment together with the patient, his/her parents and the primary psychotherapist of the former inpatient stay, since that psychotherapist is most familiar with the relevant intrapsychic and interpersonal issues. Together, we explore if readmission is necessary, and if it makes sense. If the answer to both questions is ‘yes’, the aims for the following stay should be negotiated and fixed during this appointment.

We strongly recommend not just adopting the aims from the former stay. Instead, one should focus on the factors that hindered the implementation of the learned techniques at home or that allowed for reactivation of the pain disease.

This could mean that during the second stay one should focus more on the child’s features that hampered his/her development to more autonomy independent of the parents’ assertiveness. Or it could imply a more intense training of coping with daily hassles or stress, irrespective of the actual pain intensity. Since readmission usually means more intense psychotherapeutic interventions, a second stay will be even more demanding for the child and his/her parents than the first one. This should be made clear in advance.

Occasionally, the important factors or treatment motivation cannot reliably be assessed in the outpatient appointment. Sometimes the child or his/her parents are ambivalent with respect to readmission. In this case, we advise them to ‘apply’ for readmission, writing down their aims of treatment, and how much effort they are willing to invest. We expect age-appropriate but detailed information. Such an approach seems hard, but it is our experience that clarifying these questions before readmission is essential to making the stay a success.

Case Report: Maren (17 Years), Pain Disorder with Headache, Mild Depressive Episode

At an outpatient appointment 12 months after discharge from inpatient pain treatment, Maren and her parents reported that her pain and mood had very much deteriorated again. Since the time on the ward ‘had been very good for Maren’, Maren and her parents asked for readmission. Maren was currently suffering a mild depressive episode which presented as joylessness, lack of energy, and difficulties in falling asleep. During the outpatient appointment, Maren expressed the view that she would like ‘to see us again’. But since she could not imagine any reason for the relapse, she was unable to say how the aims set during the last pain treatment could be modified for sustained improvement. Thus, we asked both Maren and her parents to write down their modified aims of treatment as well as their assumptions concerning the factors maintaining Maren’s negative mood and pain, and mail them to us before we could make any decision. While the parents were doing their homework well, Maren wrote the following letter.

Maren’s Letter

‘I can’t tell you what exactly contributed to my impairment in the last few weeks. I wish I could relearn how to better cope with my pain, and how to become more self-confident, as I did during my last stay. Maybe some new techniques to deal with my problems. For the time after the second stay, I wish to be able to implement the learned techniques and to better manage my problems’.

We rated this letter as insufficient. Maren seemed to have problems precisely naming the various factors contributing to her current situation and her relapse. Hence, we decided to pose our questions more precisely in a letter to Maren.

Our Letter to Maren in Response

> 'Dear Maren, many thanks for your letter. To better prepare your re-admission, we need more precise information. The problem is that we can't just do the same things as last time. Since you answered our questions the best you could, we decided on posing more precise questions. We beg your pardon that we did not already do so during our last appointment. Please answer the following questions and send us back the answers in writing.
>
> 1. At the moment, what makes you feel sad when thinking of friends?
> 2. At the moment, what makes you feel sad when thinking of school?
> 3. At the moment, what makes you feel sad when thinking of your pain?
> 4. At the moment, what makes you feel sad when thinking of your mother?
> 5. At the moment, what makes you feel sad when thinking of your father?
> 6. At the moment, what makes you feel sad when thinking of your future?
> 7. At the moment, what makes you feel sad when thinking of yourself?
> 8. How well do you generally cope with stress?
> 9. How many Stress Days will you need on the ward?
> 10. Apart from pain, what do you think you still have to learn to lead a happier life in future?
>
> Finally, a very specific request: Will you and your parents please organise an outpatient psychotherapy? As we did the last time, we will focus on doing the first steps towards active pain and stress coping. We are sure you will be able to do those steps on the ward. But, 3 (or 4) weeks is not enough time to learn to stabilise your mood on your own forever. Usually after discharge, outpatient support is needed for a while. There is still some time left until the next inpatient stay. So, take the time you need to answer our questions'.

One week later, we received a nice and much longer letter from Maren with all the required answers that enabled us to better prepare the second inpatient stay. Again, it is very important early on to be as clear as possible about how much active co-operation is required from the child and his/her family. Particularly in children with a passive attitude and/or depressive symptoms, the described procedure can help discover not only available resources but also the disease-maintaining negative factors still present in the child and the family system.

In some very rare cases, it may be indicated to schedule a date for readmission at the time of discharge. This readmission should be planned following outpatient appointment 4–6 weeks after discharge. This procedure is an important source of security for the affected child and his/her family, especially in case of rare pain disorders (i.e. CRPS type I and II), an extreme degree of chronicity, or in the presence of substantial psychosocial stress factors. To minimise the risk that these patients become too closely attached to the ward, we emphasise that this will be a unique intervention to consolidate the treatment effect in order to find a compromise between the following four aspects:

1. The health insurance will rightly insist on an outpatient treatment when inpatient pain treatment is not indicated any more.
2. Between the two inpatient treatments, both the child and his/her family have the chance to discover which individual factors are helpful or dysfunctional without the help of inpatient treatment and its structured life. This will enable them to better substantiate any wishes on how to proceed with outpatient treatment. It is

essential to communicate this strategy in advance with the family. Nevertheless, in spite of many doubts ('Can we stand it?'; 'Isn't it too early now?'; 'Shouldn't we have waited another fortnight before discharging our daughter?') for the families described above, it is a relief to have a second inpatient treatment already scheduled at discharge. This gives the child and his/her family the opportunity to try out the long-term implementation of the learned techniques at home without pressure. If the families are not successful in implementing the learned strategies at home, there is the risk for example of a permanent impairment of the affected part of the body with CRPS, be it hand or foot. On the other hand, a planned readmission offers psychosocially highly burdened families (grade of severity one to three; see Sect. 11.5) who are very sceptical of offers from the youth welfare office, the possibility of first trying out the interventions themselves.

3. Due to the risk of further chronification, sometimes the families request an extension of the inpatient treatment, since it is 'so beneficial' for the child, or so that any treatment success can be 'stabilised'. Certainly, in some children it seems reasonable to extend their stay by a couple of days (e.g. to allow them to pass another Stress Test). But we feel that any additional extension is not a long-term solution, because it would support the child in his/her tendency to avoid the exposure to everyday life in the family or at school. Furthermore, a longer inpatient stay is counterproductive since we want to avoid the possibility that the child will feel safer in the institution than at home. Such a development would be detrimental to the patients, because it would lead to fear in the face of discharge which could evoke a deterioration of their complaints in order to postpone the day of discharge.
4. Some pain disorders are progressive (e.g. CRPS) and require readmission after a short interval if, in the course after inpatient treatment, a renewed deterioration occurs. Nevertheless, the child and his/her family should be given enough opportunities to use individual resources in case of difficulties arising during the time after treatment (and not ask for readmission as soon as the first problems arise). An ethically sound compromise is to aim for readmission approximately 8–10 weeks after discharge, in case of relapsing symptoms of CRPS.

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Part III

Add Ons

Specifics of Pain Treatment in Children with Psychological Disorders, Severe Somatic Diseases, or Psychosocial Stress Factors

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Michael Dobe and Boris Zernikow

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M. Dobe (✉) · B. Zernikow
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_14

Abstract

The main goal of this chapter is to present general aspects for the treatment of children suffering a pain disorder and a comorbid psychological disorder. These aspects may be implemented in both the outpatient and inpatient setting. We furthermore describe the specific therapeutic needs of children with learning disabilities or intellectual giftedness. Finally, we discuss children with chronic pain also suffering a severe somatic disease or living in complex family systems.

14.1 Specifics of Pain Treatment in Children with an Anxiety Disorder

The following case report depicts the close relationship between a pain disorder and an anxiety disorder.

Case Report: Lea (10 Years), Pain Disorder and Anxiety Disorder

Lea had always been an affectionate child, anxious in new and unknown situations. When she started kindergarten, she had difficulty separating from her mother, frequently crying when her mother dropped her off. Sometimes she complained about abdominal pain in the morning, however, the pain did not last long. When she became used to the kindergarten, she was a reserved but very popular child. The symptoms did not re-emerge until she started primary school, but again, they vanished after a couple of months. According to Lea's mother, Lea's empathetic teacher had been a big help in this process.

A year ago, Lea was shocked when she found out her teacher had to quit her job due to a severe illness. Shortly thereafter, Lea developed a severe gastroenteritis along with high fever, nausea, vomiting, stomach cramps and diarrhoea. After her symptoms had diminished, Lea frequently reported abdominal pain over a period of weeks. The pain ceased after a recreational vacation in autumn. Resuming school, the abdominal pain reoccurred and became more frequent, and more intense. Lea has now been suffering permanent daily pain for about half a year. There are no pain-free episodes anymore. The new teacher has repeatedly stated her doubts and incomprehension concerning the situation; she openly assumed educational issues to be the problem behind the pain. Since Lea's spasmodic pain peaks occur suddenly and unexpectedly, even after school, Lea has been refraining from her hobby (horseback riding) and has withdrawn from most of her friends, fearing that her mother might not be beside her during pain peaks.

The desperate parents ordered many medical investigations which did not yield any pathologic result. Frustrated from all these seemingly helpless attempts to explain the disease (‘psychosomatic’; ‘functional pain’), they tried alternative therapies. Lea underwent homoeopathy and acupuncture. Furthermore, a large number of tests for allergies and intolerances were conducted. The parents were told that Lea had a lactose intolerance. As a result, Lea received a lactose-free diet. While homoeopathy and acupuncture were unsuccessful, the frequency of abdominal cramps decreased somewhat while she was on the lactose-free diet, which caused her mother to focus even more on dietary therapies.

Irrespective of the previous treatments, Lea reported permanent abdominal pain with an intensity of 7 (NRS 0–10) at her initial examination at our outpatient pain clinic. She had been absent from school for 2 months and was supported and taken care of by her mother all day. Apart from the fear of pain, she admitted fear of her teacher who, as she said, was ‘so mean’ to her. Both parents reported being exhausted and helpless.

The case report shows that Lea had already suffered slight separation anxiety and fear of unknown situations in early childhood. In these situations, abdominal pain was presumably mainly a reaction to psychological stress. At first, Lea and her family managed to cope with the situation, but then the chain of events led to the development of a pain disorder and a manifest anxiety disorder.

In the following, we will discuss the differentiation between pain-related fears and non-pain-related fears. Then, we present in more detail the general aspects of treatment for children like Lea that we have found to be important considerations. Finally, we describe some specifics of the inpatient treatment of children with a pain disorder and pronounced separation anxiety.

14.1.1 Pain-Related vs. Non-Pain-Related Fears

When treating children with pain disorders and increased anxiety, it is important to distinguish between pain-related and non-pain-related fears. In pain disorders, even pronounced pain-related fears (e.g. fear of an internal injury in case of severe pain; fear of increasingly painful movement; or fear of an underlying disease) are common and by no means signs of a separate anxiety disorder. The treatment of these fears is an implicit part of pain therapy in children with chronic pain. Children suffering an anxiety disorder and complaining of their pain as part of their anxiety symptoms usually experience few pain-related fears. Their pain will rapidly decrease as soon as the fearful situation is over or can be avoided. Thus, it is not difficult to differentiate an anxiety disorder from anxiety in the course of a pain disorder.

14.1.2 Anxiety and Pain: Which One Should Be Treated First?

If a child has chronic pain and fears that are not related to this pain, the latter (e.g. test anxiety, separation anxiety, social phobia) must be explicitly addressed during treatment. Otherwise anxiety-induced muscle tension will maintain the pain. In anxiety therapy in children, graded exposure is usually indicated, which requires a separate and detailed education session. Graded exposure is often time-consuming and will often result in transient pain amplification due to the concomitant increase in muscle tension. Hence, a child should be informed that such a pain increase may occur and should be taught pain coping strategies *before* doing graded exposure.

In the case report described above, Lea is suffering permanent abdominal pain separate to the increased pain in stressful situations. In the morning and in the evening, she needs a heating pad. Her mother worries a lot about a possible somatic cause and has already arranged several diagnostic investigations and therapies (e.g. lactose-free diet). The child's history does not always allow a clear-cut time sequence of events as presented in the case report (e.g. pronounced avoidance behaviour first, then increased abdominal pain). In Lea's case, diagnoses are most probably a pain disorder and a childhood emotional disorder with social insecurity. It does not matter which one of these diagnoses is assigned as the main one, because they are mutually maintaining.

This suggests that the education of the child and his/her parents should focus on the mutual maintenance of pain and fears.

In the treatment, pain-therapeutic techniques focusing on emotional stabilisation (e.g. imaginative techniques like 'Safe Place', distraction ABC—see Sects. 9.1–9.3) are used. After first success with these techniques, it is time to increasingly focus on the patient's fears (first, graded exercise; then pain provocation—see Sect. 9.5.5). In children and adolescents, an anxiety disorder is rarely an isolated disorder within the family system. The family sessions serve to identify maintaining factors and parental fears, to illustrate that the child is not alone with his/her symptoms, and to identify the origin of the family fears. During the family sessions it is helpful to ask the following questions: (to the child:) 'Who do you believe understands your fears best'? or (to the parents:) 'Meanwhile, much is known about the origin of fears in childhood. It is undisputed that an interaction between genetic, biological and family factors like observational learning is important in the manifestation of fears. Which one of you is best able to understand your child's worries due to his/her own (biographical) experiences'?

This procedure is also suitable for children with comorbid social phobia, a specific phobia or a panic disorder. Unfortunately, the course of treatment as suggested above cannot always be followed for other fears (e.g. separation anxiety) or a post-traumatic stress disorder. If Lea would have reported additional pain peaks before or during a situation of separation, apart from her constant abdominal pain, those pain peaks would presumably reflect a childhood anxiety disorder with fear of separation. By the way, the abdominal pain is very real, as the increased inner tension *in fact* may trigger painful intestinal cramps (separation anxiety is an extremely strong fear, comparable to fear of death). Since primarily addressing the abdominal pain in this case would most probably not be effective in itself, treatment for Lea would also have to start with a confrontation of the feared stimuli despite the pain. The following section describes an approach for treating children with separation anxiety in the context of pain treatment.

14.1.3 Special Case: Separation Anxiety Disorder of Childhood

Separation anxiety disorder of childhood requires special treatment. Since the inpatient setting of the pain treatment implies a separation, this aspect needs to be worked on first. In our experience, three agreements and interventions can be helpful:

1. Due to their pain-related worries and heavy burden, parents and their child can usually be contacted easily for a discussion prior to their separation at admission. In this discussion, we address the worries and burden that contributed to their decision for inpatient pain treatment. We address their love for their child that underlies the fear of separation, and we agree on scheduled daily times for visits or phone calls. In childhood, separation anxiety often results from an ambivalent fear-maintaining interaction of at least one of the parents and thus is actually not a disorder of the child. Therefore, it is important that the parents decide in favour of inpatient treatment and not the therapists or physicians. It is important that the child knows this. Otherwise, he/she will not be sufficiently motivated for treatment, because he/she assumes that the physicians and therapists have 'persuaded' the parents. This will rule out any treatment, because the child perceives the therapists and physicians as 'evil'. In the second part of the initial session, we discuss how to cope with separation anxiety. In order to avoid unnecessarily prolonging the parents' and the child's suffering, a member of the nursing and educational team (NET) may supervise and limit the good-byes (e.g. taking the child into one's arms, one kiss, then a 'good-bye', and the scene is over). Such a time limit should be addressed in advance in order not to shock the child and his/her parents. Finally, the parents are allowed to call the NET to find out how their child is doing after the separation (by the way, the child usually does quite well. The shorter the good-bye scene, the faster the child will show normal behaviour on the ward).
2. Motivation for treatment may be increased if good cooperation in pain treatment is rewarded by means of a reinforcement schedule with longer visiting hours or longer lasting visits at home (Stress Tests). If such a schedule is arranged and the child has experienced that his/her parents will actually separate from him/her (rendering parental behaviour predictable again), we find that during the course of inpatient treatment, separation anxiety plays only a minor role in most cases. The outlined procedure will only work if the parents understand its background, explain it to their child *and adhere to the agreements*. By no means should this task be accomplished by the therapist, physician, or NET. It is *essential* for the child to recognise that the responsibility for this action is *with his/her parents*.
3. One should avoid sending the child to his/her room 'to calm down' after a separation. In most cases, this will be counterproductive since the child will be lacking adequate strategies to regulate his/her emotions before, during, or after the separation (otherwise he/she would apply them). Instead, the child should be

actively distracted by a member of the NET and be included in a game or some other form of distraction (preferably a group activity). This will make the child feel taken seriously with all his/her worries. With this support, he/she will learn faster to cope with his/her fears on his/her own.

The boundaries between a pain disorder and an anxiety disorder can be blurred. Chronic pain is not just a side effect of an anxiety disorder. It has to be addressed during therapy to underline its seriousness. In a child with separation anxiety it often suffices to explain to him/her during the education session (Sects. 8.2 and 8.3), as follows:

> Of course, your pain is real. Nobody imagines pain or longs for it. Since you often get your pain in stressful situations (e.g. separation from your parents), it fortunately doesn't indicate inflammation or any organic disease within your body. While being in extreme distress, your body gets tense and kind of cramps which naturally results in pain. It would be odd if it didn't. Since your pain is so closely connected to fear or stress, pain medication won't help. Pain can only be resolved when you distract yourself in such a situation, or when you don't experience the stress or the fear anymore.

Some therapists erroneously worry that taking the child's pain seriously could provide him/her a secondary gain from illness in terms of increased attention. We believe this is a substantial mistake. Ignoring the pain will rather jeopardize the course of treatment since the child will feel devalued and not taken seriously with all his/her aims and wishes. As a result, he/she will boycott or discontinue treatment, or the compliance will become insufficient. From our viewpoint, this 'resistance' is understandable and should be regarded as a warning signal requiring fundamental changes in the therapeutic interaction or treatment plan.

14.2 Pain Treatment in Children with Depressive Symptoms

A pain disorder is frequently accompanied by depressive symptoms (Pinquart and Shen 2011). What are the resulting consequences for pain treatment? In order to answer this question, the origin of the depressive symptoms has to be clarified first.

1. Do they reflect grief after having lost a beloved attachment figure (e.g. the grandmother)? Complicated (or sometimes traumatic) grief reactions may persist for years and are not limited to a period of 2 years.
2. Do they arise from low self-confidence and the experience of failure (or the lack of success), or from devaluations within the family (e.g. narcissistic attachment figure) or the social environment (e.g. bullying)?
3. Does the child report generalised negative thoughts regarding him/herself, the world, or his/her future (*cognitive triad*)?
4. Are the symptoms dependent on certain situations (e.g. symptoms arising when being reminded of something)?
5. Does the child gradually withdraw from both his/her family and his/her peers, or does he/she have a normal social life?
6. Does the child have problems falling asleep or staying asleep?

It makes a substantial difference whether a child has sad thoughts concerning the deceased grandmother for some time in addition to a long-lasting pain disorder, or whether he/she has lost faith in him/herself due to massive bullying combined with numerous devaluations in the family environment. In Chaps. 9–10, we already discussed some interventions for impacting depressive symptoms. In this section, we describe the inner attitude and general procedures for treating children with chronic pain and a concomitant depressive episode or an adjustment disorder with a depressive reaction. The example case reports of Svetlana and Mike serve to illustrate the different approaches.

Case Report: Svetlana (15 Years), Pain Disorder, Depressive Episode

Together with her mother, Svetlana, a very neat girl, presents at our outpatient clinic with constant severe headache (score 9/10, NRS 0–10) for the last 3 years. Numerous medical investigations yielded no pathological result. Svetlana reports that apart from the constant pain, once in a while she also experiences pain peaks (10/10 NRS) with accompanying nausea, vertigo and increased sensitivity to noise and light. Several types of migraine medication have been prescribed without effect. During the course of the session, however, it becomes obvious that Svetlana has been taking an analgesic on at least 5 days a week (mostly ibuprofen, sometimes paracetamol or acetylsalicylic acid). The respective doses and intake patterns remain uncertain. Meanwhile Svetlana is missing school 1 day a week and is withdrawing from her family and friends, spending much time alone in her room. Every now and then Svetlana meets her friends but this has no significant impact on her headache.

In addition, her mother is worried about her daughter, because Svetlana occasionally cuts her arms with a knife. This started after Svetlana was bullied in school for months. Meanwhile, the bullying was supposedly clarified and had stopped. Svetlana's mother presumes that the cause of Svetlana's social withdrawal and self-harm is that she either has problems she does not want to discuss with her, or that she is seeking attention 'although everything is revolving around her'.

While her mother is either heaping reproaches on her daughter or addressing her readiness to open her heart, Svetlana denies her mother's reproaches, at times being dysphoric and irritable, then depressed again and then keeping silent. Due to her symptoms and a clinically relevant score on the depression questionnaire (Sect. 3.3), Svetlana is queried for any suicidal intentions which she credibly denies. But she says that she does not like herself very much and has previously thought about 'not being anymore'. Svetlana's mother reacts irritably and reproachfully to her daughter's statement, since at home everything 'is perfectly fine'. The mother tells us that due to her numerous symptoms, Svetlana has started with outpatient psychotherapy which has not led to any positive change so far. Svetlana was very motivated for pain treatment despite obvious depressive symptoms. She convinced her very sceptical mother to consent to the inpatient treatment.

Svetlana told us at the beginning of pain treatment that she suffered from her mother's permanent devaluations, that her father was an alcoholic, and that she was still badly bullied at school. She reported being beaten by her parents (especially her mother) during her childhood; and this is still the case once in a while. She did not tell her outpatient psychotherapist since she did not know if she could trust her. On the cognitive level, she reported general dysfunctional cognitions with respect to herself, her surroundings and her future. Generally, her situation was difficult to bear, and she was tense most of the time. She reported that cutting herself would improve her well-being for a couple of hours. This was the reason why she regularly cut herself before meeting her friends. Basically, her mood was sad, but she still had the capacity to act. She did not know which was more burdensome to her, the pain or the sadness. Her belief was that it would be easier to reduce the pain than the sadness, and this ‘would be a first step’.

In the following, we will explain what needs to be considered when simultaneously treating a pain disorder and depressive symptoms.

14.2.1 Modified Education for Depressive Symptoms

During the education, we explained at length to Svetlana the vicious cycle of pain, the origin of chronic pain and the impact of negative emotions with the help of neurobiological charts. According to Svetlana, her pain was making her sad, and increasing sadness would reinforce her pain. She would perceive her pain more intensely while being passive, or alone, or unable to get the necessary distance from her negative thoughts (which was mostly the case). She was very interested in the neurobiological charts and very relieved to know that there was ‘proof’ that her pain was not imagined (as her mother was blaming her for) but real. She was very astonished that pain inhibition is a predefined basic cerebral function. Based on her education, we agreed to first set up an experiment to prove that both pain perception and negative thoughts can be interrupted for a couple of minutes. To this end, distraction techniques (chaos ABC with permanently altered themes, or ABC using lines of poems) were used. It turned out that Svetlana had very good imaginative abilities. Based on this ability, she created two very different Safe Places (one for use in public, the other in privacy) which were very helpful for influencing her general mood. Biofeedback helped her verify the effectiveness of the various techniques. During the following six individual therapeutic sessions, she worked on her negative core beliefs (for details, see Sect. 10.5; for Svetlana the following interventions were helpful: protocol of thoughts, analysing and observing exceptions from her negative experiences and collecting arguments for or against her negative basic assumptions) as well as working on training verbal interaction strategies for contact with her mother. Like many children with depressive symptoms, Svetlana was highly able to reflect her own thoughts and behaviour. With the help of the support during her short stay on the ward, she succeeded in significantly influencing her mood for the better; she was able to notice this change herself. It turned out that the severe pain attacks were due to internal or external tension, and thus the presence of an additional migraine could be excluded (and a pharmacological treatment with potentially severe side effects was unnecessary).

This procedure is limited to children and adolescents with a mild depressive episode. For moderate depressive episodes, particularly distraction strategies or imaginative techniques should not be implemented (see Sect. 5.2 for contraindications for pain treatment). For children and adolescents with comorbid moderate depressive symptoms who are sufficiently motivated for treatment, the installation of a daily structure takes priority (see Sect. 14.2.2). During education, it is important that the children understand that increased physical activity and a fixed ‘active’ daily structure are prerequisites for pain treatment. Additionally, education should be repeated if necessary, as many children and adolescents with moderate depressive symptoms have difficulties remembering and concentrating.

14.2.2 Adapting the Daily Routine for Patients with Depressive Symptoms

Parallel to the approach outlined in Sect. 14.2.1, Svetlana set up a structured plan for her daily activities together with the NET and a ‘list of pleasant activities’ (Sect. 10.3 and Chap. 15, worksheet #14). In the evening, Svetlana had a 10-min talk with her contact person from the NET (positive evening reflection). The member of the NET gave her feedback on her behaviour, her personality, or special skills and abilities observed during the day. During the positive evening reflection, only positive feedback is allowed. The children are asked to listen carefully. Positive feedback will not be discussed (‘You may perceive yourself differently. But this feedback is how one member of the NET perceives you and I don’t want to argue about this subjective view. If you like, you can speak to him/her personally’). Sometimes, the question arises in the NET why these children and adolescents cannot simply report what they themselves perceived positively regarding their own behaviour etc. However, if these children were able to do this, they would not have a depressive episode and the intervention would be superfluous. In addition, Svetlana was asked to query her peers and the therapeutic team about what they liked about her, and to record their answers several times during treatment. This intervention can only be successful if only honest feedback is provided. Sometimes, the other patients need to be informed that wrong or artificially positive feedback may harm the patient and is strictly forbidden. These records are integrated into the individual therapeutic work for cognitive restructuring. The primary aim is that the patient recognises that others’ perceptions may deviate from one’s own subjective reality and may be more positive. Thus, they must have previously unknown abilities that elicit these positive perceptions.

14.2.3 Working with the Family in Patients with Depressive Symptoms

The interrelationship between pain perception, depressive thoughts and inner tension can be demonstrated in the family sessions using examples from everyday life. Contrary to Svetlana’s expectations, her parents actively cooperated, and they repeatedly expressed their deep concern about their daughter’s future.

The primary issue of the following family session was appreciating the parents' various efforts to educate their daughter. From our experience, it is important to highlight and compliment the parents' good intentions irrespective of any obvious dysfunctional patterns of family interaction; particularly in family systems such as the one described for Svetlana. (Note: This is only true as long as there is honest motivation to cooperate, and any acute endangerment of the child's well-being is absent.)

As mentioned before, also in this case, a humorous approach has proven helpful to increase the parents' motivation to cooperate. After having reflected their own biography, the parents were able to admit to their daughter that they unintentionally contributed to her problems. The father's problematic consumption of alcohol was discussed, as well as long-lasting parental conflicts. It became more and more obvious that the family atmosphere was mostly tense and there was rarely space for laughter or praise. Instead, devaluations and reproaches prevailed. Physical violence was denied. Svetlana had described her mother as hard and stubborn. Contrary to Svetlana's expectations, her mother burst into tears during one session. On this basis, they came to binding agreements regarding the further course of psychotherapy. At the end of her stay, Svetlana was able to decrease her pain up to 3 points (11-point rating scale), and to better control her dysfunctional thoughts. During the Stress Tests, Svetlana's mother tried to praise her daughter, and not to interrupt her when she was talking. After obtaining privacy release consent, the background and course of the disease were discussed with the outpatient psychotherapist allowing a seamless continuation of the therapeutic process. Motivated by the positive experiences from the inpatient stay, outpatient psychotherapy was more successful because now Svetlana had learned to be open with her therapist.

Svetlana's case illustrates how a simultaneous treatment of pain disorder and depressive symptoms may be helpful even if not all relevant factors can be determined and addressed.

14.2.4 Adjustment Disorder: Coping with Grief and Death

The case of Mike illustrates our approach in a case of a very sad experience (e.g. the death of a beloved one) being the trigger of depressive symptoms.

Case Report: Mike (12 Years), Pain Disorder, Adjustment Disorder

Twelve-year-old Mike is quite a content and calm boy. According to himself and his mother, he had a happy, though unremarkable, childhood. Due to his above average intelligence, he passed primary school and transitioned to high school without any problems. Every now and then he would suffer from migraines which presumably was inherited from his mother (and from *her* mother). An analgesic (ibuprofen 400 mg) taken early in the course of the episode would help effectively (almost no complaints after 45 min), thus migraines had never really impaired him. Because both parents were employed, he often visited his grandparents living in the neighbourhood. He loved his grandfather passionately and did a lot with him. Unfortunately, 1½ years ago, after having played together with Mike all day, his grandfather suddenly and unexpectedly died at home, apparently due to stroke. From that moment, everything became worse for Mike and his family. Only a few weeks after the grandfather's death, his father lost his job because of the economic crisis. Five months later, his mother suffered disc herniation 'presumably due to all the stress' and had to attend a rehabilitation clinic for 4 weeks. Mike changed from a fun-loving boy to a secluded, depressed and contemplative boy who hardly went out. Apart from constant headache, Mike also often reported very severe headache attacks. During those headache attacks, his migraine medication would not help anymore. It was no longer possible to attend school because Mike was not able to get out of bed in the morning, crying due to pain. Due to the extremely high number of school days missed, it was not possible to grade him, and passing to the next class was in doubt. His parents seemed very exhausted and desperate. They told us that they didn't know how to go on and that they were 'running on empty'.

On the background of a very well-treated migraine (without aura), Mike developed both a pain disorder and an adjustment disorder with a depressive reaction after the very stressful loss of a beloved one. The high family burden is obvious. When we explored the case history, it was important to find out how much Mike's mother was burdened by the mourning process and therefore failing to support him. How should Mike's history modify the necessary inpatient pain treatment?

According to our experience and contrary to what could be assumed, the implications for treatment are minor. A 'standard' pain treatment for a child with a pain disorder with an underlying migraine is not much different from that in a child with additional adjustment disorder after the loss of a beloved one. Of course, the mourning process needs to be integrated into treatment, but this can be done simultaneously to pain treatment.

The basic therapeutic strategies as educated for use in 'standard' pain treatment are also suitable to improve coping with grief.

Active pain coping in everyday life, better differentiation between migraine and pain disorder, and much normalising, resource-oriented reinforcement are of value for a sad child as well. Particularly in the treatment of mourning children, one should consider the following:

1. During the *first* education session, the therapist should point out the close relationship between severe pain and sad Black Thoughts using the vicious cycle of pain: 'Many children report that apart from 'normal' Black Thoughts regarding pain (such as 'Why me'?), severe pain further provokes other Black Thoughts or stressful memories that worsen the situation. Does that make sense to you? Do you know this from your own experience? What level of pain intensity automatically provokes bad memories or thoughts'? (in Mike's case: '… reminders of your grandfather'?)
2. Frequently, feelings of guilt or the wish to tell something really important to the deceased play a role. Since these feelings are very burdensome, they are frequently repressed (particularly if a family system has no helpful models for constructively dealing with negative emotions). The aim regarding mourning in the context of pain treatment is to confront the negative feelings, because

repressing them will only lead to physical tension and thus an increase of pain. Much caution is needed here. Children appreciate when the therapist reflects their mood and thoughts in an appreciative and normalising way. Any therapeutic options (e.g. to accompany the child in his/her process of grief, for instance in writing a farewell letter to be laid down at the grave, or talking about thoughts and feelings of guilt) should be cautiously offered to communicate to the child that the therapist respects not only his/her needs but also boundaries.

3. Helpful interventions should be established for reducing stressful memories in the evening—at the time when 'everything comes to rest' and the probability of stressful memories increases (e.g. Safe Place, cognitive restructuring, mindfulness-based interventions). If the child states that he/she is sufficiently stabilised, pain provocation (Sect. 9.5) is a suitable technique to simultaneously reduce fear of pain and stressful memories conditioned to pain. The affected children report that after frequent application of the method the stressful memories are always 'far away' and even the most severe pain would more and more seldom trigger stressful memories. Since they have successfully faced their memories and pain, they mostly experience an increase in self-efficacy. For traumatic grief reactions, trauma methods, such as narrative exposition, imagery rescripting and reprocessing therapy (IRRT) or eye movement desensitisation and reprocessing (EMDR) may be more useful.
4. All these aspects should be addressed at length in the family sessions. Usually, sadness in at least one of the parents is a factor maintaining the pain disorder. Just expressing that assumption while the child is listening may validate the child's perception and may therefore be very helpful. The child's choice not to talk 'about that' with his/her parents to protect them from their own feelings is normalised. Then we jointly ponder which steps the mother or the father could take in order to work on their own grief or sadness. Finally, we emphasise that the parent's own efforts will relieve the child by relieving his/her worries concerning the parent.

14.3 Pain Treatment in Children with Trauma Disorder

Traumatised children frequently suffer chronic pain (e.g. Seng et al. 2005). Additionally, a substantial proportion of children with chronic pain suffer symptoms of posttraumatic stress disorder (PTSD) or a full-blown PTSD (Stahlschmidt et al., in prep). The significantly increased comorbidity of chronic pain and symptoms of PTSD in adults was emphasised nearly 20 years ago (e.g. Sharp and Harvey 2001; Asmundson et al. 2002). The need for new treatment methods that cover both disorders was highlighted. Anxiety sensitivity (the fearfully increased perception of bodily signals; maladaptive interoception) was identified as one maintaining factor of both disorders. Wald and Taylor (2008) were able to show that harmless physiological activation, such as sports, could trigger stressful intrusions in up to 60% of adult patients with PTSD. They supposed that the perception of physiological activation triggers traumatic memories because high physiological activation was closely associated with the traumatic situation (interoceptive conditioning). If there is an additional pain disorder in traumatised children, increased body awareness may enable mutual conditioning (Liedl et al. 2011). A recent review describes how any form of perception of bodily signals may lead to increased physiological activation (as a consequence of the activation of the fight or flight response in the limbic system), similar to interoceptive conditioning in panic disorders (Holley et al. 2016; De Peuter et al. 2011). Implications for the clinical context are illustrated in the following case report.

Case Report: Wiebke (13 Years), Pain Disorder and PTSD

Wiebke presented at our outpatient clinic accompanied by her mother with the diagnoses of juvenile fibromyalgia syndrome and a moderate depressive episode. She scored extremely high on the depression and anxiety questionnaires (*T*-values: depression = 68; general anxiety = 80), and she rarely attended school due to her pain. Several inpatient therapies focusing on 'rheumatic therapy' were successful only for as long as Wiebke was in the clinic. As a consequence, pharmacological treatment escalated. When Wiebke presented at our clinic, she was on two different antidepressants and a retarded opioid. Despite substantial adverse effects of these drugs (excessive weight gain; lack of concentration; constipation) there were no positive effects at all. The treating physicians and therapists offensively questioned the presence of pain as well as Wiebke's motivation for treatment. This led to a worsening of the conflict-ridden relationship between Wiebke and her mother. The neat, friendly and sociable girl seemed hopeless when we first met her. She did not believe her life could change for the better. But a friend had told her about the German Paediatric Pain Centre and her positive experiences with inpatient pain treatment. With respect to Wiebke's severe emotional burden (high scores in depression and anxiety), we told her our assumption that she was suffering not only pain but was also impaired from other stressful life events. Wiebke was astonished at first but confirmed our assumption that there were very stressful memories. She was curious about the inpatient treatment. After giving an extended overview of our work with a focus on individual therapeutic sessions, Wiebke agreed to our conditions for inpatient treatment.

During her inpatient stay, we were able to identify several critical, and two traumatic life events (witnessing severe domestic violence by her biological father; sexual abuse by a stranger). Regarding the sexual abuse, the criteria for PTSD were fulfilled. As a result, Wiebke had experienced mutual conditioning of pain and trauma factors. Since Wiebke had so far not been told about these interactions, she did not dare to talk about these issues. Following inpatient treatment, we tapered the medication, monitored by several follow-up visits. Family sessions were an important part of the treatment. One year after inpatient treatment, Wiebke was off medication, free from constant pain, attending numerous social activities and regularly attending school. She told us that her emotional burden was steadily decreasing due to successful outpatient psychotherapy. Both her mother and her stepfather were still sticking to the arrangements made during the stay on the ward, and the dysphoric and tense family mood had normalised.

In children with PTSD, the very high emotional burden and decreased ability to regulate one's emotions is problematic for pain treatment. A further problematic factor is the fact that the previous passive pain coping behaviour of the affected child was some kind of problem-solving strategy (avoidance) in the coping with stressful memories. The indicated active pain coping would take away an effective short-term problem-solving strategy, resulting in an increased emotional burden which very well could become critical in a child with an impaired ability to regulate his/her emotions. As the case report shows, children do not generally report stressful life events, and their parents likewise do not like to talk about stressful family conflicts. Thus, there is the risk of missing a diagnosis and an escalation of medical and pharmacological treatment, as seen in Wiebke. Apart from such an escalated treatment, psychological questionnaires may provide hints for a PTSD. Children and adolescents with a PTSD frequently report an increased physical tension (permanently increased physiological activation to enable an immediate reaction in case of danger), are more vigilant and more easily startled, and have sleep problems. Other physical (frequently changing) symptoms emerge over time, such as vertigo, nausea, paraesthesia or dissociative symptoms of unknown origin (e.g. syncope). In most cases, there is a dysfunctional cognitive processing of traumas and a large number of dysfunctional generalised negative cognitions can be identified (I am worthless, it's my fault, I am mad, an unlucky person, I magically attract bad luck, …). Due to the interoceptive conditioning, bodily signals are interpreted as signs of danger leading to increased and fearful body awareness. Children whose trauma resulted from physical or sexual violence are often seemingly friendly and conformist, but extremely suspicious behind the façade. Affected children often repress the traumatic memory, but fear to be crazy or to be questioned about the stressful memories. This, in combination with the suspicious attitude, may lead to a pronounced somatic fixation. Psychotherapists and biopsychosocial models are rejected at first. It is helpful for the therapist to remain aware that such complex symptoms have not developed by chance. How can the hypothesis of a combined trauma and pain disorder be explored without jeopardising the therapeutic relationship?

Affected children and adolescents often have high scores in questionnaires assessing generalised anxiety, depression or panic disorder. If in addition, the above-mentioned physical symptoms are reported, the therapist should explain to the children that all these symptoms may occur after having experienced stressful life events. This gives them the opportunity to talk about stressful events. Furthermore, the therapist should clarify that the pain treatment cannot be successful if only pain, and not traumatic memories and perceptions (conditioned to pain), are treated in case of a combined pain and trauma disorder. Many traumatised adolescents start asking questions and open up step-by-step after this education, which is very surprising for them. In case it is difficult for them to directly report on the events, a semi-structured interview can be useful.

As a general rule for evaluating the medical history, the probability of emotionally extremely burdensome problems increases with increasing numbers of medical and pharmacological treatment attempts, and with increasing invasiveness of recommended or implemented medical procedures. In case of additional specific results of psychological questionnaires and typical trauma symptoms, the existence of a trauma disorder should be actively explored according to the current state of research.

14.3.1 Coping with an Increased Need for Control and Security

Children like Wiebke learned during their life that they have only a small impact on things happening to them or their body. Their experience has been that people are generally malevolent, not respecting a person's basic needs. This makes the child cautious and suspicious in his/her interactions. In addition, most of these children report that they fear becoming 'mad' due to the longstanding excessive emotional demands of their chronic pain, intrusive memories, reduced stress tolerance, lack of concentration, or other dysfunctional cognitive beliefs. It is understandable if at first these children behave in a reserved or suspicious way towards the team, the psychotherapists and any new information. It is helpful to anticipate this interaction. In patients with a strong need for control, it may be advisable to make the therapeutic attitude, and any therapeutic decision, very transparent. In addition, we ask the child to scrutinise the therapist, all information given, and the communication within the team, and to give feedback on any discrepancy.

With traumatised children, we discuss all steps and therapeutic interventions extensively in advance. The child should understand the purpose of all interventions. Such an approach is very time-consuming and requires good communication within the interdisciplinary team.

We advise against inpatient treatment of traumatised children with chronic pain in an institution where the therapeutic approach of the nurses, therapists, or physicians on the ward is not predictable (e.g. team conflicts; disputes about competences, responsibilities and power), since lacking predictability will cause the patient to experience loss of control. As a result, the patient would try to stay in control of his/her behaviour, which could lead to the avoidance of single treatment steps or complete refusal of treatment. His/her increased physiological activation as a consequence of loss of control would result in adverse somatic symptoms. These symptoms make the patient insecure and will often lead to more frequent consultation with the physician. The patient's insecurity may transfer to the physician, which frequently leads to an escalation of the pharmacological treatment. All this increases the risk of a split of perception within the team (e.g. 'She is seeking attention' vs. 'She cannot help but react like this') being more detrimental than beneficial to the patient.

14.3.2 Adaptation of the Education

During the course of treatment, the therapist should try to find out if certain traumatic contents are triggered by a certain type of pain and vice versa. The context in which the pain and/or traumatic symptoms occur should be determined (e.g. school or home environment). The education should address the dysregulation of the limbic system due to traumatisation and the concomitant permanently reduced ability to cope with stressors.

Supplementary Pain Education in the Traumatised Child

> 'Broadly speaking, as a consequence of one or several traumatising events, a cerebral emergency mechanism is triggered in order to prevent you from having to go through that horrible event a second time. You will become more vigilant, scanning your environment for any sign that *it* could happen again. Your experience has been so stressful/traumatising that you were overburdened with the task of processing the event, and you grew stiff. Memories re-emerge, especially when you try to rest. These memories are called 'intrusions' or 'flash-

> backs'. A main feature is their liveliness and intensity; this makes it difficult to distinguish memory from reality.
>
> As a consequence, you are unable to relax because you think that the stressful memories may re-emerge any time or *it* may happen again. Falling asleep or staying asleep can become difficult. Frequently, nightmares emerge. And after not having slept well, you will wake up tired in the morning. Some children have experienced such horrible things that their only way of dealing with it is that their brain splits the memory into small packages. Hence, they can only remember one package at a time, or only certain packages, or the flashback is confined to hearing, feeling, smelling or tasting. It becomes quite confusing if certain people or actions reflect aspects associated with the trauma (e.g. a certain haircut, voice, threatening gesture) and trigger a flashback confined to purely somatic perception (e.g. severe pain; intense heartbeat; extreme dizziness; other sudden physiological reaction). The association between the trigger and the flashback may not be clear which often leads to feelings of insecurity.
>
> The result is a permanently fearfully increased tension combined with vigilance, anxiety and sleeping problems, which may lead to a gradually reduced ability to cope with daily hassles. In the end, difficulties with concentration arise. Regarding emotions, wide swings of mood can be observed, or feelings of emptiness and numbness. Sometimes this happens in fast sequence. Affected children may wonder 'Why'? and try to cope with the event. Many affected children come to the conclusion that it was their fault, or that they are doomed to awful experiences. This is not 'standard' logic but trauma logic arising from the desperate attempt to make sense of what happened in order to keep a minimum level of control. However, the price is high, as this mostly leads to substantial self-devaluation. The patient starts to hate him/herself for not having done anything to prevent the event, because he/she was paralysed by fear. Depending on the type of trauma, a feeling of shame may arise which makes it difficult to verbally address what happened.
>
> After some time (sometimes weeks, mostly months, seldom years), a so-called dysregulation of the stress system occurs. Normal demands lead to excessive, or missing stress reactions. This is accompanied by wide swings of mood. Needless to say, almost all children experience problems in coping with everyday life and an increase in pain frequency resulting from the permanent tension and fear. Many patients start to withdraw from social activities because they feel exhausted. Finally, dysregulation of the stress system impairs the immune response of the body, the patient is ill more often, and the frequency of minor inflammatory illnesses increases. Due to the increased body awareness caused by the trauma, the patient perceives these body signals as very differentiated and intense. This strengthens the concern that something is wrong with the body and oneself. In case of any acute painful event (e.g. accident; severe flu; common cold; migraine attack; or relapse of a rheumatic disease), the probability of the chronification of acute pain is high'.

Complex traumatised children (e.g. children with a year-long history of neglect and/or witnessing or experiencing physical and/or sexual violence) need an even more specifically adapted and detailed education as well as specific consideration of their basic interactional needs. In these children, the education should be provided by a physician or therapist especially trained in trauma treatment.

Chronic pain that suddenly occurs after a traffic accident requires special education. In most of these cases, traumatic aspects of the accident significantly contribute to the chronification of the pain. With respect to the education, it is especially important to address the point that the experience of pain often triggers the memory of the accident and vice versa. As mentioned above, the memory of the accident is often fragmented, requiring meticulous inquiry as to what exactly happened during that accident.

Having explained the inter-relationships, it is essential to repeatedly and empathetically normalise the patient's experience, perception and his/her dysfunctional thoughts during treatment. For many children it is beneficial to learn to better anticipate their somatic symptoms as this increases control and security. The child is encouraged to pose any question (even repeatedly) about any somatic symptom experienced which triggers a feeling of insecurity. In addition, the child's homework is to record a few times a day how his/her body reacts depending on which situations and on which appraisal (ABC model according to A. Ellis, Sect. 9.3). Unlike standard cognitive therapy, the focus should be to identify dysfunctional thoughts that are directly or indirectly associated with the traumatisation (so-called 'trauma thoughts'), because these thoughts contribute to the maintenance of trauma symptoms. Usually, these trauma thoughts follow a certain rule (e.g. 'I am to blame, because I didn't defend myself' or 'That this happened to me is the proof that I am worthless/can't defend myself/that anyone can do with me whatever he/she wants…').

14.3.3 Specifics Concerning Active Pain Coping

For many children with a combined pain and trauma disorder, passive pain coping represents a kind of trauma avoidance and thus problem-solving or coping strategy. Thus, increased active pain coping may result in an increased emotional burden and in potentially ambivalent motivation for treatment. This should be addressed during education. The therapist may refer to this ambivalence (avoidance behaviour vs. desire for reduced emotional distress) during education in order to value and normalise the child's feelings and behaviour (particularly striving for control and mistrust of other people). If the inter-relationship between active pain coping and an increase in trauma-associated emotional burden is not addressed, this should be made up for at the first sign of ambivalent treatment motivation. Otherwise, there is the risk of splitting the team in the inpatient setting because the child's behaviour allows for several different and contradictory interpretations.

Apart from normalising and appreciating their previous efforts, it should be made clear to the child and his/her parents that passive pain coping will increase both pain and trauma symptoms in the long run. After having normalised the patient in acute ambivalent treatment motivation, we usually discuss the following aspects with the patient:

> Which way do you want to go now? The way of passivity and avoidance that made your life the way it is now and prompted you to decide for an inpatient treatment? Do you want to continue in this way? Or would you prefer to change to active coping? What do you fear will happen when you start to get more active?

At this point, it is worthwhile once more explicitly addressing the seemingly simple and understandable solutions like somatic fixation, medication, and in some cases alcohol, where one does not have to leave the course of passivity and avoidance. We discuss this openly and can understand their wish.

> It would be great if there was a pill available that would just wipe everything out, wouldn't it? This is what we all wish for once in a while. The question is, what can you do now to make yourself feel better? How can we support you?

For the parents, it is also important to develop an understanding of these associations. This is the only way to enable them to expect active pain coping from their child. With this issue, most parents are as ambivalent as their children. Some parents fear that their child will do worse if they apply educational consequences. The child knows about this and will take advantage of it when planning his/her behaviour. Some parents feel pity and do not want to expect 'even more' of their child.

Parental education should make it clear that only increased active pain coping in everyday life (e.g. family, school) provides the chance for healing.

14.3.4 Coping with Avoidance Presenting as Increased Somatic and Dissociative Symptoms

In therapeutic jargon, the expression 'avoidance' can imply something negative and may be used in conjunction with a devaluating view of the patient's motivation. Some children with low motivation for treatment try to avoid or prevent certain situations, bad memories or discussing tabooed family issues by presenting with increased somatic or behaviour-related symptoms. Mostly, however, the presence of avoidance behaviours is an indicator of an extreme emotional burden of the child. If children do not dare to ask questions or criticise out of shame or social insecurity, they try another way to get answers to their questions, for instance by presenting more somatic symptoms. In this respect, a self-critical attitude while talking to the child will pay off, which does not mean that the therapist should give up basic positions (e.g. active pain coping in everyday life), but it may be advisable to take an increased somatic concern of the child seriously and let him/her talk to the doctor about his/her worries for 10 min a day. This explicitly also applies for somatic symptoms which are obviously induced by fear or stress (hyperventilation, tightness in the throat, paraesthesia, …). Under no circumstances should the physician, therapist or the NET assume a 'gain from illness' or 'attention seeking'. This would minimise the child's inner distress and may lead to a splitting of the team or a discontinuation of the treatment. Dissociative symptoms need to be taken seriously. If possible, the child should be provided with biological reasons for the symptoms. Usually such an approach will result in a reduction in the number of avoidance behaviours. If these measures are ineffective, presumably, an approach as outlined in Sect. 14.3.5 is necessary.

If, nevertheless, the child is considerably overburdened with inpatient pain treatment, he/she might show dissociative symptoms presenting as psychogenic syncope, sudden loss of vision, deafness, muscle weakness, or paralyses. Transitory clouding of consciousness, non-responsiveness, de-realisation or de-personalisation are observed as well as (seldom) psychogenic seizures. Primarily complex traumatised children present with these symptoms.

These symptoms severely hinder inpatient pain treatment or make it even impossible (this is different with outpatient psychotherapy). Whether a continuation of inpatient pain treatment despite the presence of these symptoms is reasonable, depends on how well aware the child is of these dissociations. With regard to the dysregulation of the stress system, we recommend normalising the symptoms by talking to the child:

> You have experienced and survived so much in the past. So far you haven't had the opportunity to process all those stressful experiences and make 'it' end. Hence your brain and your body are still in emergency mode, which might mean that your body is protecting you from further overburdening by switching off your awareness for a while. This is harmless, nothing will be damaged in your brain. And you definitely aren't mad.

Simultaneously, the therapist should state his/her concerns about the child's well-being (e.g. in case of psychogenic syncope: 'You know life can't go on like this. Your brain is protecting you from overburdening, but this way it is impossible for you to learn how to cope with stress, problems, or memories more appropriately. In the long run, leading a normal life becomes impossible').

If exploration of the symptoms shows that the child at least has a presentiment of the context triggering dissociative symptoms (or of trigger memories, or external triggers), and is motivated to learn to better influence the symptoms, it is appropriate to continue with inpatient treatment with a special focus on the dissociative symptoms. However, tabooed family issues and the degree of endangerment of the child in his/her surroundings should be explicitly explored with the help of psychological questionnaires (e.g. Adolescent Dissociative Experience Scale, Traumatic Events Screening Inventory for Children). Particularly children with dissociative seizures or psychogenic syncopes (without previous hyperventilation) should be repeatedly asked for traumatic life events and the degree of endangerment. We have experienced ourselves that often children and adolescents with dissociative seizures report sexual traumatisation (with ongoing contact with the offender) only one or two years after inpatient treatment.

Case Report: Nusara (15 Years), Pain Disorder, Recurrent Depressive Episodes

> Nusara was treated on the pain ward due to a pain disorder and recurrent depressive episodes. One of the authors (M.D.) continued outpatient psychotherapy with the girl. By and by, symptoms improved, but inexplicable mood swings, sleeping difficulties and a strong fearfully increased body awareness remained. One and a half year after the start of outpatient psychotherapy, her mother called and was worried, because Nusara had started to frequently 'fall over' and twitch uncontrollably. Nusara did not respond during these periods. Neurological examination (which was once conducted during such an attack) did not reveal any pathological finding. When Nusara was confronted with the hypothesis of an experienced trauma (in a very respectful but insistent way), she hesitantly reported a very violent sexual assault that she had experienced half a year before her inpatient pain treatment. She had tried to repress the memories. But this was no longer possible, because she

> saw a picture of the offender on Facebook, where he was accidentally recommended as a friend for her. Furthermore, her step-grandfather had made salacious remarks some weeks ago when she visited her terminally ill grandmother. He also sent her pictures of naked 15-year-old girls on her phone. Since then, the memories were 'permanently present' and she was extremely afraid that 'it could happen again'. So far, she had not yet told her parents, because she was afraid that her father (who is prone to violence) would try to find the offender and kill him. Then, 'I am to blame when my father is in prison'. Now, the girl agreed to inform her mother and later her father. After the girl was protected and the feared reaction of her father did not appear, trauma treatment was conducted. Within a few months, the symptoms completely disappeared and Nusara became happier and more fun-loving.

If the trauma symptoms are predominant, inpatient treatment in a paediatric psychiatric institution focusing on dissociative and trauma disorders is the better choice (Sect. 14.3.5).

If the family wishes to continue inpatient treatment, limiting the dissociative symptoms is of primary concern.

If this is the case, some interventions for working with 'ego states' have proven helpful (deriving from ego state therapy, according to Watson). In this approach, the child writes, paints or creatively designs his/her different personality traits. More hidden parts of the personality (or ego states) like 'the inner child' or self-destructive and destructive personality traits should also be portrayed. Optionally, the ego states may be marked with a name and/or a symbol. When there is enough time, in the next step, it is helpful to collect biographical associations for the different ego states to highlight their specific role in coping with stressful or traumatic life events in the child's biography. This should also be done explicitly with destructive ego states (e.g. the patient's parts as offender). Then, the various ego states are supported to jointly decide how to proceed (e.g. to implement certain therapeutic interventions). For a deeper understanding of this approach and its theoretical background, we advise specific trauma-therapeutic training. We advise such an approach only if the child agrees to participate in outpatient psychotherapy after having finished his/her inpatient stay, or if outpatient therapy is already arranged.

It makes sense to accompany interventions deriving from ego state therapy with interventions such as 'weather forecast'. Since during exploration of the child, some awareness of dissociative symptoms has become evident, it is important for the control of dissociative symptoms to have the child learn to predict the emergence of his/her symptoms. Practising 'weather forecast', the child is queried each morning for the probability and frequency of the dissociative symptoms to appear that day. Interestingly, this intervention (in combination with the ego states) often results in a quick reduction of dissociative symptoms, and the child quickly recognises the interdependencies between dissociative symptoms and his/her biography.

For some children (e.g. those with psychogenic paralyses), it is helpful to gradually learn, via graded exposure, to reduce their dissociative symptoms. Graded exposure in children with dissociative symptoms is principally the same as outlined elsewhere (Sects. 9.5 and 10.4). But this procedure is only useful in the long run if the intrapsychic problems underlying the dissociative symptoms can be solved. Otherwise, symptoms will not change, or may only shift.

14.3.5 Contraindications for Inpatient Pain Treatment of Traumatised Children

Children with severe emotional instability with self-harming and/or aggressive behaviour do not fulfil the criteria for inpatient pain treatment.

After extensive education about the requirements (no self-harm; no aggressive behaviour; sticking to the ward rules; regularly doing therapeutic homework—otherwise immediate interruption of therapy), it might make sense for some of the children to contractually demand their agreement and evaluate their motivation in a written letter before admission (for ambivalent motivation, see Sect. 13.3). For some of our older patients with an early-stage emotionally unstable personality disorder and/or antisocial behaviour, this procedure was beneficial, because they succeeded in following the rules during their inpatient stay.

Traumatisation with concomitant ongoing drug abuse and severe antisocial or dissociative symptoms is an absolute contraindication for our type of inpatient pain treatment.

In case of any doubt about the eligibility of a patient that arises during the first outpatient appointment, we generally recommend performing a detailed and written motivation check. This will allow the child to become aware of what he/she wants and what he/she is ready to invest. At the same time, we protect the child from otherwise inevitable disappointment. In all other cases, outpatient or inpatient treatment focusing on the dissociative or traumatic symptoms is preferable to inpatient pain treatment.

To summarise, in the treatment of children with both a pain and a trauma disorder, an adapted education focusing on processes of interoceptive conditioning and aiming at normalisation of physical symptoms is a prerequisite for successful therapy. Thus, treating only the pain or trauma symptoms is useless. For these patients, predictability of interventions and agreements is very important. This requires close interdisciplinary cooperation during the inpatient treatment programme. Any suddenly arising emotional or somatic symptoms should trigger self-critical evaluation by the therapist, a detailed exploration of the symptoms and intensified education. If this does not suffice to confine the symptoms, one should critically evaluate the indication for participation in the treatment programme and initiate a transfer to a paediatric psychiatric institution, if necessary. In the light of the variability and complexity of traumatic or dissociative symptoms demanding special knowledge, we recommend that at least one member of the therapeutic team be certified in trauma therapy.

14.4 Pain Treatment in Children Suspected of School Truancy

Children with chronic pain and frequent school absenteeism are often suspected of school truancy by the teachers, classmates, paediatric psychiatrists, paediatric psychotherapists, responsible paediatricians or general practitioners. The child is accused of lacking motivation, lacking readiness to perform, idleness and laziness. The pain is regarded as an excuse.

14.4.1 Myth and Reality

Many children with chronic pain act insecurely in their interactions with teachers or classmates. They cannot deal with their daily hassles and display social withdrawal. However, to assume school truancy from this behaviour is inadequate and does not capture the impact of their disorder. One argument against assumed school truancy is that after successful inpatient pain treatment, even in the long run, these children do not show abnormal absenteeism from school (Eccleston and Malleson 2003; Hechler et al. 2009; Zernikow et al. 2018). Interestingly, a reduced number of school days missed is seen in children even without significant pain reduction (in line with the aims of acceptance-based treatment). These results support the hypothesis that children miss school due to pain and a lack of appropriate coping strategies, and not due to school aversion.

14.4.2 Specifics in Pain Treatment

In a child with high pain-related school absence, pain treatment needs to focus on the improvement of his/her ability to cope with everyday life and daily hassles. The Stress Day (see Sects. 9.5 and 10.1), active pain coping irrespective of pain intensity and an age-appropriate daily schedule are of special importance. In many cases, even two Stress Days during the inpatient stay are advisable as it often does not become obvious before the first Stress Day which specific coping abilities in everyday life should be addressed during the further course of treatment.

Finally, we would like to mention four other aspects relevant for the treatment of children with high school absence:

1. Children with a high number of school days missed should *not* be admitted for treatment during school holidays. During holidays, the daily routine on the ward is less stressful and more different to everyday life, partially because the patient does not have to attend the clinic's school. During holidays, it is impossible to schedule Stress Tests with attendance at the home school, but in these children, the Stress Test at school is of special importance, allowing for targeted treatment planning.
    (a) Is the patient motivated to attend school due to his/her knowledge and newly learned abilities?
    (b) How do the parents cope with their child's school problems after a total of two family sessions and extensive education on active pain coping in everyday life?
    (c) How do the teachers and the classmates react to the patient who in some cases did not or only sporadically attend school for months? (Quite often, the patient has to bear mocking comments from the teachers, which later must be addressed during individual therapy sessions).
    (d) In case of increased pain: when exactly is it observed? Is it already there in the evening before the school visit is scheduled? Or does it emerge at night, in the morning, on the way to school, at school, or even after school has finished?

   (e) How does the patient cope with his/her pain?
   (f) Do the learned techniques and strategies work?
   (g) Are there contextual factors independent from school associated with less pain? What is the daily structure at home; how much media consumption? Are the parents able to implement the supportive measures as discussed? Is there a relationship between pain and family mood (sometimes children do not go to school, because they worry so much about a parent that they want to stay home to take care)?
2. The therapist should discuss with the child and his/her parents the signs signalling that the child is refusing school irrespective of pain, and that it is not primarily the pain disorder that is responsible for concomitant absenteeism from school. Children refusing school will quickly learn to use the learned strategies to influence their pain on the ward. In their family surroundings they still have these abilities but use them primarily outside the time scheduled for school, so that they still do not attend school regularly. Some of these children will suddenly exhibit altered symptoms, e.g. tiredness, exhaustion, or a prolonged flu. It quickly becomes obvious that the family's structures are unable—or sometimes unwilling—to implement the therapeutic arrangements. If this is the case, one must inform the youth welfare office with its outpatient, or inpatient offers. Often, these children have to be moved to alternative accommodation, and this not seldom at the parents' request because they are running on empty.
3. The possibility of the presence of trauma-associated disorder or PTSD, or permanent bullying at school, should be examined. In one of our patients where we discussed school truancy, it finally turned out that the child had been repeatedly sexually abused at school, and was getting death threats from the offender in person, by phone, and via the internet. In another case, a boy was attacked by a group of adolescents from another school on his way home and threatened with death if he talked to his parents. Most (but unfortunately not all) children will report such experiences in the individual sessions if they are informed about professional confidentiality.
4. In treatment, pain coping techniques (particularly behavioural distraction) should only be implemented when the child is sufficiently motivated to change. This is not as trivial as it sounds. Many affected children know exactly what is expected from them and respond in a socially desirable way. In many cases, it is helpful to describe the current situation and one's own worries in a respectful but drastic way at the beginning of treatment (this is only useful for children with pronounced school absenteeism!). In addition, it may be helpful to discuss further problems that will arise, even when the child is highly motivated (e.g. socialising; pain increase in school due to increased stress). All this should be discussed at the beginning of (outpatient and inpatient) pain treatment with the 'two-ways-intervention': 'You can either walk this difficult path and face school and your life irrespective of pain, stress and unpleasant emotions or you continue the path of pain chronification and the search for pain causes, avoiding any unpleasant emotion, and ending without graduation, without future, without prospects'. Needless to say, this intervention is not appropriate for children with depressive symptoms. If children agree to the active path, a graded exercise plan is installed with stress times, Stress Days and confrontation in addition to the standard pain treatment.

14.5 Pain Treatment in Children with Learning Disabilities or Intellectual Giftedness

If the patient's intelligence is out of the normal range, the pain-therapeutic approach has to be adapted.

14.5.1 Children with Chronic Pain and Learning Disabilities

In children with learning disabilities, the pain treatment programme should be modified as follows:

1. The lessons teaching theoretical knowledge or techniques are shortened. Each session is confined to just *one* topic.
2. Many affected children know by intuition that it is harder for them to grasp complex inter-relationships as quickly as their peers. This will evoke shame and insecurity with regard to theoretical content. Some of the children try to hide their weakness by not asking much or pretending that they did comprehend everything. But a basic understanding of the biopsychosocial model is necessary for pain treatment. Hence, it is very important to prompt these children to cooperate honestly. We have had good results when the therapist has humorously and self-ironically communicated any assumed insecurity or difficulty in understanding by the child as a sign of the therapist's lack of didactic capabilities. It may be worthwhile to try the following approach to check the child's comprehension: 'Sorry, I realise that I did not explain this very well and I just lost my thread. Could you please help me to resume the last topic by telling me what you have learned so far'?
3. We recommend asking the child to summarise the content of the crucial education sessions the way he/she understood the topic. If the child is able to write, this should also be done in children with learning disabilities. It is advisable to add 'in your own words'; 'just as you understood the education'; 'in keywords'; or 'as you like'.
4. In general, rather behavioural distraction strategies, simple distraction ABCs should be implemented. For many children, it is helpful to create a 'distraction box' that contains notes with pictograms or small sketches illustrating the different distraction strategies (e.g. 'animals' → for an ABC with animals; 'blue note' → search for ten blue things in the room; 'musical note' → listening to music …). Furthermore, a reinforcement schedule should be installed so that the children can collect rewards for using the distraction box.
5. Regarding education of the parents, it is particularly important that they understand how they can actively support their child in distraction. Children with learning disabilities usually need a structured setting and are frequently overstrained with active pain coping on their own.

14.5.2 Children with Chronic Pain and Intellectual Giftedness

An intellectually gifted child needs a lot of input and wants to be challenged (more or less consciously). Often, an intellectually gifted child judges an education that is below his/her competence level as an insult and does not feel taken seriously.

But even a highly gifted child with a high number of school days missed cannot know the missed subject matter. In addition, some intellectually gifted children tend to overrate their cognitive capabilities, and similar to their peers with learning disabilities, their feelings are easily hurt. Thus, the line between too few and too many demands is very narrow. The following conclusions are important for the educational process.

1. An intellectually gifted child needs more exercises or homework than other children.
2. An intellectually gifted child seems to love to scrutinise any existing structure. Yes, this could be very annoying. But this also gives the therapist the chance to modify pre-existing therapeutic methods and interventions for the better. One way could be to give the child the task to check the methods or interventions for any flaws, and to make any suggestions for improvement.
3. As with any child, the therapeutic process should be made as transparent as possible. The various options and interventions in the current as well as future therapeutic process should be addressed *early*. This will increase the amount of information to be exchanged, sometimes significantly stretching the appointments. But, at the end of treatment, many of our intellectually gifted patients explicitly tell us that they always felt they were taken seriously and integrated into the therapeutic process by this very approach, and were able to impact the course of treatment.
4. Cognitive treatment should particularly focus on identifying core beliefs.
5. For many intellectually gifted children, ‘being different’ is a big issue. They may either strive for normality/adaptation or are particularly proud of their otherness/specialty. Both strategies are dysfunctional and are usually accompanied by negative beliefs and a strong fear of criticism. It is useful to openly and directly address this issue and to take this opportunity to explore how the child deals with criticism.

14.6 Pain Treatment in Children with a Burdening Underlying Disease

> *Pain is always there. It is the worst if I sit in my wheelchair for too long—Christina (17 years), pain disorder and spina bifida*

Children with a severe underlying somatic disease (e.g. spina bifida; multiple sclerosis; dystrophic epidermolysis bullosa; Ehlers-Danlos syndrome; juvenile poly- or oligoarthitis; celiac disease; or Crohn's disease) or with permanent physical damage after severe accidents (e.g. paraplegia) are prone to developing a pain disorder. For most physicians and psychologists, this is difficult to detect. They see the primary disease and they know that it is often combined with pain. Severe pain in juvenile idiopathic arthritis, for example, indicates an inflammatory relapse and is regarded as an important diagnostic marker. A pain disorder is present and has to be diagnosed if the patient reports high pain intensity, shows typical pain behaviour, and is emotionally impaired, without the somatic disease being strongly active. At the time the patient presents at the paediatric outpatient pain clinic, pharmacological treatment has often already been escalated (corticosteroids; biologica; anti-inflammatory drugs) without any decrease in pain. Such a combination, with the disease activity not explaining the pain severity and pain-related impairment, hints at the presence of a pain disorder. In most cases pain-modulating psychosocial factors can be explored. To diagnose a pain disorder on top of an 'obvious' severe somatic disease is difficult not only for somatically focused physicians, but also for psychologists not familiar with the biopsychosocial model.

Children with chronic pain and a burdening underlying disease need a multiprofessional therapeutic team with good interdisciplinary cooperation.

Because there are a lot of potentially painful severe somatic diseases, we will confine our discussion to some important general pain-therapeutic principles.

14.6.1 Adaptation of Education

Many children suffering a severe underlying somatic disease have become used to medical examinations and inpatient stays over the years. Over and over the child and his/her parents have been queried for various somatic symptoms. Dependent on his/her specific diagnosis, the child will depend more on parental support than his/her peers. A significant part of his/her leisure time is sacrificed to disease-related matters. What does that mean for education?

1. *First*, these children and their parents are accustomed to both a very somatic approach and somatically-oriented disease models. Due to their proximity to at least one parent, these children rely very much on this parent for judgement of their physical symptoms; much more so than is age-appropriate. The resulting increased somatic focus and worries are presumably *normal* and *appropriate* considering the underlying disease, but they could make education extremely difficult. This specific feature should be openly addressed in the first family session to explore how much it applies to the respective child and family. The respectful and normalising discussion usually dispels fear of devaluation, so that many families openly talk about this issue. Mostly, parents are well aware of this, but just do not know how to behave differently, because they are afraid to do something wrong that could burden their child even more.

   With the background of emotional or physical burden of any severe underlying somatic disease, the therapist should appreciate the individual distressing experiences and the resources used for dealing with the disease. This is crucial for establishing a good therapeutic relationship. For most affected children it is a challenge to engage in pain treatment, leaving familiar diagnostics or medication behind.

This aspect is important to the child, but even more important when working with the parents. There is a high risk that at least one of the parents suffers depressive symptoms facing such challenging experiences. If there was ever a life-threatening event related to the child's underlying disease, one should bear in mind that the patient, the parents, or siblings might suffer PTSD. All these aspects should be considered in the family session, which is best done by directly asking for current sources of strength, worries and the degree of exhaustion. In so doing, the therapist will quickly gain an overview of the current burden and resources of the family. If the parents feel taken seriously with their coping strategies, they usually agree to readjust their behaviour as best they can.

2. *Second*, with regard to the complexity of the biological problem, it is important to address the brain's innate ability to inhibit pain during the education session. Due to the family's background in these cases, we choose a somatically oriented education programme. It may be helpful to use metaphors such as 'pain killers naturally produced in the brain' or 'integrated pain-inhibition system' meaning that the ability to distract ourselves from pain is intrinsic to the brain. Such a system may prove to be life-saving in case of danger (e.g. Stone Age: fighting a sabre-toothed tiger), or just beneficial (today: going to work or pursuing one's hobby in spite of injury). Thus, mental or social aspects of pain do not contradict physical ones but use the same biological systems that can also cause disease (Eippert et al. 2009). The child and his/her parents will be keen to know why pain inhibition does not work properly anymore. Before coming to the details, one should summarise the essentials.

> The more I focus on my body, the more I worry and the more I rest when pain emerges, the more cerebral pain inhibition is switched off. (Break). This is one of the main reasons why in many children suffering a severe painful disease, the risk of developing impairing chronic pain in addition to their acute pain increases with time. Let me explain this to you in more detail (now follow Sect. 8.3).

3. *Third*, it is important to distinguish between acute pain (e.g. due to a relapse in rheumatic disease) and chronic pain. With this differentiated education, we aim to instruct the patients to a more differentiated body awareness and appraisal. In the long run, this is the only way to allow them to distinguish pain signals indicating acute disease from those due to somatic sensitisation. Since this is a challenge to pain treatment, we will address in detail the specific aspect of a medically necessary body awareness in pain treatment in Sect. 14.6.3.

14.6.2 Striving for Independence and Autonomy with an Underlying Somatic Disease

The older the child, the more he/she wants to follow his/her own path, enforce his/her own will and use his/her own problem-solving strategies. Resulting conflicts are a normal part of growing up. But many children with a severe underlying somatic disease cannot readily walk this path. In the presence of further stress factors, especially in puberty, severe conflicts between the child and the family may emerge, making coping with the disease and pain treatment much more difficult. This will be illustrated in the following case report.

Jürgen (15 Years), Pain Disorder and Ehlers-Danlos Syndrome

> For many years, Jürgen has been medically treated due to various complications of his underlying disease. The last treatment was surgical stabilisation of his spine. Afterwards, Jürgen was able to cover short distances without a wheelchair again. In spite of this success, his family has been running on empty for some time now. Because of the increased nursing efforts, the many visits to the doctor, and Jürgen's various surgeries, his mother feels burned out. She always says 'The next crisis is just around the corner!' During the last couple of years, Jürgen has not learned to look after himself. Being intellectually gifted, he attends senior high school supported by an integration assistant. However, social contacts outside of school are rare because Jürgen's family lives in the countryside, and Jürgen would need transportation for every contact. Being severely handicapped, Jürgen cannot cover longer distances without his wheelchair. After school, Jürgen is often frustrated; this has been going on for several years already. According to his mother, this is due to Jürgen's lack of ability to proactively make social contacts. She has always tried to help him but that is something he does not want to talk about. There are continuous conflicts between Jürgen and the rest of the family instead, as all family members agree. Meanwhile, Jürgen refuses to practice his essential physical therapy exercises or to actively improve his situation. He would prefer to sit in his wheelchair and let someone push him. This is, however, causing his physical symptoms to deteriorate. Now the parents are too exhausted to enforce their will. As his mother told us, resignation is spreading across the family. Hence his parents restrict their contact to Jürgen to a minimum. Jürgen retreats more and more to his room. With his exaggerated and worrying body awareness, he focuses on numerous somatic processes and has been repeatedly admitted into an inpatient clinic for diagnostics of unclear complaints. The association between the frequency and intensity of his complaints and regular school attendance is obvious to the family.

Such conflicts are not necessarily that severe. This example illustrates how increasing parental exhaustion, learned passivity, medically indicated increased body awareness, physical disability, low social competence, resulting psychological problems and difficulties in school merge to a vicious cycle in which no way out is obvious.

Certainly, there is no panacea. On the contrary, especially in the family sessions with the physician or the therapist, substantial conversational skills as well as knowledge of systemic relationships are needed in order to create the prerequisites for successful treatment. In such a situation, the first step is to address the parents' burden and exhaustion and to appreciate their efforts during the long course of the disease. The next step is to check if any family member still believes in a change for the better. Then, the family members should briefly record what they could contribute to an improvement of the situation. Those family members who are no longer confident should write down an alternative solution for the family. If they are unable to find one, we address the solution of boarding schools or other types of accommodation outside the family. Certainly, such a family session is emotionally quite stressful. But it will make the resources present, or those lacking, obvious. Do not forget to ask the child in an individual session the same questions, guaranteeing professional confidentiality. With Jürgen, it became obvious that a boarding school would be the best possible trade-off. The reader should be aware that any solution based on accommodation outside of the family can usually only be put into practice together with the respective youth welfare office. With the widespread shortage of money, it requires a good argument to get a financial subsidy for external accommodation. During the family session, the therapist should try to convince the family to ask for the clinic's social worker's support to set up the respective application.

14.6.3 'Double-Entry Accounting': Blessing and Curse of Body Awareness

Due to the unpredictable course of most severe underlying somatic diseases, it is medically important for the children to pay attention to certain physical symptoms that indicate a relapse or increased disease activity. This is a matter of survival. But the increased body awareness is the largest obstacle for successful pain treatment. Given the great variety of somatic disorders or complications, each patient has to find their own way to manage body awareness according to their own and their family's resources and accompanying stress factors.

A successful way will provide the answers to the following six questions:

1. Did I understand that I can influence pain perception (both acute and chronic)?
2. How can I distinguish disease-related acute pain from chronic pain?
3. To what degree am I ready to work actively and autonomously to improve my pain and my situation?
4. Which strategies can I use for acute or chronic pain?
5. How can I contribute to the de-escalation of family problems?
6. What is the plan for after my stay on the ward (or after treatment has finished)? What can I contribute to making my success last? Where do I need support? Who will support me?

14.6.4 Considering Painful Medical Procedures

It goes without saying that chronically ill children—as any child—should be supported in their coping with painful medical procedures. Unfortunately, adolescents are often treated in hospitals for adults where they and their parents are confronted with phrases such as 'This doesn't hurt. Don't make such a fuss'; or 'The way your child is acting, there must be another underlying problem'. Painful medical procedures, especially those not sufficiently supported, will contribute to an aggravation of a pain disorder because they provoke helplessness and fear, and often trigger any pre-existing traumatic memories. Both will result in increased tension.

Quite often, children report that they experience painful medical procedures as so stressful that symptoms similar to PTSD arise, including flashbacks of procedures perceived as particularly horrible. This is devastating for pain chronification.

In order to render the necessary medical procedures as gentle as possible, the therapist, the NET and the child should jointly set up a graded exercise plan with the last step being the very procedure perceived as especially stressful (e.g. lumbar puncture). According to the model of systematic desensitisation, the steps preceding the last one should gradually make the child familiar with the medical procedure, thus reducing anxiety. Simultaneously, a detailed plan should be set up to schedule at what point the child should practice which helpful technique (mostly distraction techniques, imaginative techniques, or distraction with the help of a smartphone).

14.6.5 Coping with Pain and Future Prospects

Treated adequately, most children with a pain disorder will face quite a normal life with all its common challenges. Children with a severe underlying somatic disease resulting in permanent handicap (e.g. spina bifida) or advancing impairment of quality of life (e.g. multiple sclerosis) are facing a much bigger challenge: typically, they perceive fear, insecurity, resignation or despair. In some children such an emotional challenge is more than they can handle. As a consequence, they may develop dysfunctional coping strategies regarding their thinking and acting, which could be diagnosed as an adjustment disorder. The dysfunctional appraisal of somatic processes, as well as stressful, but quite realistic, future prospects result in increased tension. This increase in internal and external tension contributes to pain amplification and chronification.

The patient's task is to develop an attitude of acceptance towards the underlying disease. The aims for therapy and life need to be adapted to their individual possibilities.

This is often of significance not only to the patient but also to his/her parents. At the beginning of pain treatment, the Three Letters (Sect. 9.3; Chap. 15, worksheet #16) and projective questionnaires (Sect. 3.3.3) are well-suited to gaining an overview of the current state of acceptance of the disease. Furthermore, the therapist will get information about the resources currently available. This gives an idea of how to best support the patient with his/her disease coping. Sometimes, an increased acceptance of the disease and a more realistic future prospect contribute to successful pain treatment, due to the concomitant emotional relief and improved ability to regulate stress and emotions.

14.7 Contraindications for Pain Treatment

Contraindications of paediatric pain treatment have so far not been investigated. We believe that one should be cautious with the usage of pain-therapeutic methods in children with anorexia nervosa, psychotic symptoms, severe depressive symptoms, or pronounced self-harm beyond control. While contraindication for severe depressive symptoms directly arises from the symptoms, further details are provided for contraindication with regard to anorexia nervosa, psychotic symptoms and self-harm.

14.7.1 Children with a Pain Disorder and Concomitant Anorexia Nervosa

In our past experience, pain treatment as described in this manual was not successful in children with not yet sufficiently treated concomitant anorexia nervosa, even if bodyweight had stabilised for some time. Extremely increased body awareness and distorted body perception are two of the main symptoms of anorexia nervosa. Both cannot be influenced in the context of pain treatment and will lead to increased pain perception. A sufficient and successful treatment of anorexia nervosa seems to be a prerequisite for successful pain treatment.

14.7.2 Children with a Pain Disorder and Psychotic Symptoms

Generally, it is possible that children with chronic pain and concomitant psychotic symptoms (e.g. a mild schizotypal disorder) will benefit from some pain-therapeutic methods. Psychotic disorders may be accompanied by disturbed attention, vigilance or thinking. Additionally, there may be unpredictable fears along with very high mental and muscle tension. Thus, we urge not using imaginative techniques or those based on altering thoughts (e.g. ‘Colourful Thoughts’; ‘Black Thoughts’) or relaxation (e.g. autogenic training; PMR). It goes without saying that these methods are absolutely contraindicated during an active episode of psychosis. However, a very experienced therapist might apply more simple variants of distraction techniques or acceptance-based techniques to improve the patient’s situation during the course of inpatient psychiatric treatment. Recent therapeutic approaches favour the implementation of metacognitive strategies. In some male adolescents with mild schizotypal symptoms we were able to achieve a slight improvement of the pain with such techniques.

14.7.3 Children with a Pain Disorder and Self-Harm

A primary pain treatment is usually not possible for children with a pronounced tendency towards self-harm. Self-harm is an extreme form of problem-solving, resulting from a lack of other strategies for emotion regulation (to punish oneself for one’s behaviour, to prevent flashbacks, or to reduce unbearable inner tension). Thus, reasons for self-harm need to be explored first, and alternative behaviour needs to be established. Otherwise, pain treatment will only increase the pressure for self-harm due to its confrontational nature and resulting stress and tension.

For some children, who do not regularly and not deeply harm themselves, pain treatment may be useful. The prerequisite is that these children are sufficiently motivated to discuss the reasons for self-harm and to establish alternative actions. The therapist has to point out that pain can only be changed, if he/she sufficiently understands the reasons for self-harm. In many cases, we were able to explore previously tabooed traumatic events in the inpatient setting, to stabilise these children and discharge them into a suitable outpatient or inpatient treatment. For children who hurt themselves as a form of punishment, and children who hurt themselves to reduce inner tension or feelings of emptiness, initially, a treatment of these symptoms and not primarily pain treatment, is indicated.

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Practical Tools and Worksheets

15

Julia Wager, Michael Dobe, and Boris Zernikow

Abstract

The following pages present some practical tools, the most important instructions for their use, and several worksheets used in our education.

The first six worksheets comprise three questionnaires for the assessment of resources and to get to know each other, two questionnaires on special resources and stress factors, and a projective questionnaire.

1. Everything I judge as good
2. Everything I judge as bad
3. The five best events, the five worst events
4. Three things that should change soon
5. ‘Wanted’ poster
6. Complete the sentences

The next 11 worksheets depict charts for psycho-education and instructions for certain therapeutic interventions.

7. Distraction ABC
8. “54321” technique for children and adolescents
9. Chart: Distraction from pain
10. Chart: The Vicious Cycle of Pain
11. Describe your Safe Place
12. Observation sheet for distraction strategies
13. Example of a Stress Day

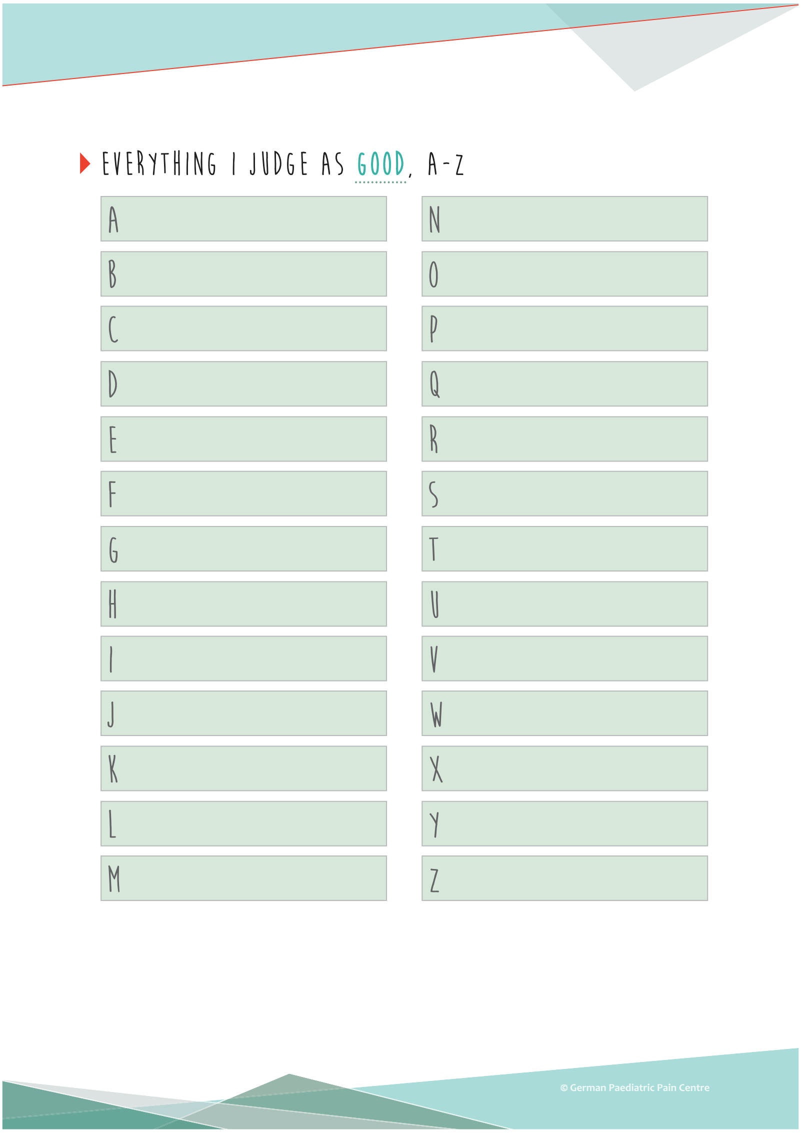
J. Wager (✉) · M. Dobe · B. Zernikow
German Paediatric Pain Centre, Children’s and Adolescents’ Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: j.wager@deutsches-kinderschmerzzentrum.de; M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_15

14. List of pleasant activities
15. “That's Me” poster
16. The “Three Letters”
17. Pain provocation

The last three worksheets refer to family interventions (Stress Test, parent’s observation on the ward).

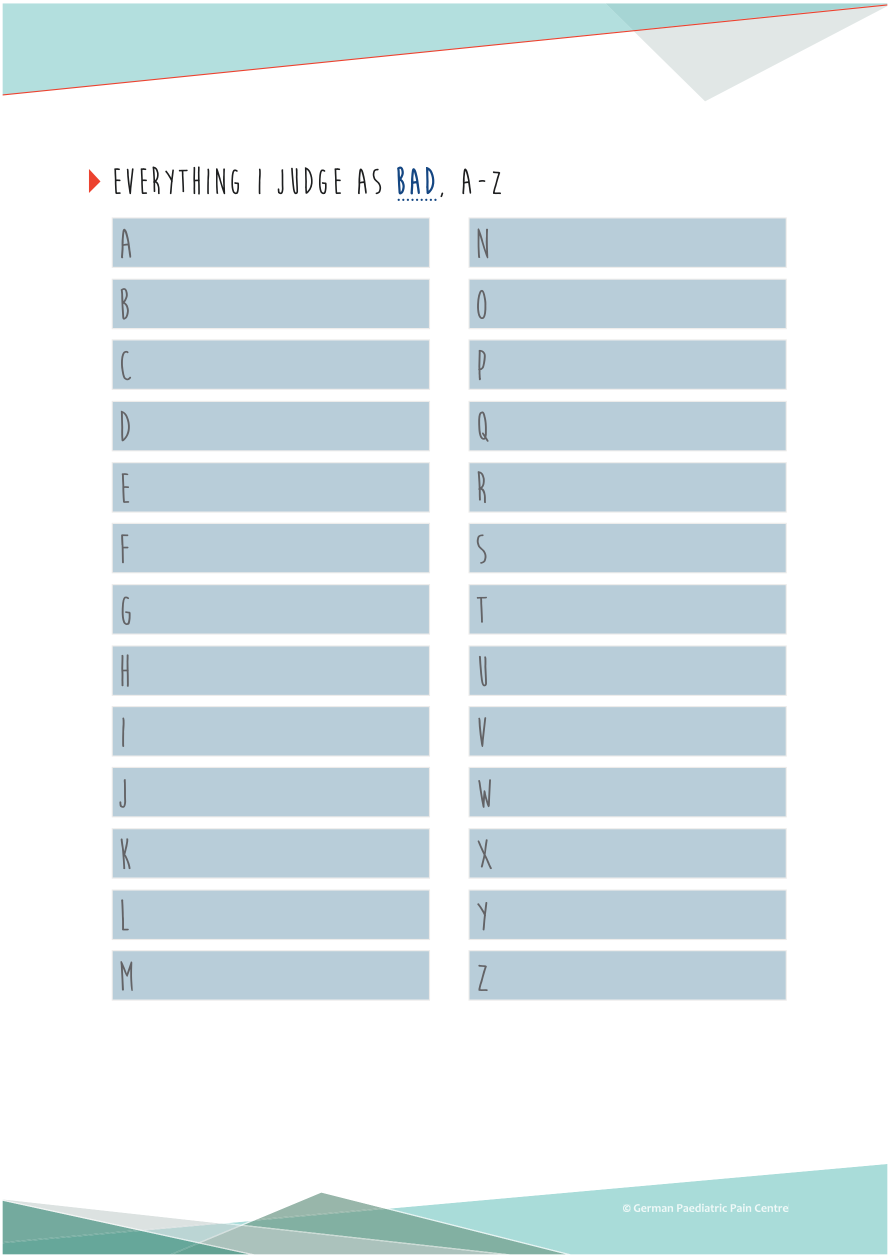
18. Weekend observation sheet: Stress Test
19. Parent’s observation on the ward
20. Parent’s observation on the ward—Reflection



EVERYTHING I JUDGE AS GOOD, A-Z

A
B
C
D
E
F
G
H
I
J
K
L
M
N
O
P
Q
R
S
T
U
V
W
X
Y
Z

Worksheet #1. Everything I judge as good



EVERYTHING I JUDGE AS BAD, A-Z

A
B
C
D
E
F
G
H
I
J
K
L
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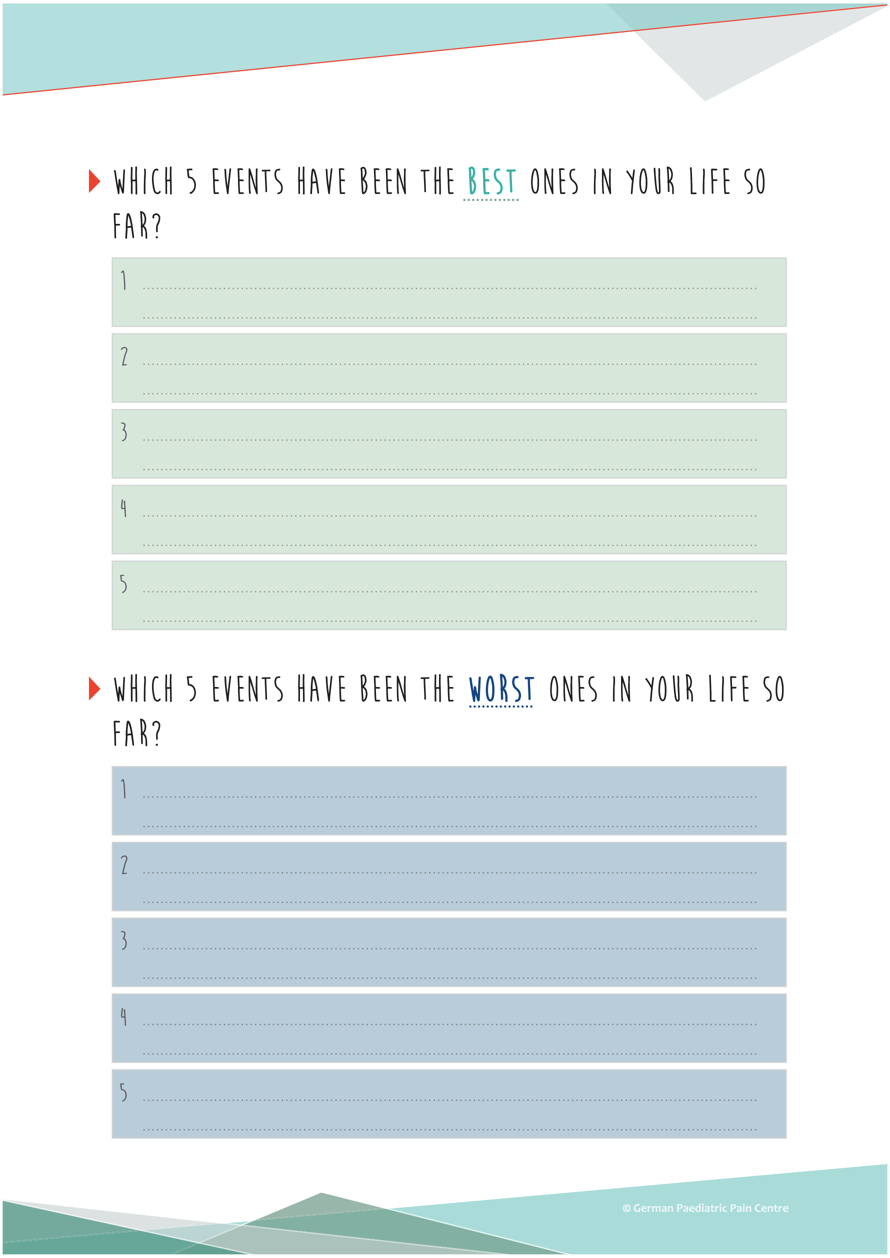
V
W
X
Y
Z

Worksheet #2. Everything I judge as bad



WHICH 5 EVENTS HAVE BEEN THE BEST ONES IN YOUR LIFE SO FAR?

1 ……………………………………………………

2 ……………………………………………………

3 ……………………………………………………

4 ……………………………………………………

5 ……………………………………………………

WHICH 5 EVENTS HAVE BEEN THE WORST ONES IN YOUR LIFE SO FAR?

1 ……………………………………………………

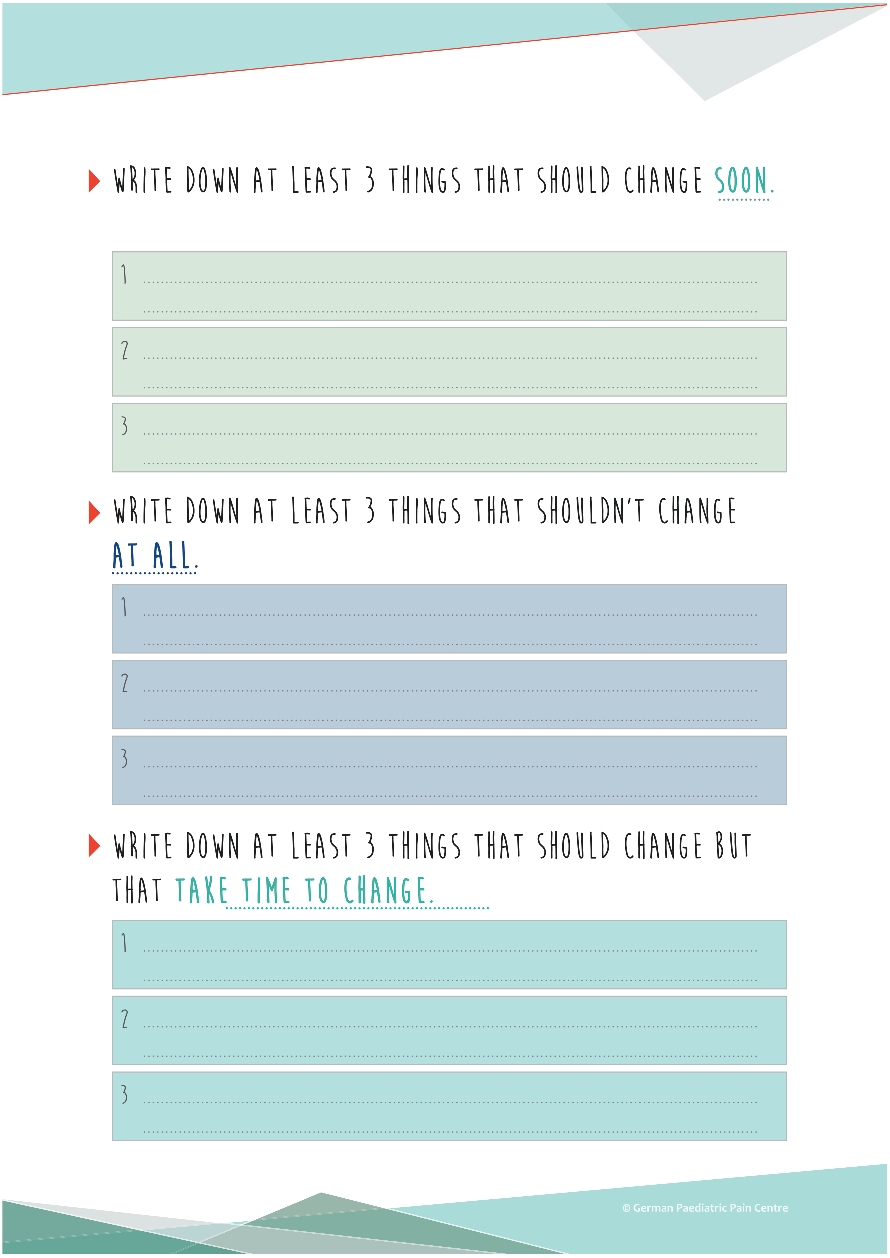
2 ……………………………………………………

3 ……………………………………………………

4 ……………………………………………………

5 ……………………………………………………

Worksheet #3. The five best events, the five worst events



- WRITE DOWN AT LEAST 3 THINGS THAT SHOULD CHANGE SOON.

1 ....

....

2 ....

....

3 ....

....

- WRITE DOWN AT LEAST 3 THINGS THAT SHOULDN'T CHANGE AT ALL.

1 ....

....

2 ....

....

3 ....

....

- WRITE DOWN AT LEAST 3 THINGS THAT SHOULD CHANGE BUT THAT TAKE TIME TO CHANGE.

1 ....

....

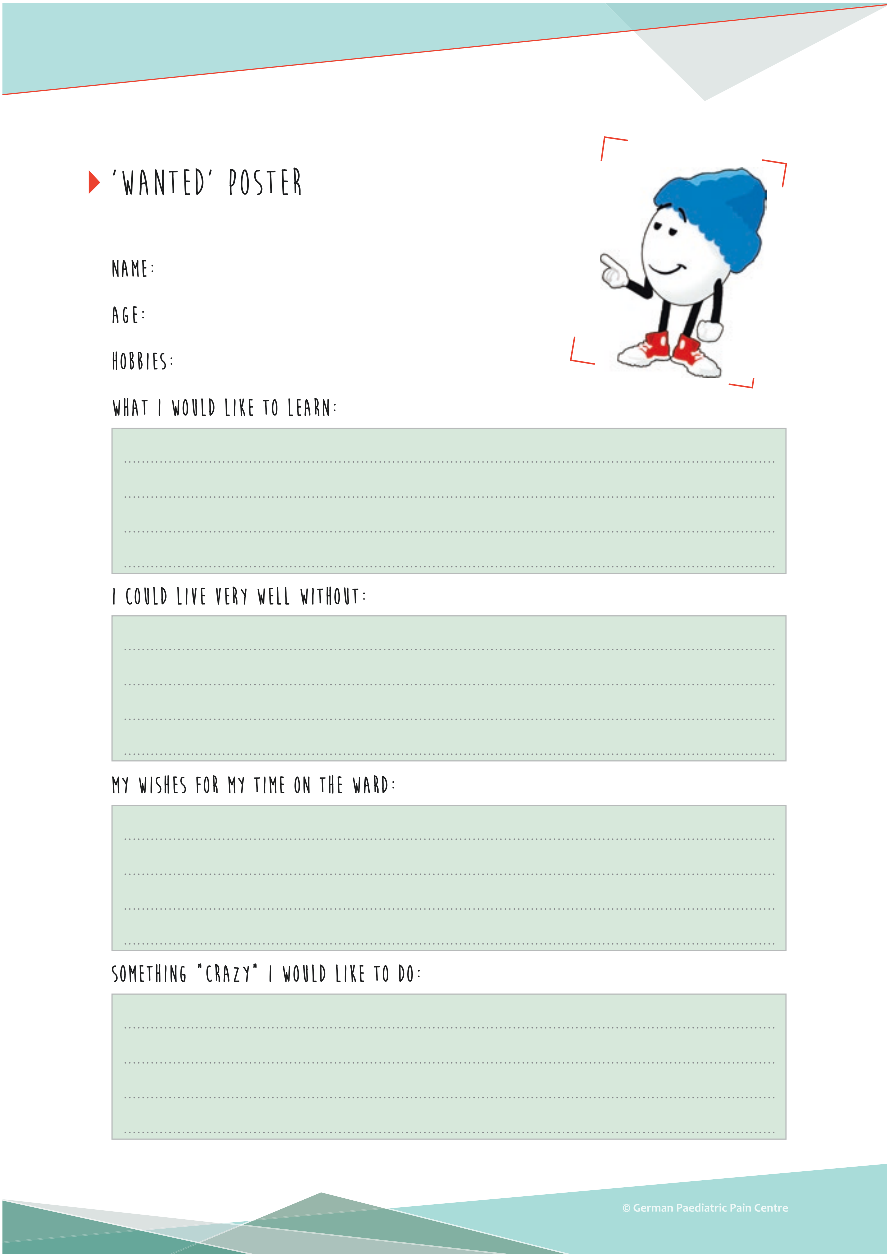
2 ....

....

3 ....

....

Worksheet #4. Three things that should change soon



‘WANTED’ POSTER

NAME:

AGE:

HOBBIES:

WHAT I WOULD LIKE TO LEARN:

I COULD LIVE VERY WELL WITHOUT:

MY WISHES FOR MY TIME ON THE WARD:

SOMETHING "CRAZY" I WOULD LIKE TO DO:

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Worksheet #5. ‘Wanted’ poster

Name: .... Test Supervisor: .... Date: ....

PLEASE COMPLETE THE FOLLOWING SENTENCES:

1. GOING TO SCHOOL IS ....
2. WHEN I AM GROWN UP I'D LIKE TO ....
3. MY FATHER IS ....
4. THE BEST THING I KNOW ....
5. I OFTEN DREAM ABOUT ....
6. HAVING BROTHERS AND/OR SISTERS ....
7. THE PERSON MAKING DECISIONS WITHIN OUR FAMILY ....
8. IT IS AWFUL IF ....
9. THE ONLY THING I REALLY FEAR ....
10. I ENJOY ....
11. MY MOTHER IS ....
12. I'D LIKE MY FATHER TO ....
13. IN MY OPINION, MY TEACHER ....
14. MY CLASSMATES ....
15. THE PERSON PREFERRED IN OUR FAMILY ....
16. MY FATHER IS PROBABLY THINKING THAT I ....
17. I THINK MY PAIN ....
18. IF I DON'T OBEY ....

Worksheet #6. Complete the sentences

19. IF I COULD MAKE DECISIONS AT HOME ....

20. MY MOTHER IS PROBABLY THINKING THAT I ....

21. WHAT I DON'T LIKE AT ALL IS ....

22. IT IS DISGUSTING WHEN ....

23. WHAT I LIKE DOING MOST IS ....

24. I GET SAD IF ....

25. THE OTHER BOYS/GIRLS PROBABLY THINK I ....

26. THE WORST THING I KNOW ....

27. I WISH MY MOTHER ....

28. IF I COULD CHANGE MYSELF THEN ....

29. IF I HAD 100 EUROS THEN ....

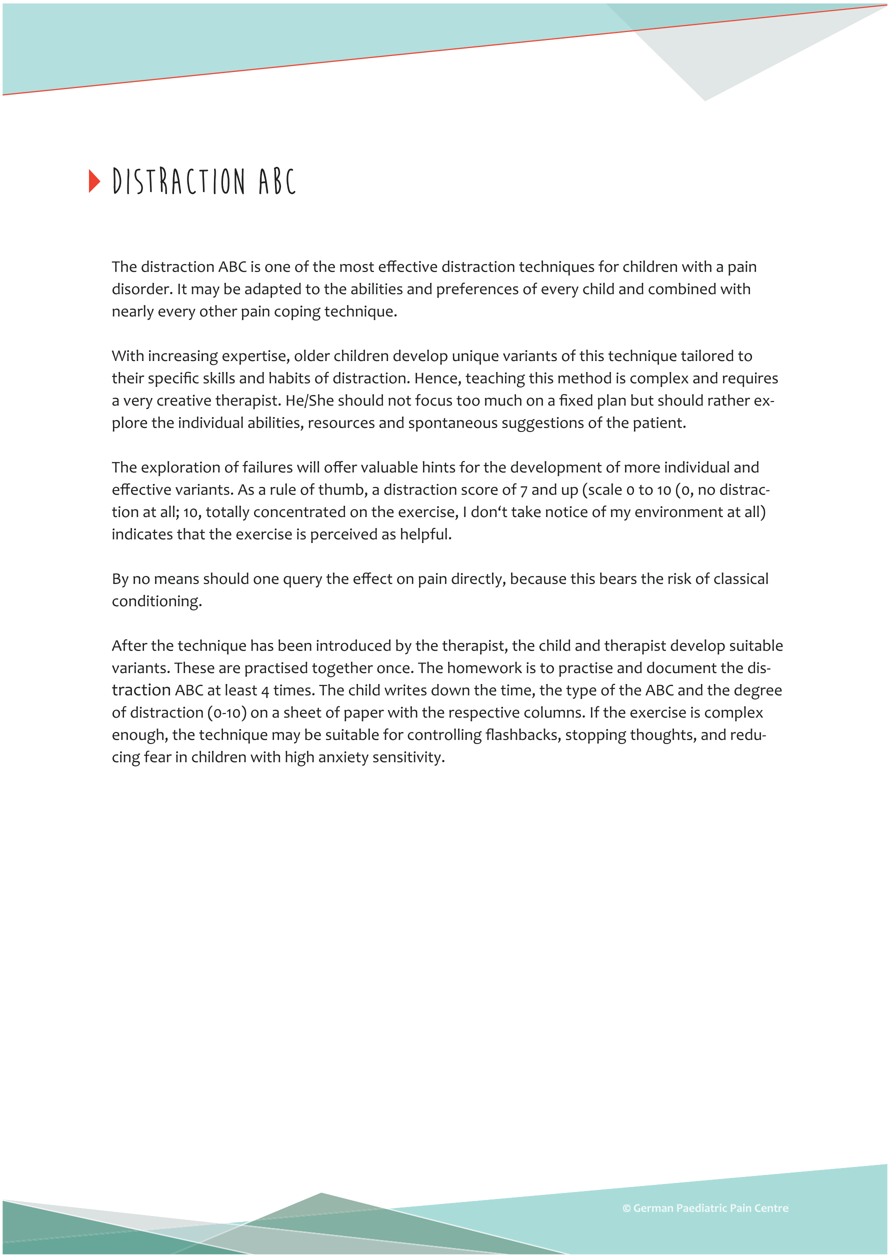
30. IF I HAD 3 WISHES ....
    1ST WISH ....
    2ND WISH ....
    3RD WISH ....

31. WHICH ANIMAL WOULD YOU LIKE TO BE? ....
    WHY? ....

32. WHICH ANIMAL WOULD YOU NOT LIKE TO BE? ....
    WHY? ....

33. WHAT TYPE OF WORK WOULD YOU LIKE TO DO? ....
    WHY? ....

Worksheet #6. (continued)



DISTRACTION ABC

The distraction ABC is one of the most effective distraction techniques for children with a pain disorder. It may be adapted to the abilities and preferences of every child and combined with nearly every other pain coping technique.

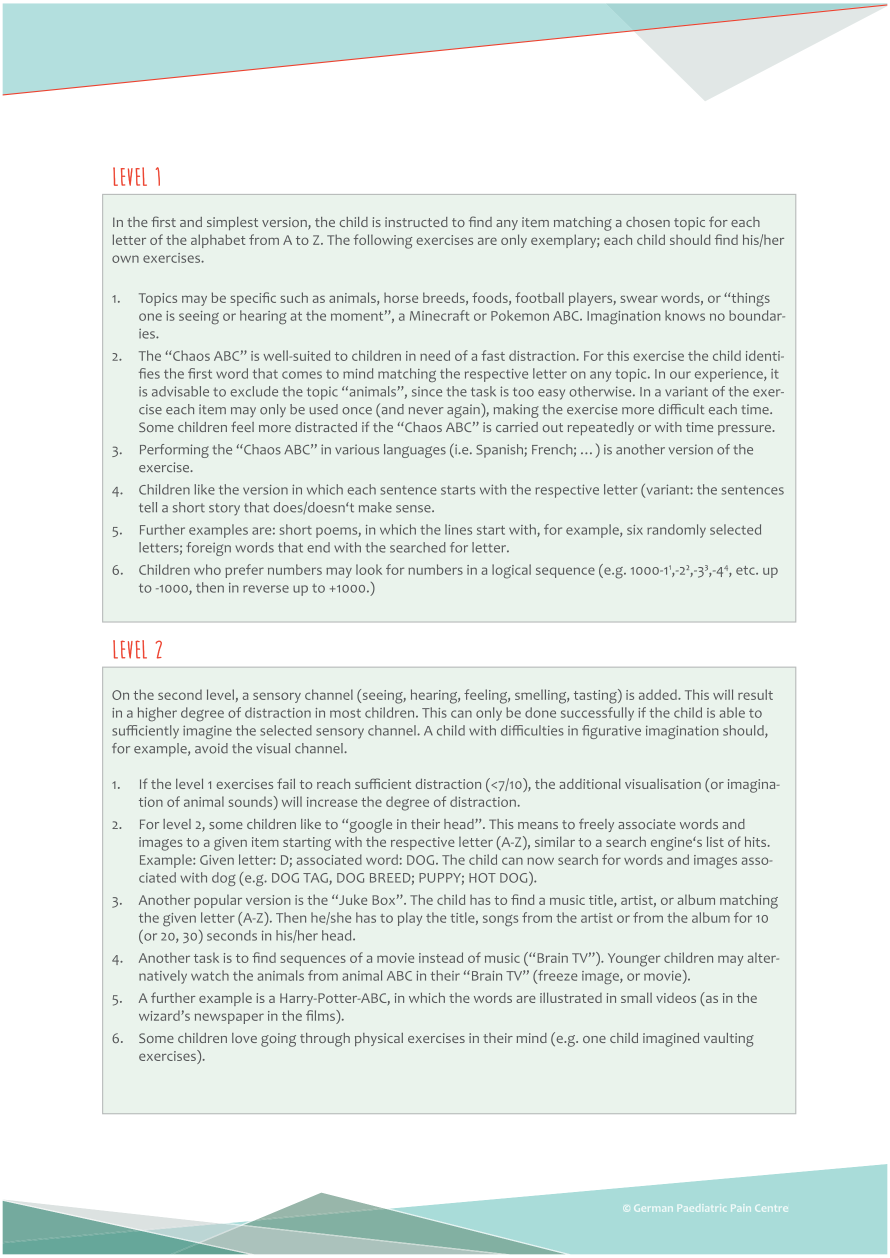
With increasing expertise, older children develop unique variants of this technique tailored to their specific skills and habits of distraction. Hence, teaching this method is complex and requires a very creative therapist. He/She should not focus too much on a fixed plan but should rather explore the individual abilities, resources and spontaneous suggestions of the patient.

The exploration of failures will offer valuable hints for the development of more individual and effective variants. As a rule of thumb, a distraction score of 7 and up (scale 0 to 10 (0, no distraction at all; 10, totally concentrated on the exercise, I don‘t take notice of my environment at all) indicates that the exercise is perceived as helpful.

By no means should one query the effect on pain directly, because this bears the risk of classical conditioning.

After the technique has been introduced by the therapist, the child and therapist develop suitable variants. These are practised together once. The homework is to practise and document the distraction ABC at least 4 times. The child writes down the time, the type of the ABC and the degree of distraction (0-10) on a sheet of paper with the respective columns. If the exercise is complex enough, the technique may be suitable for controlling flashbacks, stopping thoughts, and reducing fear in children with high anxiety sensitivity.

Worksheet #7. Distraction ABC



LEVEL 1

In the first and simplest version, the child is instructed to find any item matching a chosen topic for each letter of the alphabet from A to Z. The following exercises are only exemplary; each child should find his/her own exercises.

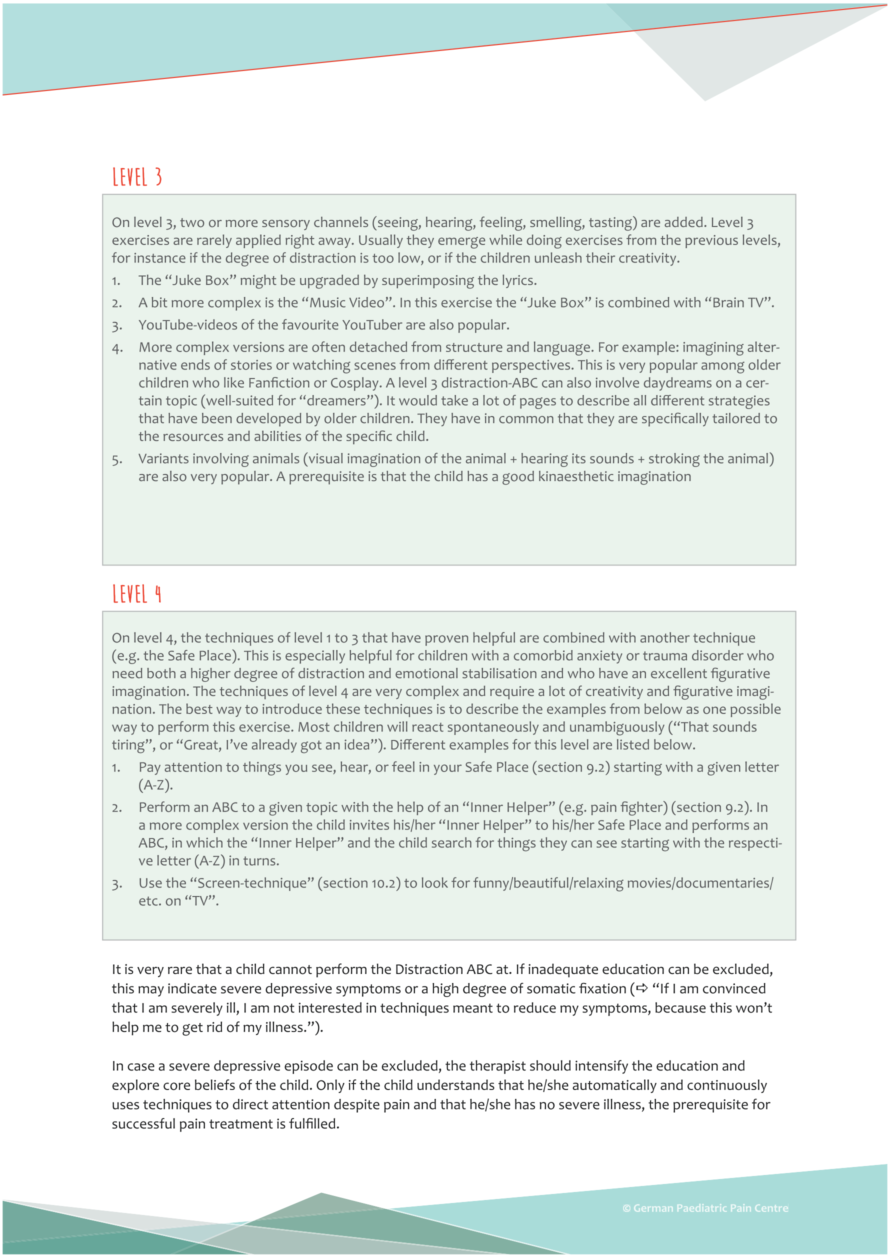
1. Topics may be specific such as animals, horse breeds, foods, football players, swear words, or "things one is seeing or hearing at the moment", a Minecraft or Pokemon ABC. Imagination knows no boundaries.
2. The "Chaos ABC" is well-suited to children in need of a fast distraction. For this exercise the child identifies the first word that comes to mind matching the respective letter on any topic. In our experience, it is advisable to exclude the topic "animals", since the task is too easy otherwise. In a variant of the exercise each item may only be used once (and never again), making the exercise more difficult each time. Some children feel more distracted if the "Chaos ABC" is carried out repeatedly or with time pressure.
3. Performing the "Chaos ABC" in various languages (i.e. Spanish; French; …) is another version of the exercise.
4. Children like the version in which each sentence starts with the respective letter (variant: the sentences tell a short story that does/doesn't make sense.
5. Further examples are: short poems, in which the lines start with, for example, six randomly selected letters; foreign words that end with the searched for letter.
6. Children who prefer numbers may look for numbers in a logical sequence (e.g. $1000-1^1,-2^2,-3^3,-4^4$, etc. up to -1000, then in reverse up to +1000.)

LEVEL 2

On the second level, a sensory channel (seeing, hearing, feeling, smelling, tasting) is added. This will result in a higher degree of distraction in most children. This can only be done successfully if the child is able to sufficiently imagine the selected sensory channel. A child with difficulties in figurative imagination should, for example, avoid the visual channel.

1. If the level 1 exercises fail to reach sufficient distraction (<7/10), the additional visualisation (or imagination of animal sounds) will increase the degree of distraction.
2. For level 2, some children like to "google in their head". This means to freely associate words and images to a given item starting with the respective letter (A-Z), similar to a search engine's list of hits. Example: Given letter: D; associated word: DOG. The child can now search for words and images associated with dog (e.g. DOG TAG, DOG BREED; PUPPY; HOT DOG).
3. Another popular version is the "Juke Box". The child has to find a music title, artist, or album matching the given letter (A-Z). Then he/she has to play the title, songs from the artist or from the album for 10 (or 20, 30) seconds in his/her head.
4. Another task is to find sequences of a movie instead of music ("Brain TV"). Younger children may alternatively watch the animals from animal ABC in their "Brain TV" (freeze image, or movie).
5. A further example is a Harry-Potter-ABC, in which the words are illustrated in small videos (as in the wizard's newspaper in the films).
6. Some children love going through physical exercises in their mind (e.g. one child imagined vaulting exercises).

Worksheet #7. (continued)



LEVEL 3

On level 3, two or more sensory channels (seeing, hearing, feeling, smelling, tasting) are added. Level 3 exercises are rarely applied right away. Usually they emerge while doing exercises from the previous levels, for instance if the degree of distraction is too low, or if the children unleash their creativity.

1. The "Juke Box" might be upgraded by superimposing the lyrics.
2. A bit more complex is the "Music Video". In this exercise the "Juke Box" is combined with "Brain TV".
3. YouTube-videos of the favourite YouTuber are also popular.
4. More complex versions are often detached from structure and language. For example: imagining alternative ends of stories or watching scenes from different perspectives. This is very popular among older children who like Fanfiction or Cosplay. A level 3 distraction-ABC can also involve daydreams on a certain topic (well-suited for "dreamers"). It would take a lot of pages to describe all different strategies that have been developed by older children. They have in common that they are specifically tailored to the resources and abilities of the specific child.
5. Variants involving animals (visual imagination of the animal + hearing its sounds + stroking the animal) are also very popular. A prerequisite is that the child has a good kinaesthetic imagination

LEVEL 4

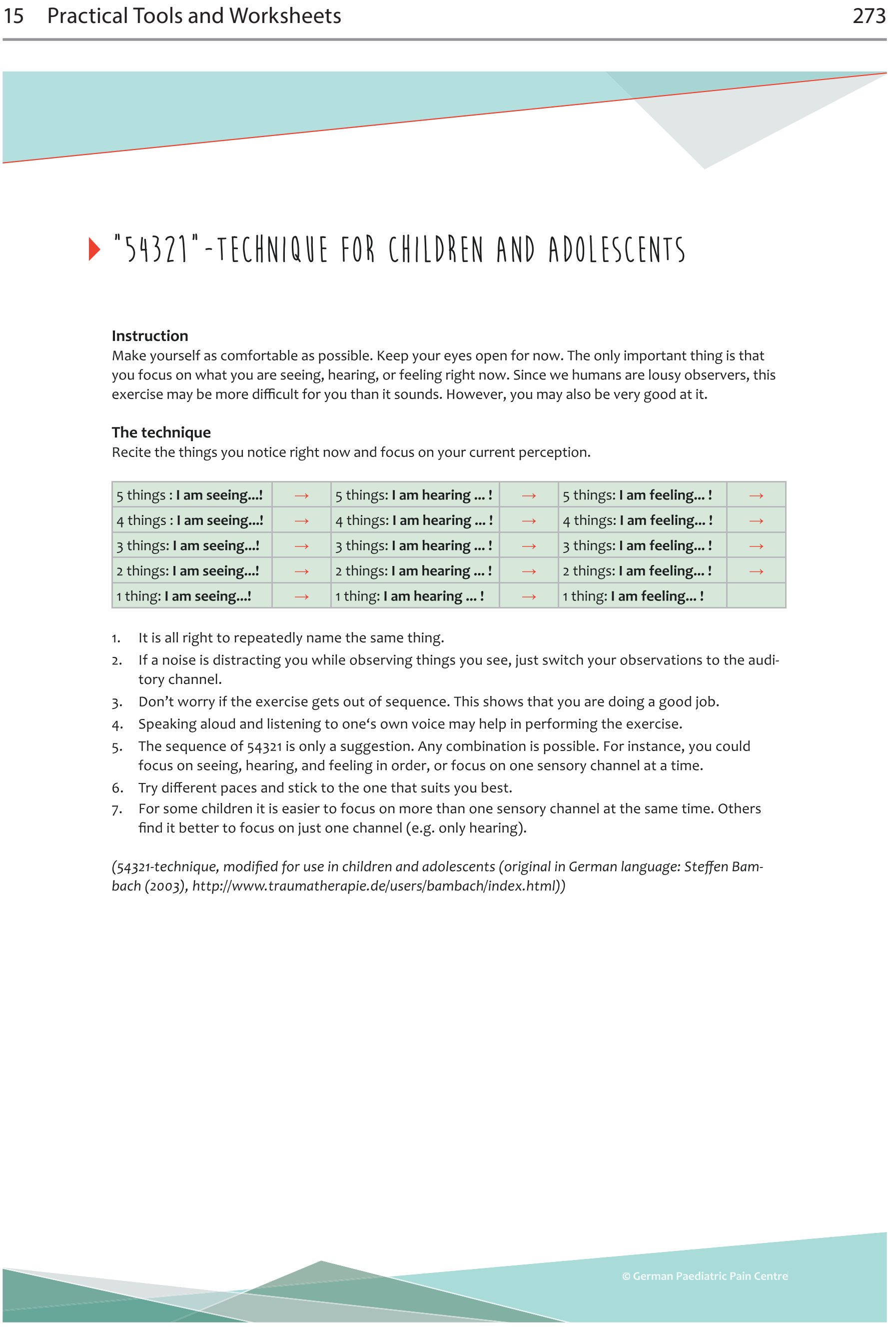
On level 4, the techniques of level 1 to 3 that have proven helpful are combined with another technique (e.g. the Safe Place). This is especially helpful for children with a comorbid anxiety or trauma disorder who need both a higher degree of distraction and emotional stabilisation and who have an excellent figurative imagination. The techniques of level 4 are very complex and require a lot of creativity and figurative imagination. The best way to introduce these techniques is to describe the examples from below as one possible way to perform this exercise. Most children will react spontaneously and unambiguously ("That sounds tiring", or "Great, I've already got an idea"). Different examples for this level are listed below.

1. Pay attention to things you see, hear, or feel in your Safe Place (section 9.2) starting with a given letter (A-Z).
2. Perform an ABC to a given topic with the help of an "Inner Helper" (e.g. pain fighter) (section 9.2). In a more complex version the child invites his/her "Inner Helper" to his/her Safe Place and performs an ABC, in which the "Inner Helper" and the child search for things they can see starting with the respective letter (A-Z) in turns.
3. Use the "Screen-technique" (section 10.2) to look for funny/beautiful/relaxing movies/documentaries/etc. on "TV".

It is very rare that a child cannot perform the Distraction ABC at. If inadequate education can be excluded, this may indicate severe depressive symptoms or a high degree of somatic fixation (➪ "If I am convinced that I am severely ill, I am not interested in techniques meant to reduce my symptoms, because this won't help me to get rid of my illness.").

In case a severe depressive episode can be excluded, the therapist should intensify the education and explore core beliefs of the child. Only if the child understands that he/she automatically and continuously uses techniques to direct attention despite pain and that he/she has no severe illness, the prerequisite for successful pain treatment is fulfilled.

Worksheet #7. (continued)



"54321"-TECHNIQUE FOR CHILDREN AND ADOLESCENTS

Instruction
Make yourself as comfortable as possible. Keep your eyes open for now. The only important thing is that you focus on what you are seeing, hearing, or feeling right now. Since we humans are lousy observers, this exercise may be more difficult for you than it sounds. However, you may also be very good at it.

The technique
Recite the things you notice right now and focus on your current perception.

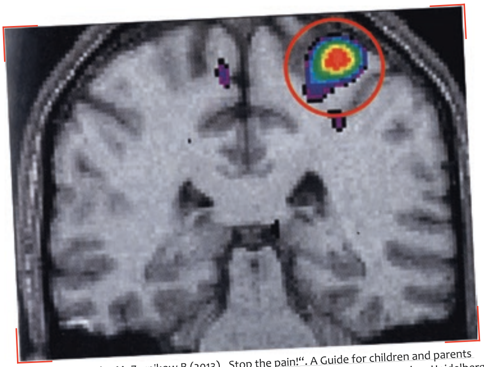
5 things : **I am seeing...!**	→	5 things: **I am hearing ... !**	→	5 things: **I am feeling... !**	→
4 things : **I am seeing...!**	→	4 things: **I am hearing ... !**	→	4 things: **I am feeling... !**	→
3 things: **I am seeing...!**	→	3 things: **I am hearing ... !**	→	3 things: **I am feeling... !**	→
2 things: **I am seeing...!**	→	2 things: **I am hearing ... !**	→	2 things: **I am feeling... !**	→
1 thing: **I am seeing...!**	→	1 thing: **I am hearing ... !**	→	1 thing: **I am feeling... !**	

1. It is all right to repeatedly name the same thing.
2. If a noise is distracting you while observing things you see, just switch your observations to the auditory channel.
3. Don't worry if the exercise gets out of sequence. This shows that you are doing a good job.
4. Speaking aloud and listening to one's own voice may help in performing the exercise.
5. The sequence of 54321 is only a suggestion. Any combination is possible. For instance, you could focus on seeing, hearing, and feeling in order, or focus on one sensory channel at a time.
6. Try different paces and stick to the one that suits you best.
7. For some children it is easier to focus on more than one sensory channel at the same time. Others find it better to focus on just one channel (e.g. only hearing).

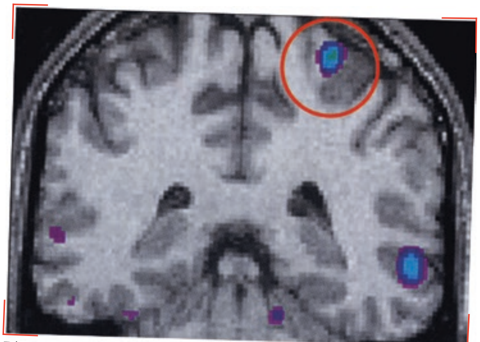
(54321-technique, modified for use in children and adolescents (original in German language: Steffen Bambach (2003), http://www.traumatherapie.de/users/bambach/index.html))

Worksheet #8. "54321" technique for children and adolescents

DISTRACTION FROM PAIN



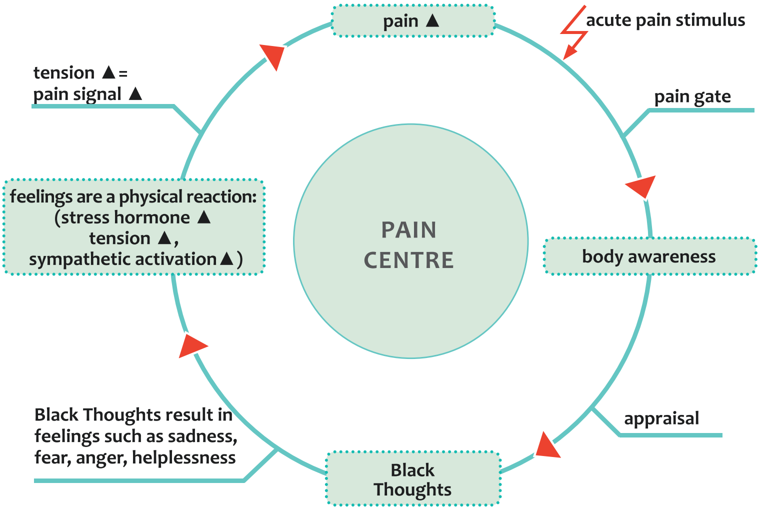
Taken from: Dobe M, Zernikow B (2013) „Stop the pain!“. A Guide for children and parents to understanding and escaping the vicious cycle of chronic pain. Carl-Auer-Verlag, Heidelberg .Printed with permission (modified after Bushnell et al., 1999).



Taken from: Dobe M, Zernikow B (2013) „Stop the pain!“. A Guide for children and parents to understanding and escaping the vicious cycle of chronic pain. Carl-Auer-Verlag, Heidelberg . Printed with permission (modified after Bushnell et al., 1999).

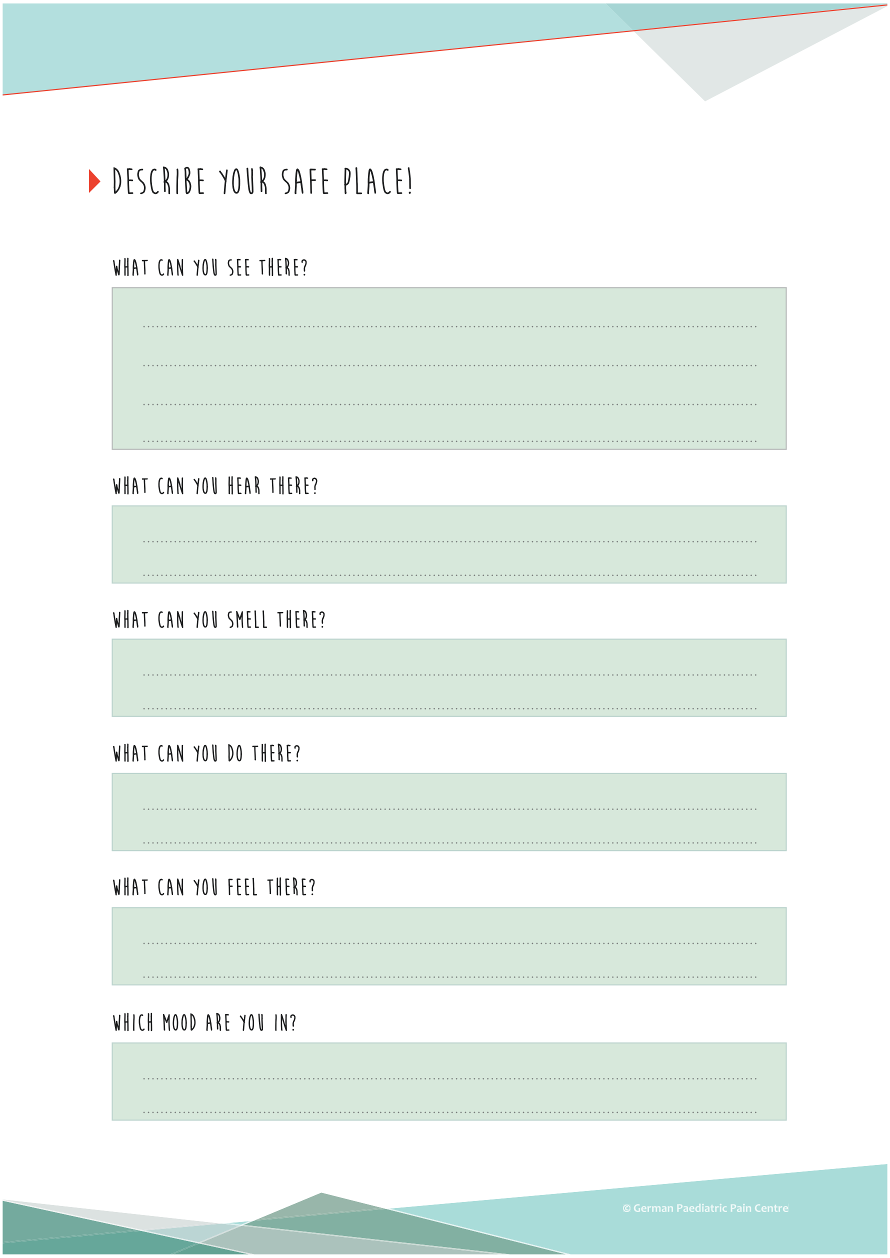
Worksheet #9. Chart: Distraction from pain

THE VICIOUS CYCLE OF PAIN



Modified from: Dobe M, Zernikow B (2013) „Stop the pain!“. A Guide for children and parents to understanding and escaping the vicious cycle of chronic pain. Carl-Auer-Verlag, Heidelberg . Printed with permission

Worksheet #10. Chart: The Vicious Cycle of Pain



DESCRIBE YOUR SAFE PLACE!

WHAT CAN YOU SEE THERE?

WHAT CAN YOU HEAR THERE?

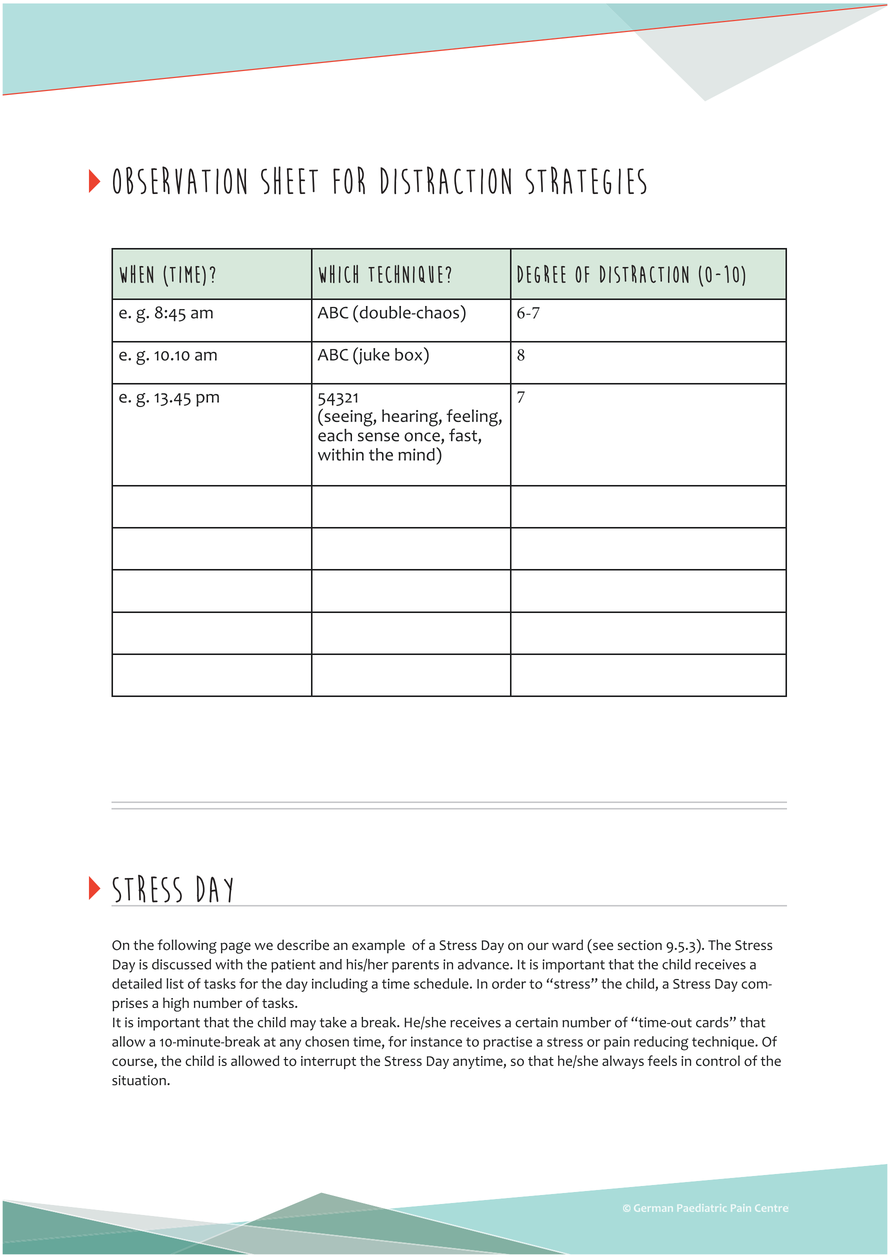
WHAT CAN YOU SMELL THERE?

WHAT CAN YOU DO THERE?

WHAT CAN YOU FEEL THERE?

WHICH MOOD ARE YOU IN?

Worksheet #11. Describe your Safe Place



OBSERVATION SHEET FOR DISTRACTION STRATEGIES

WHEN (TIME)?	WHICH TECHNIQUE?	DEGREE OF DISTRACTION (0-10)
e. g. 8:45 am	ABC (double-chaos)	6-7
e. g. 10.10 am	ABC (juke box)	8
e. g. 13.45 pm	54321 (seeing, hearing, feeling, each sense once, fast, within the mind)	7

STRESS DAY

On the following page we describe an example of a Stress Day on our ward (see section 9.5.3). The Stress Day is discussed with the patient and his/her parents in advance. It is important that the child receives a detailed list of tasks for the day including a time schedule. In order to “stress” the child, a Stress Day comprises a high number of tasks.

It is important that the child may take a break. He/she receives a certain number of “time-out cards” that allow a 10-minute-break at any chosen time, for instance to practise a stress or pain reducing technique. Of course, the child is allowed to interrupt the Stress Day anytime, so that he/she always feels in control of the situation.

Worksheet #12. Observation sheet for distraction strategies, and Worksheet #13. Example of a Stress Day.

TANJA'S STRESS DAY

DID IT ☑	WHEN	WHAT
☐	6:00	Get up, wash, and tidy your room.
☐	6:20	Wake up the other children.
☐	6:45	Check if all other children are up.
☐	6:47	Room check (all beds should be made).
☐	6:48	Collect any pain questionnaires still missing from the other patients.
☐	6:50	Set the table for both groups.
☐	7:20	Rate your "Mood Barometer"
☐	7:22	Call all patients for the morning round. Call the NET. Conduct the morning round. Distribute the notes with the scheduled appointments.
☐	7:30	Breakfast (if any item is missing on the table, you have to get it).
☐	8:00	Clean the table for both groups.
☐	8:15	Write a short biography about 3 of your nurses (you may chose for whom).
☐	9:00	See that all children pack their bathing suits.
☐	9:10	Take all children to the swimming lesson.
☐	10:15	See that each child hangs up and dries his/her bathing suit and bath towel.
☐	10:20	Walk along the hall singing a children's song aloud.
☐	10:25	Tidy up your room and have it checked by a nurse.
☐	10:30	Stand outside the nurse's room for at least 10 minutes and ask the nurses passing by various questions.
☐	10:40	Look for the book "Wizard of OZ" on the book shelf, make a short summary and present it to the nurses during a nurse meeting.
☐	10:55	Count all lighthouses on the ward and give the number to the nurses.
☐	11:05	Query 3 nurses or therapists on what they like about you.
☐	11:15	Set the table: clear out the cart from the kitchen, heat up the food in the microwave.
☐	11:30	Lunch time: (if any item is missing on the table, you have to get it)
☐	11:50	Clean the table for both groups.
☐	12:00	Rate your "Mood Barometer". Call all children for the group session.
☐	12:10	Group therapy.
☐	13:00	Prepare the seagull table for coffee time.
☐	13:15	Break / Time spent in the patient's room. See that all children go to their room and engage in something quiet.
☐	13:20	Write a French text (1 sheet) on "How to cope with chronic pain" and hand it to your nurse.
☐	14:00	Rate your "Mood Barometer".
☐	14:05	Biofeedback therapy
☐	14:30	Individual therapeutic session.
☐	15:15	Organise the joint afternoon for all children.
☐	17:30	Set the table for both groups.
☐	17:55	Rate your "Mood Barometer"
☐	18:00	Dinner (if any item is missing on the table, you have to get it).
☐	18:30	Clean the table for both groups.
☐	18:40	Collect any pain questionnaires still missing from the other patients.
☐	18:45	Prepare a plate of fruits and vegetables for the late night snack.
☐	18:55	Call all children for the evening round.
☐	19:00	Conduct the evening and "Beef" round.

✓ CONGRATULATIONS. YOU DID IT!

Worksheet #13. (continued)

LIST OF PLEASANT ACTIVITIES

SPORTS
- jogging
- playing football
- playing basketball
- playing table tennis
- going for a swim
- boxing

RELAXING
- taking a bath
- snoezelen
- lying in the sun/in bed/elsewhere, snuggling and dreaming
- getting a massage
- having tea and cookies
- taking a really warm shower
- having tea and cookies
- enjoying a piece of chocolate
- magic journey

BEING CREATIVE
- setting up a photo album
- writing a letter or a story
- cooking, or baking something tasty
- painting using Window Color
- tinkering
- decorating my room
- knitting
- sewing
- painting Mandalas
- creating a bracelet with pearls
- kneading
- painting a picture using black light

MAKING MUSIC
- singing
- playing the piano
- playing guitar or your favourite instrument
- composing a song
- clapping rhythms

OUTDOOR ACTIVITIES
- going for a walk
- collecting things outdoors (flowers, stones, sticks, chestnuts, etc.)
- visiting the playground
- swinging
- riding my bicycle
- picking flowers
- gardening
- romping in the leaves
- jumping in puddles in the rain

ALONE
- reading a book
- listening to music
- browsing through photographs
- doing a crossword puzzle, Sudoku, etc..
- looking through the window and watching what is happening outside
- playing with Lego/Playmobil
- watching YouTube

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Worksheet #14. List of pleasant activities

LIST OF PLEASANT ACTIVITIES

WITH OTHERS

- playing billiard
- kidding around
- laughing
- playing a board game
- listening to a story being read out for me
- playing cards
- meeting a friend
- paying someone a compliment
- visiting someone
- staying at a friend's house overnight
- planning and preparing a party
- planning my holidays
- listening to others
- giving someone a gift

BEAUTY

- polishing toe nails
- polishing finger nails
- trying a new haircut, or a new hair style
- visiting the hairdresser
- enjoying a face mask
- body exfoliation with salt/oil/peeling
- doing my make-up
- tidying up the wardrobe and sorting out clothes
- Making oneself up and going out

IN THE CITY

- buying something
- going shopping
- buying a newspaper/magazine/comic or reading a novel
- going for a stroll
- going to the library
- visiting an ice cream parlour and having an ice cream

MY ACTIVITIES

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MEDIA

- spending time at your PC/Tablet
- contacting friends using my smartphone
- watching TV
- borrowing a DVD, watching a DVD
- listening to the radio
- chatting
- playing Nintendo, DS, PSP
- playing Sing Star
- playing Wii console
- surfing the internet

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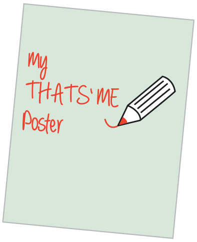
Worksheet #14. (continued)

"THAT'S ME" POSTER



Please create a picture, a collage, or something similar, showing your

- characteristics
- skills
- previous successes
- wishes/dreams
- friends/family
- other things important to you.

Feel free to choose any style, or any type of artwork (painting, writing, photographs, symbols, etc.).

Worksheet #15. "That's Me" poster

THE "THREE LETTERS"

Dear ________, I would like to give a brief introduction to a somewhat more extensive exercise. It will help you to better grasp your abilities and skills. It will also allow us to work out which areas you may still need some support from us or someone else in order to reach your goals.

Basically, the exercise is to write 3 letters. As you can imagine, these letters are not "standard" letters, but special letters in which you think about yourself and your life. I would like to point out the posssible side effects of this exercise. Since you will look at all important aspects of your life with much more detail than usual, you will be able to see some issues much more clearly. Apart from setting your personal goals more precisely, this also means that you may identify any obstacles on your way to reaching these goals. This realisation and clarity is *irreversible*. Is this a risk you are willing to accept? Or would you like to ponder it for a while? (In case of unambiguous acceptance, proceed with this introduction. Otherwise support the child to find his/her answer, e.g. by using a list of pros and cons). Well then, now I will explain the content of the three letters. Please feel free to interrupt me as we go along if you have any questions.

Let‘s start with an essential point: The letters should cover *all* important areas of your life, e.g. apart from your pain they should cover your family, friends, relationship, leisure time activities, school, future and everything that is important to you. This means you will need at least 1 page to describe everything. Some children manage to say everything in just half a page, but most children need more than one. Are you ok with that? Okay, here is another important point: between letter 1 and letter 2 you may take a break of hours, or even some days; that doesn‘t matter. But, having finished letter 2, you should immediately start with letter 3 (only a short break is allowed). It is very important to write letter 3 immediately after letter 2. This means you should take at least 2 hours for letters 2 and 3 in order to avoid time pressure. Is this ok for you? When we get to the letter content, I will explain why this is so important. Okay, now I will explain content of the different letters in detail.

Worksheet #16. The "Three Letters"

LETTER 1

In this letter you describe how your life will be for the next 2 years (alternatively, until your next birthday or another significant future event) in the best case after this therapeutic session (alternatively, after inpatient treatment; after outpatient psychotherapy; …).

The challenge is to write the letter from a future and first-person perspective to yourself in the present (“Dear … , two years have passed since you decided to do an inpatient pain treatment. Since then, … ”). It is important that you describe your development in all relevant aspects of life very precisely (i.e. not just concerning pain but also friends, relationships, school, family, leisure activities, etc.) and comment on which of YOUR OWN decisions, appraisals, and behaviour contributed to steering your life into just that direction (Incorrect: “I won the lottery, and suddenly everybody was overwhelmingly nice to me”; correct: focus on your own efforts and changes).

Do you understand the instructions? Or are there any questions left?

LETTER 2

Letter 2, in a way, is the counterpart of letter 1. As in the first letter, it is written from the future to yourself living in the present and reports about the worst imaginable course of the pain condition.

The procedure is analogous to that from the first letter (“Dear _____, since your stay on the ward everything turned out for the worse. You decided to … .”). You should describe precisely your own behaviour, appraisals, and decisions that contributed to that disastrous course. The aim of the letter is to make you think about what would be the worst imaginable course for you with respect to pain, family, friends, relationship, leisure time activities, etc. (for clarification: not the worst thinkable course in general, but the worst course imaginable FOR YOU).

After having finished letter 2, don‘t forget to immediately proceed with letter 3. If you are under time pressure when starting with letter 2, it’s better to not start with it until you are sure you will have enough time to also finish letter 3. Otherwise letter 2 will remain in your memory for too long, which will definitely be unpleasant.

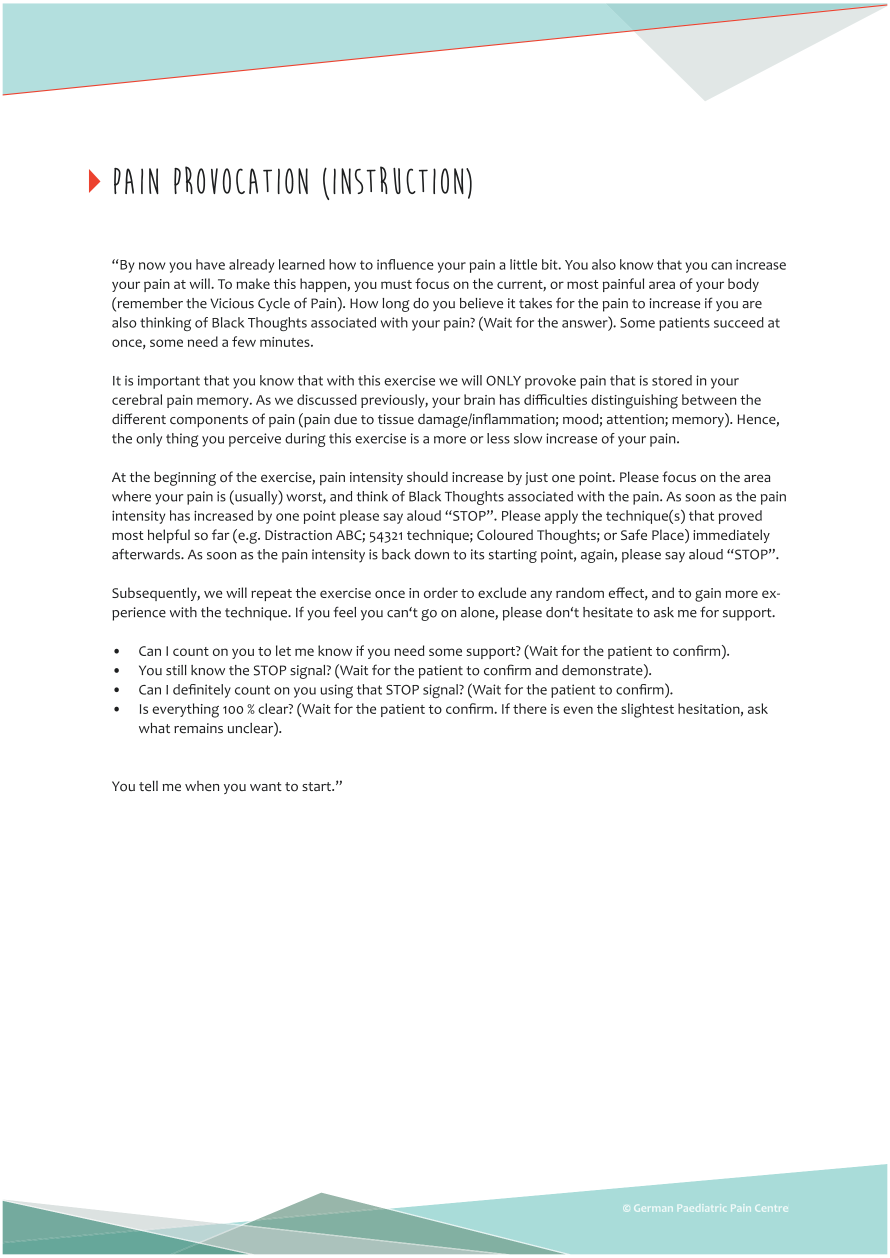
Do your dare to do this? Are you sure you will be able to proceed with letter 3 immediately after having finished letter 2, no matter how you will be feeling then?

LETTER 3

Most children regard this letter as the one most difficult to write. While it is quite simple to imagine the best possible, or the worst possible course, it is a challenge to imagine a realistic one (a probability of at least 50% that this will happen), taking into account one’s own personality and perception of abilities. And that is exactly the aim of letter 3: to find a realistic course; somewhere between the extremes described in letters 1 and 2 considering your own behaviour, appraisals and decisions.

The structure of letter 3 is no different to that of letters 1 and 2. The point is that you decide on a realistic course from YOUR point of view in all relevant aspects of your life.

Worksheet #16. (continued)



PAIN PROVOCATION (INSTRUCTION)

“By now you have already learned how to influence your pain a little bit. You also know that you can increase your pain at will. To make this happen, you must focus on the current, or most painful area of your body (remember the Vicious Cycle of Pain). How long do you believe it takes for the pain to increase if you are also thinking of Black Thoughts associated with your pain? (Wait for the answer). Some patients succeed at once, some need a few minutes.

It is important that you know that with this exercise we will ONLY provoke pain that is stored in your cerebral pain memory. As we discussed previously, your brain has difficulties distinguishing between the different components of pain (pain due to tissue damage/inflammation; mood; attention; memory). Hence, the only thing you perceive during this exercise is a more or less slow increase of your pain.

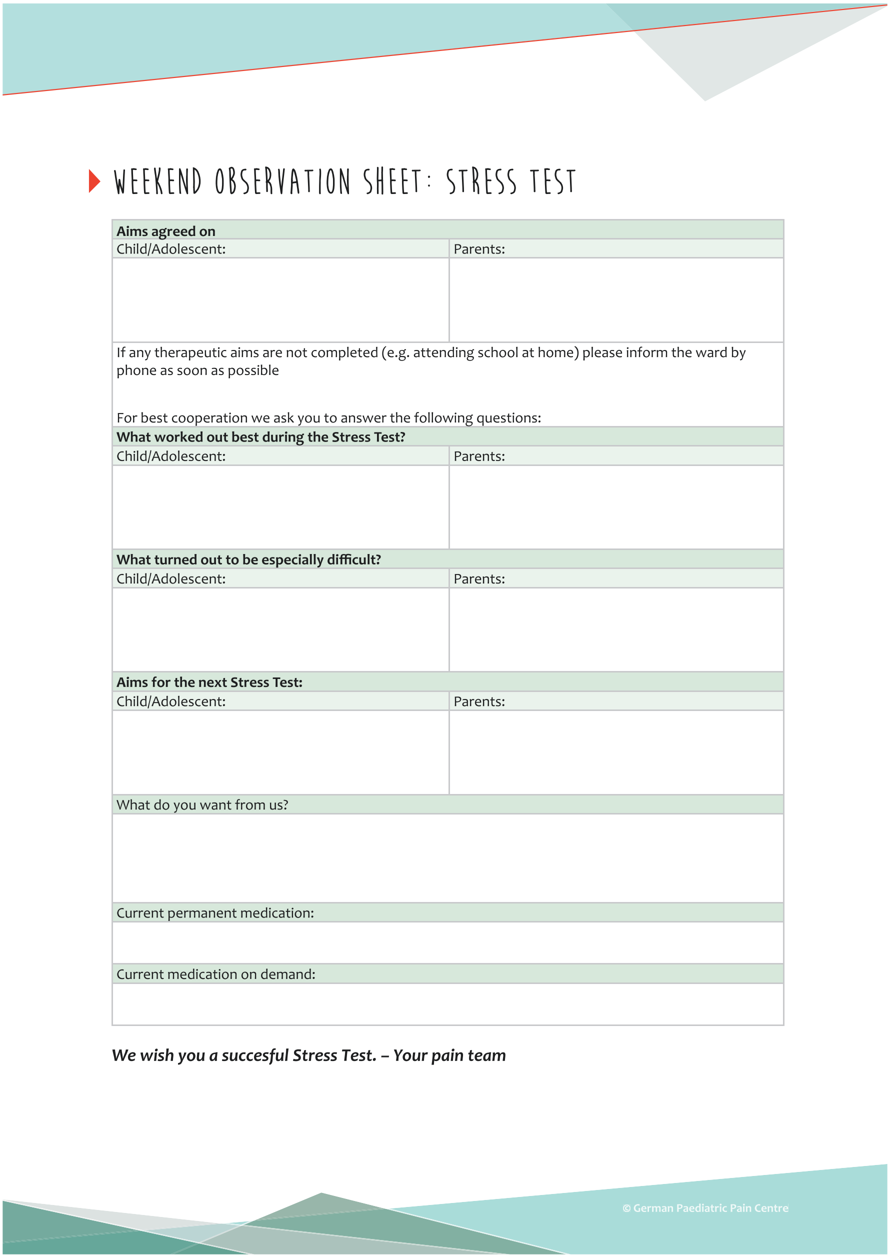
At the beginning of the exercise, pain intensity should increase by just one point. Please focus on the area where your pain is (usually) worst, and think of Black Thoughts associated with the pain. As soon as the pain intensity has increased by one point please say aloud “STOP”. Please apply the technique(s) that proved most helpful so far (e.g. Distraction ABC; 54321 technique; Coloured Thoughts; or Safe Place) immediately afterwards. As soon as the pain intensity is back down to its starting point, again, please say aloud “STOP”.

Subsequently, we will repeat the exercise once in order to exclude any random effect, and to gain more experience with the technique. If you feel you can‘t go on alone, please don‘t hesitate to ask me for support.

- Can I count on you to let me know if you need some support? (Wait for the patient to confirm).
- You still know the STOP signal? (Wait for the patient to confirm and demonstrate).
- Can I definitely count on you using that STOP signal? (Wait for the patient to confirm).
- Is everything 100 % clear? (Wait for the patient to confirm. If there is even the slightest hesitation, ask what remains unclear).

You tell me when you want to start.”

Worksheet #17. Pain provocation

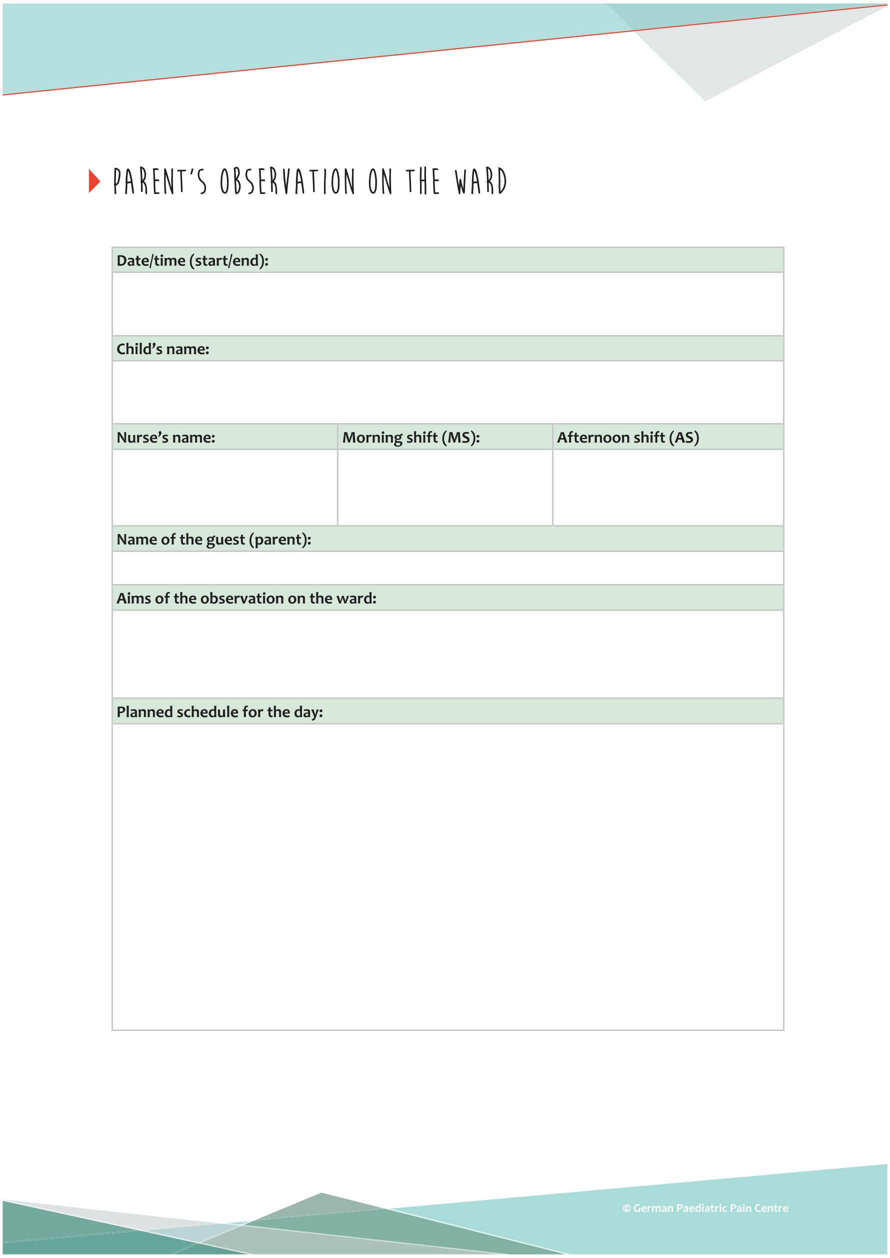


WEEKEND OBSERVATION SHEET: STRESS TEST

Aims agreed on	
Child/Adolescent:	Parents:
If any therapeutic aims are not completed (e.g. attending school at home) please inform the ward by phone as soon as possible For best cooperation we ask you to answer the following questions:	
What worked out best during the Stress Test?	
Child/Adolescent:	Parents:
What turned out to be especially difficult?	
Child/Adolescent:	Parents:
Aims for the next Stress Test:	
Child/Adolescent:	Parents:
What do you want from us?	
Current permanent medication:	
Current medication on demand:	

We wish you a succesful Stress Test. – Your pain team

Worksheet #18. Weekend observation sheet: Stress Test



PARENT'S OBSERVATION ON THE WARD

Date/time (start/end):

Child's name:

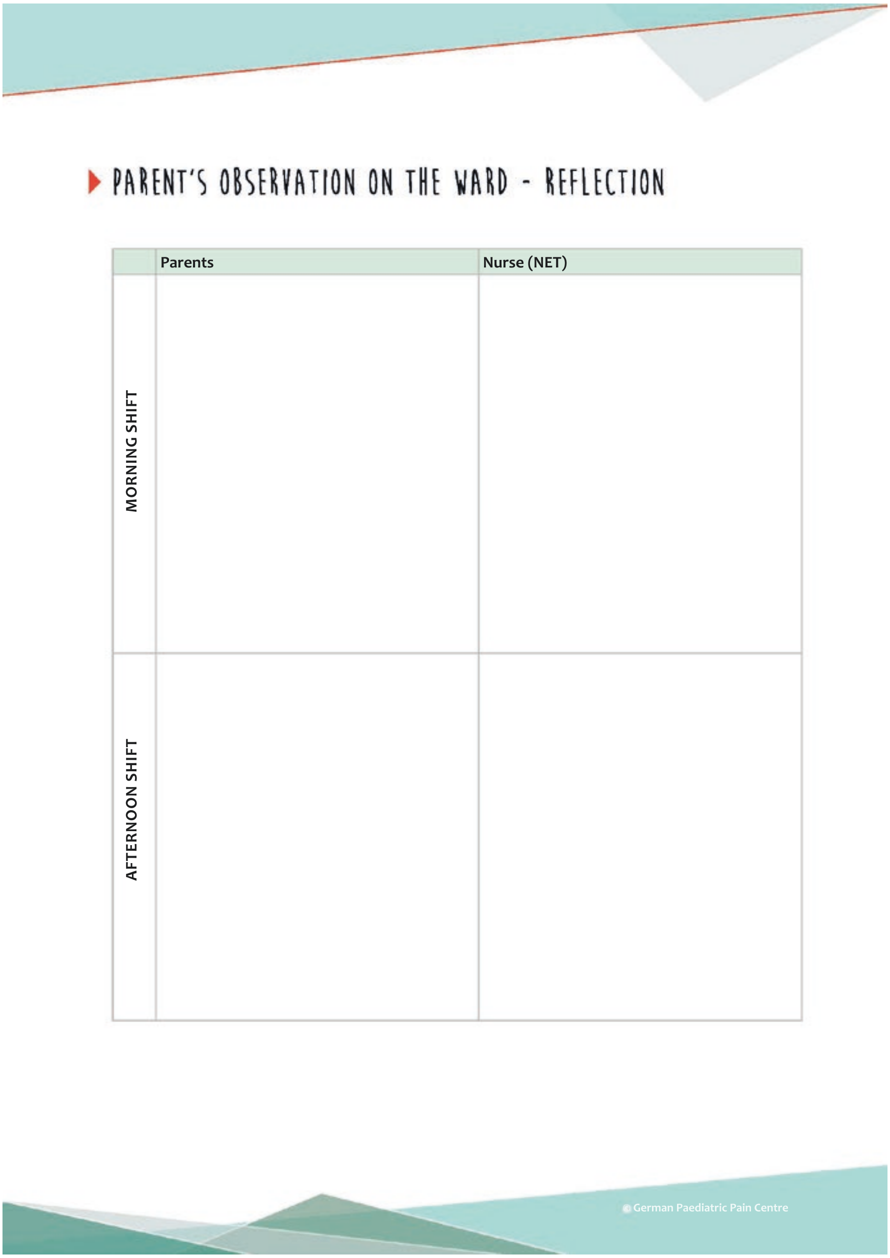
Nurse's name:	**Morning shift (MS):**	**Afternoon shift (AS)**

Name of the guest (parent):

Aims of the observation on the ward:

Planned schedule for the day:

Worksheet #19. Parent's observation on the ward



PARENT'S OBSERVATION ON THE WARD - REFLECTION

	Parents	Nurse (NET)
MORNING SHIFT		
AFTERNOON SHIFT		

Worksheet #20. Parent's observation on the ward - Reflection

Is It All Worthwhile? Effectiveness of Intensive Interdisciplinary Pain Treatment

16

Lorin Stahlschmidt, Michael Dobe, Boris Zernikow, and Julia Wager

Contents

Abstract

Chronic pain in childhood is likely to persist into adulthood, if not treated adequately. At the beginning of this chapter, we shortly present the long-term consequences of no or insufficient treatment of chronic pain in children and adolescents. Then, we discuss the effectiveness of the inpatient treatment programme of the German Paediatric Pain Centre (GPPC) described in detail in this manual. Finally, results of international studies on the effectiveness of similar treatment programmes for children and adolescents are summarised.

L. Stahlschmidt (✉) · M. Dobe · B. Zernikow · J. Wager
German Paediatric Pain Centre, Children's and Adolescents' Hospital – Witten/Herdecke University, Datteln, Germany
e-mail: l.stahlschmidt@deutsches-kinderschmerzzentrum.de; M.Dobe@kinderklinik-datteln.de; B.Zernikow@kinderklinik-datteln.de; j.wager@deutsches-kinderschmerzzentrum.de

M. Dobe, B. Zernikow (eds.), *Practical Treatment Options for Chronic Pain in Children and Adolescents*, https://doi.org/10.1007/978-3-030-19201-3_16

Chronic and recurrent pain is a common problem in children and adolescents. In representative studies, 25–40% of all children and adolescents are affected (Ellert et al. 2007; Huguet and Miro 2008; Perquin et al. 2000). Approximately every 20th child has a pain disorder (Huguet and Miro 2008) that leads to such strong physical and emotional impairment that an interdisciplinary pain treatment is indicated to prevent negative long-term effects on the physical, psychological and psychosocial level (e.g. developmental deficits, emotional disorders, medication overuse or misuse).

For children and adolescents who are less severely affected, an outpatient interdisciplinary pain treatment focusing on education, active pain coping and adequate pharmacological treatment may suffice (Hechler et al. 2011; Hechler et al. 2014b; Stahlschmidt et al. 2017). But if the chronic pain leads to a substantial number of school days missed, social withdrawal, and a high emotional burden for the child and his/her family, an inpatient interdisciplinary pain treatment is indicated (Hechler et al. 2010c). In these cases, continuing outpatient pain treatment is likely to fail (Hechler et al. 2014b) and there is an urgent need for action in light of the severe impairment in life and school (see Sect. 5.1).

If chronic pain in childhood remains untreated or is not treated adequately, it is likely to persist into adulthood (Brattberg 2004; Brna et al. 2005; Hestbaek et al. 2006; Mirovsky et al. 2002; Walker et al. 2010). Chronic pain in adulthood will likely lead to a large number of medical treatments and considerable work loss. It is a strong burden for the healthcare system due to resulting medical and indirect costs (e.g. work loss due to illness) (Hogan et al. 2016; Mäntyselkä et al. 2002; Pradalier et al. 2004; van Leeuwen et al. 2006).

In the past, pain in childhood was assumed to be self-limiting. Meanwhile, it is well known that persistent pain in childhood is a predisposition for the development of chronic pain in adulthood (Brattberg 2004*;* Brna et al. 2005*;* Hestbaek et al. 2006*;* Mirovsky et al. 2002*;* Walker et al. 2010).

Additionally, affected children and adolescents have an increased risk of psychiatric comorbidities, such as an anxiety disorder or depression (Fearon and Hotopf 2001; Shelby et al. 2013). Chronic pain in childhood already causes substantial costs for the healthcare system and the affected families (Groenewald et al. 2014; Ruhe et al. 2013; Sleed et al. 2005). Furthermore, children and adolescents with chronic pain are often severely impaired in school, resulting in limited performance and a worse professional perspective (Logan et al. 2008). The following chapter addresses the question of whether these negative consequences can be prevented with a specialised paediatric inpatient pain treatment.

16.1 Studies on the Inpatient Pain Treatment of the GPPC

Several studies have been conducted at the GPPC to investigate the effectiveness of its inpatient interdisciplinary pain treatment. In the following, we will present these studies and the most important results.

16.1.1 Study 1: Prospective Study on Treatment Effectiveness: Sex and Age Differences

The first prospective study on the long-term effectiveness of the inpatient interdisciplinary pain treatment at the GPPC was conducted between 2004 and 2007. Patients provided data at admission and 3, 6 and 12 months after treatment. Three months after treatment, data were collected in the context of an outpatient follow-up visit. Six and 12 months after treatment, data were additionally collected via post and telephone. Overall, $N = 215$ children and adolescents received an interdisciplinary inpatient pain treatment at the GPPC between January 2004 and December 2006. Of these patients, $N = 167$ patients were included in the study 3 months later. After 6 months, data of $N = 150$ patients were available, and $N = 163$ provided data after 12 months. At all measurement time points, data were collected with validated questionnaires for pain, coping and emotional distress (see Sects. 3.3 and 3.5.1).

Statistical analysis of the long-term effects for the primary outcome of pain revealed a significant strong reduction of pain intensity, pain-related disability and pain-related school absence 3 months after treatment. These improvements were maintained 6 and 12 months after treatment, with no further improvement observed over time (Dobe et al. 2011; Hirschfeld et al. 2013). Significant reductions were also found for general anxiety, depressive symptoms and dysfunctional coping strategies (Dobe et al. 2011). The decrease of dysfunctional and the increase of functional coping strategies was directly associated with the improvements in pain-related disability (Hechler et al. 2010d).

Apart from these statistical effects, the clinical significance of the treatment effects for children and adolescents was also investigated. A *clinically significant change* implies that there is a statistically significant improvement and that additionally, the score after treatment is below a certain cut-off point. This cut-off point represents unproblematic scores. The patients have to improve from a usually alarmingly high score to a normal score which is equivalent to a score of healthy children and adolescents. The results regarding clinical significance of the pain characteristics (pain intensity, pain-related disability and school absence) are further integrated into a measure of *overall improvement*. The prerequisite for an overall improvement is that the patient did not deteriorate in any one of the pain characteristics and displays a clinically significant improvement in at least pain-related disability or school absence.

Three and 12 months after treatment, about 70% of the children and adolescents had clinically significant improvements in average pain intensity. The percentage of patients with clinically significant improvements in pain-related disability was approximately 50%, and 40% for school days missed. Emotional distress (general anxiety, depression) was clinically significantly improved for about a quarter of the patients, respectively. Both 3 and 12 months after treatment, approximately 55% of the children displayed overall improvement of their pain disorder, irrespective of any somatic or psychiatric comorbidity (Hechler et al. 2009; Hirschfeld et al. 2013). Patients with a high number of school days missed before treatment were more likely to be overall improved 12 months after treatment (Hirschfeld et al. 2013).

Apart from these general long-term effects of treatment, this study also analysed whether the progress after the inpatient pain treatment at the GPPC was dependent on the age of the patients (Dobe et al. 2011; Hechler et al. 2010a). Children (7–10 years) and adolescents (11–18 years) benefitted equally with regard to changes in pain intensity, pain-related school absence, coping strategies, anxiety and depression. However, children more frequently searched for social support and showed less passive behaviour than adolescents. Pain-related disability was more strongly reduced in adolescents than in children. Adolescents had a higher pain-related disability before treatment than children, and this difference disappeared after treatment (Dobe et al. 2011; Hechler et al. 2010a).

With regards to sex, boys reported a significantly stronger reduction in pain intensity than girls (Dobe et al. 2011; Hechler et al. 2010a). Furthermore, before treatment, boys reported more school days missed due to pain than girls, but less school days missed than girls 12 months after treatment. Further sex differences were found regarding the reduction of dysfunctional coping strategies with boys displaying a stronger decrease. Thus, boys benefitted more from treatment than girls with regard to pain intensity, pain-related school absence and coping. There were no sex differences for pain-related disability in everyday life, anxiety and depression.

Summary of Main Results

This study was the first to demonstrate that the inpatient pain treatment programme of the GPPC leads to statistically and clinically significant improvements in pain characteristics (pain intensity, pain-related disability, pain-related school absence, pain coping) and emotional distress (general anxiety, depression). Approximately 55% of patients experienced an overall improvement. No major influence of age on the effectiveness of the treatment was found. Initial evidence suggests that boys may benefit slightly more than girls.

16.1.2 Study 2: Retrospective Analysis of All Patients

In a retrospective study, the treatment outcome of all patients who initially presented to the outpatient clinic between July 2005 and June 2010 was analysed (Hechler et al. 2014b). Due to overlapping periods of data collection, some of the patients of study 1 were also included in study 2; there is also overlap with study 3 (see below). Data of pain intensity, pain-related disability and school absence were collected in the context of the initial examination before inpatient treatment and a follow-up visit in the year after inpatient treatment. Overall, $N = 512$ children and adolescents received inpatient treatment during this period. Of these patients, $N = 320$ returned to the clinic for an outpatient follow-up visit within a year (on average 3–4 months after treatment) and were included in the study. The results of study 1 regarding significant strong reductions could be confirmed for all three outcomes. Comparable to study 1, 52% of the patients displayed clinically significant improvements in pain intensity and 46% in pain-related disability.

Summary of Main Results

This retrospective study confirmed the statistically and clinically significant improvements in pain characteristics with a large patient sample.

16.1.3 Study 3: Efficacy of Treatment and Long-Term Outcome

From late 2009 to mid-2011, $N = 120$ children and adolescents were included in a randomised controlled trial on the efficacy of the interdisciplinary inpatient pain treatment for children and adolescents at the GPPC. Study participants were randomly assigned to one of two groups: they either received inpatient treatment directly after the initial examination (intervention group) or after a waiting period of 3 weeks (waitlist control group).

Short-Term Treatment Efficacy

The primary research interest was the comparison between both groups at the time point 3 weeks after initial examination when the intervention group had already received inpatient treatment and the waitlist control group had not. Validated questionnaires were used to assess pain characteristics, emotional characteristics and pain-related cognitions (see Sects. 3.3 and 3.5.1). Of the original 120 study participants, some were subsequently excluded, resulting in data available for 104 patients.

The inpatient interdisciplinary treatment had a considerable effect. Of those patients who had already received treatment (intervention group), 55% displayed overall improvement, compared with 14% in the waitlist control group. This difference was statistically significant (Hechler et al. 2014a).

Furthermore 3 weeks after the initial examination, the patients in the intervention group were significantly improved regarding pain-related disability, school absence, depression and catastrophising. No improvements were found in the waitlist control group (Hechler et al. 2014a).

Long-Term Treatment Effectiveness

Both study groups were followed over a period of 4 years with data collected 6, 12 and 48 months after inpatient treatment via telephone or post. Six months after treatment, data of 96% of the patients could be collected. After 12 months, data of 83% of the patients were available, and still 69% of the patients provided data 48 months after treatment. Since at these time points, both groups had received the inpatient treatment, no group differences between intervention and control group were analysed. At all follow-up time points, patients reported significant improvements in all pain-related and emotional parameters; these improvements continued to be stable 4 years after treatment (Hechler et al. 2014a; Zernikow et al. 2018). Particularly those patients who had a severe pain disorder with a high number of school days missed before treatment showed strong pain-related improvements (Wager et al. 2014). Four years after treatment, 66% of the patients reported clinically significant improvements in pain intensity, 54% in pain-related disability and 27% in school days missed (Zernikow et al. 2018). Overall improvement of the pain disorder was found in 60% of the patients. Younger patients were more likely to show overall improvement than older patients. Clinically significant improvement in anxiety was present in 24% of the patients and in 28% and 50% regarding depression and catastrophising, respectively.

In addition to changes observed in the children and adolescents receiving inpatient pain treatment, there were also changes in the parents who are actively integrated into the pain treatment. Parental reactions to pain changed significantly after treatment. Parents less often displayed solicitous behaviour when their child was in pain (Frerker et al. 2016). This is in line with the aims of the treatment, since intensive parental care is associated with increased chronic pain of the children (Kaczynski et al. 2009). Another goal of treatment is that parents support their children in active distraction from pain. On this matter, only a short-term significant increase of distracting behaviour was found that was not maintained in the long run (Frerker et al. 2016).

Both patients and their parents indicated that they were satisfied with the inpatient treatment at the GPPC (Stahlschmidt et al. 2018). The main reasons for the satisfaction were the treatment methods (e.g. education, psychotherapy), the interdisciplinary team and the improvement of the pain disorder. Patients reported that they were satisfied, because they were able to resume a normal life and to control their pain. The age of the patients and the extent of depressive symptoms before treatment were found to have an impact on satisfaction. Younger patients were more likely to be dissatisfied, as well as parents whose children had higher depression scores before treatment. Overall, there was no relationship between the children's and their parents' satisfaction and the long-term treatment outcome.

Cost–Benefit Analysis of the Treatment

Comprehensive economic data were collected for a cost-benefit analysis of the interdisciplinary inpatient pain treatment (Hechler et al. 2014a; Ruhe et al. 2013; Ruhe et al. 2017; Zernikow et al. 2018). Both, costs for the families (assessed in the last 6 months) and for the health insurances (assessed in the last 12 months) were considered. Before treatment and 6, 12 and 48 months after treatment, parents provided information about how many medical and social services their child had used due to pain. Additionally, they reported how many days they had been absent from work due to their child's illness and how they perceived the financial burden of the child's pain for the family. The financial burden was assessed both subjectively with categories (no burden, moderate, high, very high) and directly on the basis of incurred costs. Overall, healthcare utilisation (e.g. general practitioner, psychotherapy, physical therapy, osteopathy) was significantly reduced (Hechler et al. 2014a; Ruhe et al. 2013; Zernikow et al. 2018). Furthermore, there was a significant decrease in the number of parents' work days missed. Before treatment, parents reported 4 days of work absenteeism (median) within 6 months due to their child's pain. After treatment, the median was zero (Hechler et al. 2014a). The financial burden for the family likewise decreased. Parents reported less costs for example for medicinal products, travel costs or private lessons. Before treatment, the financial burden was 100€ per month (median). Six months after treatment, it decreased to

60€ and after 12 months, parents reported a financial burden of 25€. However, this reduction was not statistically significant (Ruhe et al. 2013). The subjective financial burden was significantly decreased 4 years after treatment (Hechler et al. 2014a; Ruhe et al. 2013; Zernikow et al. 2018). Overall, positive economic effects were particularly found for patients with an overall improvement of the pain disorder (Hechler et al. 2014a; Zernikow et al. 2018).

To investigate economic effects of the treatment for health insurances, healthcare claims data of 65 study participants were analysed for the 12 months before and 12 months after treatment (Ruhe et al. 2017). Overall, total costs for health insurances did not decrease after treatment. Costs for outpatient services even significantly increased. But results revealed that healthcare is provided more purposefully. Significantly less patients went to the radiologist, but more patients received psychotherapy. This is in line with the aims of treatment to prevent exaggerated diagnostic procedures and to initiate psychotherapy, if indicated. Furthermore, fewer patients were treated in an inpatient setting after pain treatment. Moreover, medication utilisation was significantly reduced. There was an association between treatment outcome and costs after treatment (Ruhe et al. 2017). Patients with a good treatment outcome (Chronic Pain Grading (CPG) 0 or 1; see below) had significantly less costs than patients with an unsatisfactory treatment outcome (CPG 2–4).

Summary of Main Results

The short-term efficacy of the inpatient pain treatment could be demonstrated in a randomised controlled trial with a waitlist control group. Additionally, the study revealed that the statistically and clinically significant improvements of pain characteristics and emotional distress were maintained for up to 4 years after treatment. Long-term overall improvement was found in 60% of the patients. Positive effects on parental behaviour could also be demonstrated. Patients and their parents were very satisfied with the treatment. The financial burden on the families was reduced, while costs for the healthcare system remained unchanged. Healthcare utilisation seems to be more purposeful following treatment.

16.1.4 Study 4: Monitoring Treatment Outcome by Means of Chronic Pain Grading

For this study, all children and adolescents who initially presented to the outpatient pain clinic of the GPPC during January 2013 to March 2014 were contacted 1 year after their initial examination. To investigate treatment outcome, data of $N = 267$ patients were analysed regarding pain intensity, pain-related disability and school absence (Stahlschmidt et al. 2017). The Chronic Pain Grading (CPG) was used as an overall measure of treatment outcome.

The *Chronic Pain Grading* (CPG) integrates data on pain intensity, pain-related disability in everyday life and school absence into an overall measure of pain severity (Wager et al. 2013). Contrary to the overall improvement, the CPG does not focus on change, but on the patients' state after treatment. Patients are assigned to one of five grades, ranging from grade 0 without chronic pain to grade 4 with chronic pain with high disability that is severely limiting.

Approximately half of the patients included in study 4 received an inpatient pain treatment. Before treatment, about 80% of these patients were in the highest CPG grades 3 and 4. No patient was assigned to grade 0 or 1, which can be considered clinically unproblematic grades. After treatment, approximately 30% of the patients were in grade 0 or 1 and only about 20% were in grade 3 or 4. Most patients were assigned to grade 2; this means they still had strong pain, but they were no longer impaired by this pain. Overall, 12 months after treatment, the CPG grade was improved for two-thirds of the patients, 40% were improved by two grades. This improvement was statistically significant (Stahlschmidt et al. 2017).

Summary of Main Results

One year after treatment, 30% of the patients had no longer had clinically relevant pain symptoms. Further, 50% of the patients still reported pain, but without relevant impairments in everyday life.

16.1.5 Study 5: Efficacy of Pain Provocation

In the context of study 5, the efficacy of a single treatment component (pain provocation, see Sect. 9.5.5) of the interdisciplinary pain treatment was investigated for the first time. After a pilot study had demonstrated promising results (Hechler et al. 2010b), a randomised controlled trial was conducted (Flack et al. 2018). Between May 2014 and August 2016, $N = 126$ patients who received an inpatient treatment at the GPPC participated in the study. Overall, $N = 104$ patients could be included in analyses. Study participants were randomly assigned to one of two study groups: they either were taught pain provocation in addition to the standard inpatient treatment (intervention group) or a relaxation technique, the progressive muscle relaxation (control group). The study participants completed validated questionnaires on pain data (pain intensity, pain-related disability, school absence, fear of pain) and emotional distress (general anxiety, anxiety sensitivity, catastrophising). Data were provided at admission to inpatient treatment, discharge and 3 months after treatment. Overall, both groups demonstrated significant reductions in all pain characteristics, fear of pain and catastrophising (Flack et al. 2018). However, there was no stronger decrease for patients in the intervention group compared to the control group. Results confirm the general effectiveness of the interdisciplinary inpatient pain treatment. An additional benefit of the pain provocation technique compared to the relaxation technique could not be determined. However, exploratory analyses revealed that patients with a high fear of pain before treatment and patients with abdominal pain benefitted more from pain provocation than from relaxation. These findings may be useful for deciding who should receive additional pain provocation during inpatient treatment. Such an individualised treatment may perhaps contribute to the improvement of treatment outcome.

Summary of Main Results

The pain provocation technique seems to be particularly beneficial for reducing fear of pain in patients with abdominal pain or high fear of pain before treatment.

16.1.6 Conclusion

All studies support the hypothesis that the 3- to 4-week inpatient pain treatment at the GPPC is beneficial in the long run for children with a pain disorder irrespective of pain location and somatic or psychiatric comorbidity. Apart from the positive impact on pain, impairment and emotional burden, positive financial effects result for the affected families.

At a time of limited human resources and a shift to technical medicine, the inpatient pain treatment programme of the GPPC requiring a large interdisciplinary team and focusing on the child and his/her family may seem to be a relic from the past. However, it is exactly this personnel-intensive approach that makes the programme so successful.

16.2 International Studies

Across the world, research on the effectiveness of intensive interdisciplinary pain treatment for children and adolescents has progressed a lot in recent years. Meanwhile, there are studies on different inpatient and day-hospital pain treatment programmes with a structure and treatment approach similar to the GPPC (for an overview, see Stahlschmidt et al. 2016). Two reviews have summarised the most important results of these effectiveness studies (Hechler et al. 2015; Stahlschmidt et al. 2016). Some of the studies described above were also included in these reviews. The reviews confirm that the pain treatment programmes lead to both short-term and long-term reductions in pain intensity, pain-related disability and school absence. Emotional distress also substantially decreases through the treatment. Furthermore, some studies were able to prove positive economic effects. One study concludes that an intensive interdisciplinary pain treatment is a cost-effective therapy for chronic pain in children and adolescents (Evans et al. 2016). Additionally, improvements were demonstrated regarding sleep quality (e.g. fewer sleeping disorders, daytime sleepiness, night-time awakenings).

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