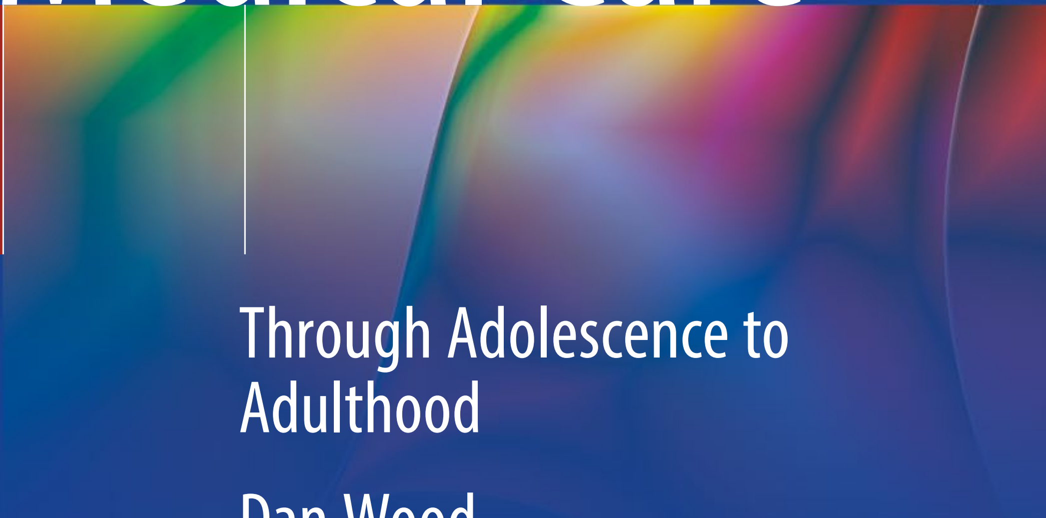
Transitioning Medical Care



Through Adolescence to Adulthood

Dan Wood
Alun Williams
Martin A. Koyle
Andrew D. Baird
Editors

Springer

Transitioning Medical Care

Dan Wood • Alun Williams
Martin A. Koyle • Andrew D. Baird
Editors

Transitioning Medical Care

Through Adolescence to Adulthood

Springer

Editors
Dan Wood
Adolescent and Reconstructive Urology
University College London Hospitals
London
UK

Alun Williams
Paediatric and Transplant Surgery
Nottingham Children's Hospital QMC
Nottingham
UK

Martin A. Koyle
Hospital for Sick Children
Toronto
ON
Canada

Andrew D. Baird
Adolescent and Reconstructive Urology
Aintree University Hospital
Liverpool
UK

ISBN 978-3-030-05893-7 ISBN 978-3-030-05895-1 (eBook)
https://doi.org/10.1007/978-3-030-05895-1

Library of Congress Control Number: 2019934090

© Springer Nature Switzerland AG 2019
This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.
The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.
The publisher, the authors, and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Contents

Contributors

Andrew Baird, MB, ChB, FRCS (Urol) Department of Urology, Alder Hey Children's Hospital and Aintree University Hospital, Liverpool, UK

Gillian Barker, MD Section of Pediatric Urology, Department of Pediatric Surgery, Uppsala University Children's Hospital, Uppsala, Sweden

Joanna Begent, MBBS, MA, MSc Department of Paediatric and Adolescent Medicine, University College London Hospitals, London, UK

Wendy F. Bower, PhD, Grad Dip Epidemiol Biostats Continence Service, Department of Medicine and Community Care, Royal Melbourne Hospital, Parkville, VIC, Australia

Faculty Medicine, Dentistry and Health Sciences, University of Melbourne, Parkville, VIC, Australia

Deborah Christie, PhD, Dip Clin Psych Department of Child and Adolescent Psychological Services, University College London Hospital NHS Foundation Trust, London, UK

Gail Dovey-Pearce, BA (Hons), Dip Clin Psych Department of Child Health (c/o Health Psychology, DRC), North Tyneside General Hospital, Northumbria Healthcare NHS Foundation Trust, North Shields, UK

Caroline Dowling, MBBS, MS, FRACS (Urol) Department of Urology, Eastern Health, Box Hill, VIC, Australia

Dominic Frimberger, MD Section of Pediatric Urology, Department of Urology, University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA

Lara Gamper, MD Department of Adolescent Medicine, University College London Hospitals, London, UK

Jessica H. Hannick, MD, MSc Department of Pediatric Urology, McMaster University Children's Hospital, Hamilton, ON, Canada

Johan Heinius, MD Department of Urology, Uppsala University Hospital, Uppsala, Sweden

Yves Heloury, MD Department of Urology, Royal Children's Hospital, Parkville, VIC, Australia

Abigail Jenkins, MBChB, MRCS School of Medicine, University of Leicester, George Davies Centre, Leicester, UK

Martin A. Koyle, MD, MSc, FAAP, FACS, FRCSC, FRCS Division of Pediatric Urology, The Hospital for Sick Children, Toronto, ON, Canada

Göran Läckgren, MD, PhD Section of Pediatric Urology, Department of Pediatric Surgery, Uppsala University Children's Hospital, Uppsala, Sweden

Rosalia Misseri, MD Department of Urology, Riley Hospital for Children, Indianapolis, IN, USA

Winnie Nugent, BSc (Oncology) Department of Urology, Guys and St Thomas Hospital, London, UK

William G. Reiner, MD Section of Pediatric Urology, Department of Urology, University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA

Division of Child and Adolescent Psychiatry, Department of Psychiatry (Adjunct), University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA

Joshua D. Roth, MD Department of Urology, Riley Hospital for Children, Indianapolis, IN, USA

Jane Simpson, MA, CANTAB, MBBS Department of Adolescent Medicine, University College London Hospitals, London, UK

Anders Stenbäck, MD, PhD Section of Pediatric Urology, Department of Pediatric Surgery, Uppsala University Children's Hospital, Uppsala, Sweden

D. Michael Whishaw, MB, BS, FRACP Continence Service, Department of Medicine and Community Care, Royal Melbourne Hospital, Parkville, VIC, Australia

Department of Urology, Royal Melbourne Hospital, Parkville, VIC, Australia

Alun Williams, MA, BM, BCh, FRCS Department of Paediatric Urology, Nottingham University Hospitals NHS Trust, Queen's Medical Centre, Nottingham, UK

Dan Wood, PhD, FRCS (Urol) Department of Urology, University College London Hospitals, London, UK

Hadley Wood, MD Cleveland Clinic, Glickman Urological Institute, Cleveland, OH, USA

Christopher Woodhouse, MB, FRCS, FEBU University College London, London, UK

Introduction: What Do Patients Worry About?

1

Hadley Wood and Dan Wood

Introduction

This book is written by a group who attended a meeting focused on transition in Toronto in 2011, many of the attendees and contributors are urologists. Thus, many of the examples discussed are based on urological diseases or patients. The very nature of this work involves topics which become increasingly relevant as a young person evolves from childhood into adulthood, including sexuality and fertility. The authors and editors all hope that you have picked up this book because you are interested in this critical developmental stage involving transition to adulthood. The message must not be that success with this complex process can be achieved by a lone clinician. Particularly at this time of complex developmental, psychological, endocrinologic, and physical change, a multidisciplinary team is necessary to meet the medical needs of the whole patient.

In short, the focus of this book is to help the reader understand what is necessary medically and developmentally for young people affected with

---

H. Wood
Cleveland Clinic, Glickman Urological Institute, Cleveland,
OH, USA
e-mail: woodh@ccf.org

D. Wood (✉)
Department of Urology, University College London Hospitals,
London, UK
e-mail: dan.wood1@nhs.net

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_1

congenital conditions to be successful as they migrate from a paediatric to an adult healthcare environment. More importantly we aim to help young adults come to terms with a developing role in their own health, diagnosis and ongoing care.

Why Does Everything Have to Change, and Why Can't I Keep My Old Doctor?

It makes sense to ask why patients are expected to move from a trusted (for the patient) group of healthcare providers to some who are unknown at a time when everything else is changing for them. Surely, most of the people reading this book will recall their own adolescence—a period of our lives when consequences of bad decisions were often not considered and questioning authority was normal. Compound these developmental changes with physiological changes happening at break-neck speed: hair growth, secondary sexual development, apocrine gland changes, etc. In short, we are asking these young people who carry a significant diagnosis, and all the concerns that emanate from that, with them to break some of the most significant bonds they have formed (outside their family) and to engage with a totally new group of people who appear to think they know everything but have yet to prove that, at a time when our patient has more concerns and questions than they have ever had.

Why? Because We Have to

Just as we would not expect a general surgeon to perform orthopedic surgery, it is a simple reality that medicine is increasingly complex and a single individual cannot have the expertise or ability to provide excellent care across the entire life span. Taking good care of patients requires not only knowledge of subject area and technical skill, but equipment, facilities, communication skills, and other subspecialists tailored towards the unique anatomic and physiologic needs of the patient. A system geared towards providing excellent medical care for a 5-year-old cannot fit the needs of a 25-year-old. Moreover, even if the system -needs are not different, *the patient's needs evolve.* Urologically speaking, the 5-year-old patient requires care to facilitate continence and renal preservation. The 25-year-old, on the other hand, needs the full spectrum of urologic expertise, including all of the above *and* sexual function and fertility assistance [1].

It is important to remember that the move from one doctor to another, or the move from one building to another, is *transfer*, not transition. Transfer constitutes perhaps the smallest part of the overall process. *Transition* takes years to prepare for and involves assisting the patient in coming to terms with his/her diagnosis and understand that he/she is ultimately responsible for his/her health and destiny. At the end of transition, patients should be autonomous in determining when treatment is needed and know how to call for help.

While achieving successful transition may seem like a gigantic step, the reader should be assured that it occurs best in many small steps over a period of years. The concept needs to be introduced early and gradually embellished over time to avoid the patient needing to jump off the cliff to independence all at once. It may and should start with small steps like administering medications or calling to schedule an appointment and then gradually expand out to autonomous management of one's own care. Parental acceptance of and insistence on marching forward towards independence can be a great barrier to success in transition. For the parents, the authors can only say that it may be the bravest and most generous thing you do for your child to insist that your child become autonomously functioning in his/her own medical care.

Who Is in My New Team?

Patient and parent expectations are high—usually, not unreasonably so. They have come from a familiar environment, where they had formed close bonds and were well cared for. They will expect the same—and may not understand that a pediatric hospital is often smaller and thus more easily controlled—than an adult hospital. Whilst the care objectives of the new team may be similar and their own standards equally high the fact that there is difference in the way things are done or that systems may be more difficult to navigate or even that care is delivered in an 'adult' way can create anxiety and tension.

Patient and parents will (usually) be very familiar and some expert in their diagnosis, care and prior needs. They will quickly spot someone who is not and this too, can create a difficult dynamic.

Why state all of this? The point is, that if these patients are simply placed in a routine, general clinic they will have a much higher tendency to 'fail' in transition—or for transition to fail them. Success in transition is difficult to achieve, but the more the adult environment replicates the multidisciplinary services and support provided earlier in life, the more likely it is that success will be achieved. The exact concoction of personnel and services needed for such a clinic depends on the diagnoses treated and expertise of the individuals and has not been well studied. In addition, successful transition requires trust and open communication between the referring and the receiving team. Many services offer some form of joint clinic between the two teams, most commonly with the adult-provider team traveling to the pediatric facility to "meet" the patient and family. This can be extremely useful for the receiving provider team and patient alike—visualization of care teams working together embeds trust and knowledge for all parties. An additional advantage is that there will at least be familiarity of the faces when the patient first sets foot into the new adult care facility, hopefully making the process less intimidating.

The principles are relatively simple and should be a set of aims to work towards:

1. Discuss and prepare for transition from an early age
2. Ensure the patient builds his/her own understanding of his/her disease and treatment
3. Encourage him/her to take ownership of that treatment
4. Introduce the receiving adult team
5. Set up a care environment in the adult center

It is important to recognize that as the provider at the adolescent/adult end of transition, there are factors that impact patient-family satisfaction that are both within and without of one's control. We can start with the easy one:

1. The young adult and their parents must feel like they are being welcomed into a new service rather than dispatched from an old one. This is just about interpersonal skills and making an effort to try and see them in their pediatric environment, explain a rough plan, introduce the team, explain where they will be seen and try to set them at their ease. What we used to call 'good manners'. Basic stuff but actually fundamental to building a good forward relationship.
2. Out with the control of an adult team is preparation for transition. Discussions need to begin early—maybe at around the age of 12 years. These need to approach a range of different subjects—most importantly is building the confidence of the patient to discuss their diagnosis and any problems for themselves—as well as starting to understand and make their own decisions. Broken down this might look like:
    (a) Introducing the need to move in the future (early discussion)
    (b) Encouraging the patient to write down or discuss what they know
    (c) Encouraging the patient to talk about their concerns or problems
    (d) As confidence grows, asking the parents to step back and reduce their involvement
    (e) Discussing the new environment
    (f) Asking about fears and finding solutions to those.

    This is a very theoretical approach, but the elements seem important. The authors have encountered patients who are both well prepared and those who are not. Both will have their challenges and at times both can have difficult problems to face but good preparation is a bit like the pediatric service giving the adult service a quality assurance mark—to say to a patient, 'these guys are okay, they will look after you'. If patients (and more often parents) don't have this the transition can be very difficult—they feel angry about moving on, let down by the fact they cannot stay with the team they liked and trusted and disoriented by their new environment. If this happens their antagonism builds and no weight of evidence about the quality of service (or the potential lack of service elsewhere) will overcome the emotional reaction and the desire to break away. Unfortunately, when patients drift or march outside of specialist units they often experience a more general approach to care that is perfect for the majority of healthcare patients but does not allow for these patients and the medical, psychological and (in some) social complexities that come with them. In our experience, the worst of the lot is when patients are transferred acutely after having fallen out of routine pediatric care with a severe or life-limiting condition, and the relationship between provider and patient is cloaked in fear, anguish, and frustration on both sides of the relationship.

What Will Happen if It Goes Wrong?

It is often true that pediatric programs are geared towards timely and excellent responses to patient/family enquiries. Pediatric programs tend to have a wide range of support personnel and greater shared responsibility for patient communication—both medical and paramedical. The cultural and resource differences on the adult side can often be the most disappointing part of the transition experience. Patients and parents can be confused about how or whom they contact their provider team to get their concerns addressed in a timely fashion. Patient focus groups for patients having undergone complex surgery have borne this out: those who were frustrated were those who had a lack of support, regardless of surgical outcome. Truth be told, adult care environments are more complex to navigate and communication with care providers can pose challenges. Evolution of electronic physician messaging and online resources can help bridge this gap for some patients. In some circumstances, virtual patient visits and shared medical appointments may help bring information to patients when and where they need it.

Specialist nurses provide an essential role in both patient education and care and the necessity of having a well-functioning physician-nurse partnership cannot be understated. Simply stated, a transition clinic will not be successful without devoted and knowledgeable nurse specialists. Most successful programs have a nurse as both the face and often the heart of the service.

It is important that the patients and sometimes in a limited fashion, their parents, assume the appropriate amount of responsibility for their care. If they are getting regular urinary tract infections and ignoring advice about fluid intake or bladder washouts, then this advice needs firm but fair reinforcement. There needs to be a consistent message that comes from all team members. Patients will gradually become experts in their own care and this is important for them to realize. Many will have rare diagnoses or atypical anatomy—they may encounter health care providers within the system who know far less than they do about their condition. These situations can result in frustration and estrangement from the medical system, particularly when and if the patients are made to feel inferior or ignored by anyone in the system. Patients need to know the team of individuals who can help advocate on their behalf and educate other providers to prevent this outcome. This often means having someone from the practice available “all the time” for calls from emergency rooms or outside hospitals.

So the key to this question is that no single individual can be successful ensuring adequate access and communication to patients and families with complex urological diseases. It takes a village of devoted personnel and often enhanced technological solutions to achieve it. Patients want to be able to contact people with questions and concerns—so being contactable is vital. Educating patients about themselves and their condition as well as setting expectations and guidelines for how and when patients should reach back to the center is also critical.

It does go wrong sometimes and knowing the safest route to safe emergency care and sound advice is important. It helps to discuss this and try to provide some advice for this—which will of course vary for all sorts of reasons including—condition, the patient, the treatment and geography.

Can I Be Normal?

It is a recurring theme in this book that teenagers are growing up. They are learning about the world around them and their place in it. As part of that they will be examining themselves and comparing themselves to peers and role models. Whilst peers can be cruel at times they are generally ‘normal’. Role models (on the other hand) may be normal or may be unrealistic either intentionally or unintentionally and thus may create unachievable expectations in our patients or, indeed, their parents.

Surgeons and doctors cannot make normal. We can improve things and sometimes return things to a status quo. So when patients have major anomalies and concerns about those they will naturally ask questions about themselves and how they fit is but they will add questions about their condition, its treatment and its effect on them in these terms. While parents and siblings will often attempt to “normalize” the patient, in adolescence in particular patients know they are different and often express insecurities around that. The physician and care team can plan an important role in validating these concerns and explaining that “normal” simply does not exist. Every individual comes onto this earth with unique characteristics and challenges that make them who they are. Patients may want to connect with others who “look like them” or face similar challenges and the medical team can play a critical role in facilitating those connections to help the individual feel less isolated.

Some are angry or upset about the reality they have to face. Others appear to accept their situation far more readily—although those who treat these patients often worry about the need for wider support—particularly psychology. This is important from a range of different aspects. Firstly, dealing with chronic disease has a major impact on one’s psyche. In isolation this would justify a need for psychological support. The authors suspect that whilst this may be straightforward in some areas it certainly is not in ours. The disclosure to a young adult about diagnosis or even the realities of that and the limitations they may face (however small they may seem) would ideally be supported by a psychologist. This is particularly true as young adults begin to understand how their sexuality and fertility may be affected by their diseases [2].

It is clear, no perfect solution exists, and many models have tried to help and look after these patients across a wide range of medical specialties and diagnoses.

Confronting the fact that something about yourself as a patient is not ‘normal’ and requires to see a doctor for life is tough and the fact that this did not end when you finished childhood and you now have to move to another team who will continue to require your attendance at hospital probably just adds the realization that there is something different about you (however small or invisible it may be to others).

Conquering the Complexities of Family, Sex, and Fertility

Family

To meet parents who have a child born with any congenital anomaly is extraordinarily humbling. Many healthcare professionals have asked themselves how they would cope themselves if they had an affected child. The range of emotions must be extraordinary the expected elation quickly replaced with concern, anxiety and an understandable feeling of guilt (what did I do wrong?).

Anecdotally, many parents ask themselves whether they did something either before or during pregnancy that affected their child and resulted in the anomaly. It is important to acknowledge that and dispel any myths that exist. The questions are normal and certainly should not be dismissed—carefully explanation is important to ensure that parents understand that their lifestyle or any single event did not affect the health of their child. They also have to face up to the worry of spending time in a hospital and the impact that may have on their own relationship, other children and their ability to work—or the impact it may have on them in the workplace.

Most of us are born into a family and whilst the dynamics of that family may change we treasure the warmth that it offers. For those without that life is much harder. As we grow and mature, relationships change—within the original family unit and external to that. The dynamics with siblings develop in all sorts of ways. Just sit in your staff coffee room and ask about people’s brothers and sister—you will not hear one story the same as another, some good and some bad. Clearly, our relationship with parents changes. As an adolescent matures they will first start to learn and then question their environment and with time they begin to test that environment—to learn their place in it and establish their independence—this is apparent in many ways although, maybe, most keenly felt by parents.

Early in life the decisions made about a child are driven by the parents. Whilst this is normal—it is important that the parents are constantly kept in the conversation and supported in their decision making. It is one thing to make a decision to have your own operation but quite another to decide that someone else should have an operation. If it goes well—it is easier to vindicate that decision. If there are problems the guilt that must sit with that is hard to imagine. Again, all of this is normal but may have a huge impact on how a parent copes individually and in partnership with their spouse.

Looking into adolescence and the background above, perhaps makes it easier to understand why parents can appear so protective or anxious about releasing control. This is explored in some detail throughout this book. It is hard enough to watch your child ride a bike on the for the first time (although the anxiety here is mixed with feelings of pride and delight) and this needs to be considered when managing a child and their family through transition. Different families will need different approaches. It is important to build in time for a young adult to talk to you as the healthcare professional, alone. It is also important to remember that the parents can be important allies—in building a relationship with the child the parents' support can be extremely helpful. For instance, when the child comes to sign a consent form for themselves (for the first time) it is good to have their parents there. The parents can see that you are explaining and talking to their child appropriately whilst the child has some support in making a big decision (for what maybe the first time).

Adolescents affected by chronic disease will clearly have aspirations of their own and these will be compared with the world they see around them. Their aspirations will be built by the combination of what others have told them they can be and what they've seen in reality. The family and the provider team can often be the most influential parties in this process.

Sometimes, patients will have care needs that require assistance, and the parents or adult siblings may evolve a role in this. As an adult care provider, you may find families in your office having performed self-care activities for a patient for over 30 or 40 years and themselves becoming increasingly debilitated. In our experience, confronting and validating those concerns, and openly discussing what the plans are for when the day comes that the patient will not have that support is critical. Anticipating the potential options down the road will provide better care for the patient and engender respect and trust from the family.

Sex and Fertility

Concerns relating to sex vary widely. Clearly, conversations relating to sex should be held in private—away from parents and siblings. This is particularly true as patients with disability have substantially higher rates of sexual abuse and care providers both within and outside the family may be involved. Many patients will be inhibited from sharing this information in front of authority figures for fear of retribution or disappointing them.

Some patients will ask for education. Questions that may seem straightforward but are of course important. It may seem as some patients are almost asking for permission and we have certainly seen couples where a very considerate individual has asked whether he/she could hurt their (affected) partner by having sex. Sex therapists, occupational and physical therapists, and other allied health providers may prove key in helping facilitate healthy intimacy and fertility.

In addition, there can be questions about genital size and appearance from both sexes. It is important to make a careful, clinical assessment. Whilst it may seem obvious—it is essential to ask whether they have had or are having sex. It is easy to assume that the reason for such questions means that they have not, cannot or will not. If they are having sex, then the reasons behind the questions is very important—are they or their partner suffering pain or discomfort? It is important to discuss other elements of sexual function—in a male, erection, orgasm and ejaculation; in a female, vaginal lubrication, ease of penetration, pain, and orgasm.

If patients are not able to achieve sexual intercourse with a partner, it is important to understand why not and whether they have attempted it. The route to treating this may not be an operation. Information and support from their healthcare team may be enough. Surgery is one possible element of treatment, but pharmacological and psychosexual options are important to explore and have available.

Fertility concerns, particularly in the un-partnered patient, can be challenging. Patients may abstain from propagating or seeking relationships for fear that they will not be fertile. The treating team need to understand the underlying condition and whether this predisposes to reduced production of or damage to germ cells or a problem with delivery of germ cells. When there are concerns about fertility potential in males, semen analysis may offer additional information upon which counselling may be based. If fertility ability is unknown, patients should be appropriately counselled for pregnancy avoidance if relevant and safe sex practices should always be reviewed in the young person who is sexually active regardless of anatomy. It is beyond the remit of this chapter to explore this fully but in taking on this kind of work understanding and anticipating questions of all types is important. Even if one is not—one must appear unshockable!

Summary

This book aims to give you a broad introduction to working in transition and the care of patients as they move from pediatric care to adult care. This first chapter starts by giving a flavor of what worries patients and their families as they enter this phase of their life. The authors cannot possibly anticipate all questions in all specialties.

References

1. Wood D. Adolescent urology: developing lifelong care for congenital anomalies. Nat Rev Urol. 2014;11:289–96.
2. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions. J Adolesc Health. 2003;33:309–11.

History of Adolescent Care in Urology

2

Christopher Woodhouse

Introduction

The author spent career specializing in long-term care of congenital urological conditions. This chapter reflects the history and development of his work and the care that the patients need throughout their lives. The aim is to outline the principles of how and why transitional care came into existence in urology. It happens to make a good example of the need, the potential for success and the challenges in many other fields. It is, therefore, relevant to a wider audience, rather than just to urologists. Whichever specialty the reader works in they will already understand the complexities of adolescence and adolescent medicine.

The Past

Mute swans form life-long partnerships and share the burden of parenting devotedly. At the end of their first year of life, however, the cygnets are forcibly expelled from the family and sent to fend from themselves [1]. There is no transitional period or adolescence—the swans form their own partnerships and start to breed. This is the old model for human children with lifelong medical needs.

In humans, the term 'adolescence' is derived from the Latin *adolescentia* and as a distinct period of growing up has been used in English at least since the fourteenth century (Oxford English Dictionary—complete edition 1971). However, until the nineteenth century, it must have been a rather short period as poor children were sent out to work as soon as possible and rich children were prepared for adult life and early marriage.

C. Woodhouse (✉)
University College London, London, UK
e-mail: christopher.woodhouse@ucl.ac.uk

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_2

So, what of ‘adolescent medicine’? Specialist care of children began in Europe with the foundation of free standing pediatric hospitals—in London the Hospital for Children, Great Ormond Street (GOSH) was founded in 1852. When pediatric patients grew up, we can only speculate what happened to them if further medical care was needed. Adolescent urology literature begins in 1955 [2]. To have a specialty to look after those who had outgrown somewhere like GOSH several things would have to happen.

Firstly, there would have to be a substantial cohort of survivors. In the past, the majority of the children with the major congenital anomalies died at an early age. Even now in underdeveloped countries congenital anomalies, especially spina bifida (SB), account for nearly 50% of infant deaths and the rate is inversely correlated with the per capita gross domestic product [3].

Spina bifida has been recorded in skeletons since the Neolithic period, but almost always affecting only the sacrum. Cooper (1809) recognized the association between SB and other neural tube defects such as anencephaly. The higher the defect up the spine, the earlier the children died. Survival to ‘middle age’ was a rarity [4]. Even in the twentieth century, survival without surgery was thought to be rare [5]. By the second half of the twentieth century better care had improved survival but in an unselected series of patients in the UK 60% still had died before 40 years of age. As noted by Cooper 200 years ago, the survival was much better with lower neurological lesions with 61% of those with lesions at L4 or below surviving at 40 years old compared to only 17% with T10 or above.

Babies born with exstrophy were often left to die, and in some countries this may still happen. ‘The disease was probably one of the “monstrosities” of nature that were better left alone in order not to interfere with the intentions of the divine’ [6]. As it is not an intrinsically fatal condition, there are many records of long term survivors in the literature at least since the sixteenth century. Nonetheless, in an important 1926 paper on Mayo’s personal patients it was recorded, historically, that 50% of children were dead by 10 and 67% by 20 years old, usually due to the complications of treatment. The contemporary series of 66 patients had reported a mortality of 28%, but half of the living patients was under 10 and the authors were not optimistic about their future. There was long term follow-up on 20 patients from 30 to 73 years old [7].

There was only one known survivor amongst babies born with cloacal exstrophy before 1960 [8, 9].

All of the advances in pediatric medicine have contributed to a dramatic fall in early mortality. There was no treatment for end stage renal failure until chronic dialysis came along in the 1960s so about a half of those born with posterior urethral valves would have died before adulthood. Good antibiotics for gram negative infections were discovered in the 1970s, before which gram negative septicemia, especially in association with renal stones was frequently fatal. The biochemical alterations caused by ureterosigmoidostomy were described in the 1950s and early ‘60s, ironically at the same time as the introduction of the ileal conduit made the rectal diversions temporarily redundant [10–12].

Secondly, those who survive into adolescence and adulthood have to have problems that are amenable to treatment. Many pediatric urology patients are cured: those having surgery for undescended testis or pelvi-ureteric junction obstruction are obvious examples. Most children diagnosed with hydronephrosis in utero with normal renal function can be discharged. There is conflict about the need for follow-up of boys operated for hypospadias—although this probably follows a spectrum.

The present-day challenge in caring for the surviving patients in adolescent urology, is the wide range of problems requiring sub-specialist knowledge. These include the renal deterioration due to congenital anomalies of the kidneys and urinary tract (CAKUT), the many options for the reconstruction of the bladder and problems in sexual and reproductive function of exstrophy, SB and PUV. Although individually it could be said that a general urologist could be responsible, in practice the rarity of each condition would make it very unlikely that best holistic care would be provided.

Thirdly, there has to be cadre of doctors with the inspiration to develop such a clinical interest. There is a dichotomy between specialists in adolescent medicine. Some say that the care of adolescents is a specialty in its own right and that at the end of adolescence, any adult management that is needed should be the responsibility of appropriate adult doctors [13]. This might be considered as managing the impact of adolescence on an already difficult medical condition. Others, including the present author, believe that there should be only one transition—from pediatric care to one that continues from about puberty until death.

This difference is based primarily on the nature of the pediatric conditions. If a child has diabetes, asthma or any other condition that has an adult equivalent, it is entirely logical for the care to be transferred to adult physicians at an appropriate age.

The problem in urology is that very few pediatric conditions have an adult equivalent. There is no adult form of exstrophy. Adult bladder outflow obstruction does not have the same consequences as obstruction from a posterior urethral valve (PUV). Spina bifida is not the same as a traumatic spinal cord injury. Similar long-term problems are found in other pediatric specialties such as cardiology and orthopedics.

Therefore, there is a need to have a specialty that can maintain the same holistic care of patients with pediatric urological anomalies from puberty to death. There seems no point in having two transfers of care. As with pediatric practice, this would involve a team of clinicians, rather than a single individual.

There is no title, at present for the specialist who looks after children from pediatric urology when they grow up. For want of anything better, the term ‘adolescent urologist’ is used and understood by pediatricians and urologists.

If the tradition of using one of the classical languages is followed, Isovial Urology could be considered from the Greek ισοβια meaning lifelong. Another possibility would be Zeg Urology using the lovely Georgian word Zeg meaning the day after tomorrow.

Fourthly, there would have to be a means of training and recruiting the clinicians. This raises the age-old question about chickens and eggs. If there is no specialty, there can be no training program.

Table 2.1 An estimate of the number of adolescent urologists required in the United Kingdom

	Births per year	Total adults in population[a]	Total consults at 2 per patient/year	Urologists needed at 1/1600 consults
Exstrophy	14	840		
Posterior urethral valves	70	4200		
Spina bifida	105	4200		
Others (estimate)		2760		
Totals		12,000	24,000	15 = 1 per 4 million population

Births per year based on published incidences

[a] Estimated adult life of 40 years for SB patients and 60 years for all others. (Reproduced with permission from Adolescent Urology and Long-Term Outcomes by Woodhouse CRJ published by Wiley, Oxford, 2015 [2])

There are three broad requirements for an adolescent urologist: knowledge of the relevant anomalies in pediatric urology and their management, an understanding of the emotional and physical changes that occur in adolescence and a broad training in adult urology. The majority of the patient requirements are in adult medicine.

The number of adolescent urologists required is difficult to predict. Table 2.1 shows a calculation based on the incidence of the main relevant pediatric diagnoses and likely longevity. It shows a need for one adolescent urologist per four million of the population.

The need could be higher than this if the heavy surgical work load from exstrophy and SB is factored in. The incidence of SB has declined due to better parental nutrition, the use of prophylactic folic acid and selective terminations but the longevity is increasing.

On the other hand, although the incidence of most of these conditions in pregnancy remains steady, selective terminations in some countries will reduce the numbers in the population.

The Development of Adolescent Urology and Transition

When looking at the development of adult care for children with major congenital anomalies, there is a fairly consistent historical pathway beginning with an increasing number of adult survivors.

The current prevalence of chronic illness in children in the UK is 17–19%. In the USA the prevalence has risen from 31% in 1992 to 54.1% in 15 years. This latter figure is taken from the 2007 National Survey of Children's Health and quoted by Bethell et al. [14, 15]. These are astonishingly high figures and include an enormous range of mental, physical and 'special needs' conditions. From the 1992 data it seems that only 5% were considered to be severe. By 2007 the increase was almost entirely accounted for by obesity. Excluding obesity, the prevalence of chronic disease in 12-to-17-year-olds was 34.4%. These would be the patients who could be in need of long term specialist care. No urological condition appears in the commonest 20 considered [15].

Initially, the long-term survivors continue to be managed in the pediatric unit to which they have belonged. In a pediatric hospital in Rio de Janeiro with no transition arrangements, adolescents and adults made up 19.8% and 2.7% of outpatients respectively [16]. In a survey of academic pediatric units in the USA from 1999 to 2008, 2% of admissions were of patients between 18 and 21 years of age and 0.8% were over 21 years. This gave 60,000 inappropriate admissions in the 10 year period and there was a 6.9% annual increase [17].

Eventually the number becomes too great. Then, for a variety of reasons, patients are scattered on the winds of medical practice unless someone starts an 'adolescent service'.

The earliest adolescent clinic that I can find was founded by Dr. J. Roswell Gallagher in the Boston Children's Hospital in 1954. He described most of the features of adolescence and their effect on health that are understood today. The clinicians who worked in the clinic were from the pediatric staff of the hospital, but the environment of the rooms was changed for the benefit of the older patients. Dr. Gallagher emphasized that he did not want to start a new specialty. Importantly, the clinic was designed for adolescents presenting de novo, rather than for the long-term care of previous pediatric patients. The upper age limit was 21 years, after which some unspecified alternative arrangements were made if further care was needed [18]. Similar special units have appeared, in the UK, USA and Australia. Adolescent wards are being built, but mainly in pediatric hospitals.

There is a further difficulty that children do not become adults over night or on achieving an arbitrary birthday. Adolescence is the phase of passing from childhood to adult life. It has a variety of formal definitions. In the Oxford English Dictionary, it is described as 'between childhood and manhood (14–25 years old) or womanhood (12–21)'. The Department of Health in the United Kingdom is imprecise about its beginning, but rules that its end is the 19th birthday which means that all care must be transferred at once to standard adult clinics. Neither of these definitions is wholly satisfactory if only because children mature into adulthood at variable rates. For example when patients with congenital bladder disorders (mean age 20 years) were asked at what age they felt able to act independently from their parents, the mean answer was 17 years but the range was 11–25 years [19].

These services, beginning with Dr. Gallagher's, are aimed at the care of adolescents who can be looked after by adult services in due time. Transition is an end in itself. They are not a useful model for the lifelong care of those with conditions that do not have an adult equivalent. The patient's role is very important—transition centers around the shift in responsibility for their healthcare from the parents as prime decision makers to the young adult able to describe their condition and make decisions about their own healthcare. For the healthcare team, transition should be a process of moving from the holistic care of childhood to a specialist holistic care that will support them for the remaining three quarters of their lives.

In the UK, the first adolescent urology clinic was born almost by accident. Sir David Innes Williams who might be considered one of the two founding fathers of pediatric urology (the other being Herbert Johnston in Liverpool), was appointed as a urologist at The Institute of Urology in 1950 and pediatric surgeon at GOSH in 1952. He gradually gave up general surgery at GOSH and adult urology at the Institute so that he became a pediatric urologist at both hospitals. His adult clinic at the Institute was used for the long-term care of his pediatric patients as they became adults. At that time, the clinical part of the Institute was housed in four small buildings called the St Peter's Hospitals.

The academic Institute itself and the children's services were in the Shaftesbury Hospital in Shaftesbury Avenue. This was wholly appropriate as the street had been named for the great nineteenth-century social reformer of children's lives, the 7th Earl of Shaftesbury. The statue of Anteros, the god of requited love, at the end of the street in Piccadilly Circus, one of the best-known statues in the world, is his memorial. The outpatient clinic for the adolescents was in St Paul's Hospital and the in-patients in another ward in the Shaftesbury. No thought was given to a process of transition. The staff was virtually the same so that there was absolute continuity of care, but the environment was adult just as Dr. Gallagher had suggested. The children from GOSH (which was a short walk from the Institute) often moved to the Shaftesbury in late childhood, but even if the move was only made at puberty, the same overlap of staff softened the blow and their notes were allowed to go with them, again ensuring continuity.

From 1990, when the St Peter's Hospitals were closed, and the services moved to the Middlesex Hospital, this happy inter-relationship slowly dissolved. By this time the care of the grown-up children had been formalized with an Adolescent Urology Unit. It is regrettable that we failed to notice the increasing difficulties that the children and their parents suffered with this change. The smooth transfer through adolescence was lost but no process of transition was conceived in its stead.

A second move to University College London Hospital (UCLH) in 2005 further weakened the links. However, the development of a full-blown Adolescent Medicine Service emphasized this problem in urology and a Transition Clinic for the GOSH/UCLH urology children was started in 2008.

Other pediatric specialties seem to have developed in a similar manner. Up until 1974, for example, 60–65% of babies with major congenital heart disease died before their first birthday. From then on, there was a steady increase in childhood survival but as late as 1990, 40–50% were dying in their 20s (mean 25.4 years), in 20% because of inappropriate management in general cardiology services [20, 21].

The response to this was the establishment of a Grown up Congenital Heart unit (GUCH) at the Brompton Hospital. The success of this unit has led other hospitals to follow. There are 55 units in the USA and 15 in Canada [22]. Unfortunately, GUCH patients make large and very expensive demands on cardiac services, especially when re-operation is needed [21].

There have also been improvements in the survival of children with cystic fibrosis and mean survival is now 37.4 years. This has stimulated the establishment of specialist adult care facilities in the USA and UK [22, 23].

Despite the success of adolescent medicine, provision of services throughout the world is patchy. In UCLH there are adolescent services for asthma, diabetes, cardiology, cancer, rheumatology, psychology, orthopedics, neurology, endocrinology, gynecology, disorders of sex development (DSD) and urology. This provision is exceptional in the UK. However, an informal survey of members of the British Association of Pediatric Urologists in 2008 showed that most had managed to identify an adult urology colleague with appropriate knowledge to whom their child patients could be passed as adults. Similar progression has occurred in the USA [24].

Adolescent Urology is gradually appearing in the rest of the world. The present book is based on an International meeting in Toronto in 2013. The European Association of Pediatric Urology has a committee working on the development of Adolescent services. The Journal of Pediatric Urology has an adolescent section with its own editor. The fact remains, however, that there are very few full time Adolescent Urologists in the world.

Specialist Adolescent Urology Units can be identified in Europe, the USA, and Southeast Asia but they are few and far between. The Howard Snyder Chair of Adolescent Urology has been endowed by the Children's Hospital of Philadelphia in recognition of Dr. Snyder's lifelong commitment to children as they aged. An appointment is expected in the near future. There are also many physicians, especially in the USA, who practice some adolescent urology. In most cases, however, it is as an extension of Pediatric Urology and ends at some age before 21 years. This is an improvement on the position 30 years ago, but further development is needed.

In Adolescent urology, the numbers are always going to be small and the problems complex. It is important that the future development is in the direction of specialist units, rather than many physicians looking after small numbers of patients. It has been shown repeatedly in diverse areas of medicine that the best outcomes are achieved in units with largest numbers of patients.

The development of transitional, as opposed to adolescent, care has been led by parents. They struggled, in some cases for decades before pediatric and family practice groups began to take action. Figure 2.1 shows the academic output in the field as judged by papers listed in PubMed. Transitional care in urology is far behind.

The principles of transitional care have been well described, especially by Professor Russell Viner in the UK and a joint committee based on the American Academy of Pediatrics (AAP) [25, 26]. There are few differences between them which is hardly surprising as the needs are the same the whole world over [13]. However, I strongly disagree with the AAP view that the ideal age for arranging transition is between 18 and 21 years old—this is far too late for urology patients. There are many issues that arise in the early-to-mid teenage years to do with body image and curiosity and concern about sexual and reproductive function. These should be addressed proactively and there is an advantage for those conversations happening in an adult environment where they can be continued and revisited when required. A clear example is the discussion about pregnancy- in particular the importance of serum hCG testing (as a result of the high false positive rate with urine pregnancy testing in the reconstructed urinary tract), folate supplemention in preparation for conception in neuropaths and the need for conscientious monitoring through pregnancy.

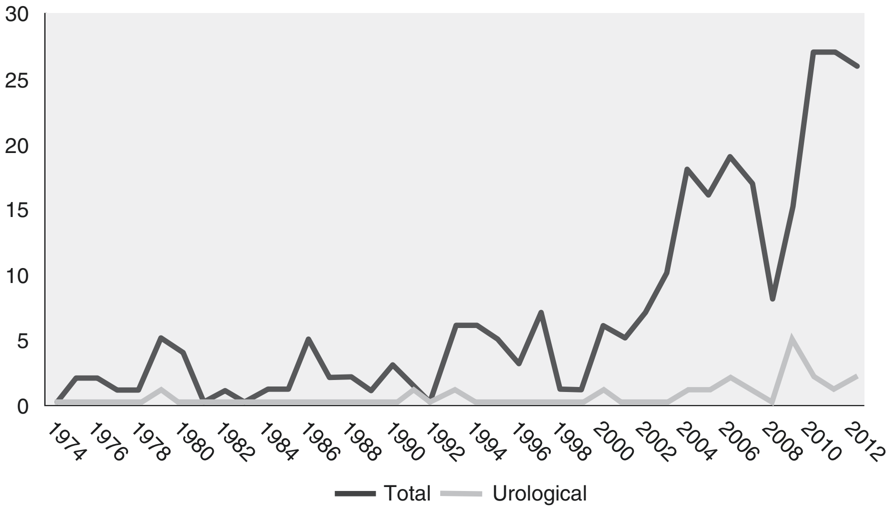


Fig. 2.1 Papers listed in PubMed under 'Transitional Care' (black) and 'Transitional Care, Urology' (gray) from 1974, when the first paper appears, to 2012. (Reproduced with permission from Adolescent Urology and Long-Term Outcomes by Woodhouse CRJ published by Wiley, Oxford 2015 [2])

In practice, very few Transition Clinics actually exist, especially in urology. In a survey in the USA published as recently as 2010 it was found that 50% of internists and 62% of pediatricians thought that it would be difficult for children with chronic conditions to find appropriate adult care [27].

Measuring Outcomes

It would seem self-evident that Transition clinics and life-long subspecialist care for complex congenital anomalies would produce good outcomes. In a survey of pediatric urologists in the USA (but with only a 31% response rate), 81% felt that an adult urologist with adolescent and pediatric training should take over long term care and 45% had such an individual available in their practice. It is not mentioned who the other 19% thought should care for them [28]!

In a patient survey in the Netherlands, 49% of potential transferees felt that they could arrange their own adult care, but of these only 24% knew what care was needed [19].

In an uncontrolled study 95% of patients thought that their attendance at a Transition clinic had been helpful [29]. In another uncontrolled study of juvenile diabetics the number of acute admissions was reduced by 23% in those who had been through a formal transition process compared to those who had not [30]. Similar improvements have been found in other fields but there was no randomization which immediately introduces a selection bias.

It would be difficult to do a randomized controlled trial (RCT). Indeed the single partly relevant RCT of a 2 day cognitive behavior program to prepare SB children for transition, showed no difference compared to standard transfer, as measured by instruments for skills, self-care and personal adjustment [31]!

As transition has become an accepted standard of care in pediatrics (even though with inadequate provision) it would be ethically difficult to have an RCT where the control group did not have it. At best, different transition programs could be tested. Assuming a protocol for transition is established, compliance with it and establishment in the adolescent clinic could be measured as a governance issue but would not show whether it was beneficial. Re-attendance of patients in the pediatric unit after transfer to adolescence would be a measure of failure and the reasons could be investigated.

There are a few conditions where the main care is in adolescence, such as varicocele and adolescent cancer. Level 1 evidence on their management really should be available.

Most patients who arrive in urologic adolescent care are in a fairly stable state having had reconstruction or other management as children. Reporting of the normal urological outcomes such as continence, stone clearance, relief of obstruction etc. are important but they are measures of the success or failure of the pediatric care. These data should be a guide to pediatric urologists who may change management as a result. However, as the long-term results are only available 20 years or more after the original treatment it is often found that management has been changed before the outcomes were known.

Data of this kind, as well as unexpected outcomes, will only be available if the patients are followed in dedicated units.

In groups of patients who appear to be stable at the beginning of adolescence, the ability to maintain the status quo would be an appropriate outcome measure. For example, 46% of patients entering adolescence with a glomerular filtration rate below 60 mL/min/1.73 m^2 develop end stage renal failure within 5 years [32]. This deterioration can be slowed or even halted, success in this domain is a good outcome measure.

If it is accepted that the adolescent and adult patients should have the same holistic care as they did in childhood, adult-type outcomes should be measured. Adults are very concerned, amongst other things, with higher education, sexuality, fertility and employment.

It could be said that success as an adult can be measured by their occupation. Disability should not be a barrier to a successful life. A survey of patients with complex urological anomalies from the UCLH Adolescent Clinic in 2010 showed that 34% were in the higher professions and 30% were in skilled or administrative jobs. Only 8% were unemployed. Perhaps the most surprising figure from the survey was that 10 of the 20 patients with neural tube defects were in a profession [33].

As it is accepted that children with complex congenital anomalies should be looked after by pediatric specialists it seems logical that their care as adults should also be with appropriate specialists. Their conditions do not become less complex just because they have grown up.

References

1. Halton W, Sheldon J, Christmas S, Findlay C, Sharpe D. The mute swan (Cignus olor)—life cycle. North West Swan Study Group. 2015. http://www.northwestswanstudy.org.uk/old/muteswan.htm. Accessed 8 Jun 2018.
2. Woodhouse CRJ. Adolescent and transitional urology—an introduction. In: Woodhouse CRJ, editor. Adolescent urology and long-term outcomes. Oxford: Wiley; 2015. p. 1–10.
3. Rosano A, Botto LD, Botting B, Mastroiacovo P. Infant mortality and congenital anomalies from 1950 to 1994: an international perspective. J Epidemiol Community Health. 2000;54:660–6.
4. Cooper S. Spina Bifida. The first lines of the practice of surgery. London: Richard Phillips; 1809. p. 543–6.
5. Waring HJ. Operations on the spinal column and spinal cord. In: Waring HJ, editor. Manual of operative surgery. Edinburgh: Young J Pentland; 1904.
6. de Vries JDM, van Gool JBDM. The history of exstrophy of the bladder: the Dutch contribution. In: Mattelaer JJ, editor. de Historia Urologiae Europaeae, vol. 1. Kortrijk: European Association of Urology; 1994. p. 145–51.
7. Mayo CH, Hendricks WA. Exstrophy of the bladder. Surg Gynecol Obstet. 1926;43:129–34.
8. Rickham PO. Vesico-intestinal fissure. Arch Dis Child. 1960;35:97–100.
9. Remigailo RV, Woodard JR, Andrews HG, Patterson JH. Cloacal exstrophy: 18-year survival of untreated case. J Urol. 1976;116(6):811–3.
10. Hayward RH, Wakim KG, Remine WH, Grindlay JH. An experimental study of the role of the colonic mucosa in hyperchloraemic acidosis. Surg Gynecol Obstet. 1961;112:357–65.
11. Jacobs A, Barr-Stirling W. The late results of ureterocolic anastomosis. Br J Urol. 1952;24:259–316.
12. Parsons FM, Powell FJ, Pyrah LN. Chemical imbalance following ureterocolic anastomosis. Lancet. 1952;2(6735):599–602.
13. Viner RM. Adolescents' health needs: the same the world over. Arch Dis Child. 2013;98(1):2.
14. Newacheck PW, Taylor WR. Childhood chronic illness: prevalence, severity, and impact. Am J Public Health. 1992;82(3):364–71.
15. Bethell CD, Kogan MD, Strickland BB, Schor EL, Robertson J, Newacheck PW. A national and state profile of leading health problems and health care quality for US children: key insurance disparities and across-state variations. Acad Pediatr. 2011;11(3 Suppl):S22–33.
16. Jesus LE, Dekermacher S, Frota J, Braganca JJ, Anderson KM. Adolescents and adults in pediatric urology clinics. J Pediatr Urol. 2013;10(3):408–11.
17. Goodman DM, Hall M, Levin A, Watson RS, Williams RG, Shah SS, et al. Adults with chronic health conditions originating in childhood: inpatient experience in children's hospitals. Pediatrics. 2011;128(1):5–13.
18. Gallagher JR, Heald FP. Adolescence; summary of round table discussion. Pediatrics. 1956;18(6):1019–25.
19. van der Toorn F, Cobussen-Boekhorst H, Kwak K, D'hauwers K, de Gier RP, Feitz WF, et al. Needs of children with a chronic bladder in preparation for transfer to adult care. J Pediatr Urol. 2013;9(4):509–15.
20. Somerville J. Near misses and disasters in the treatment of grown-up congenital heart patients. J R Soc Med. 1997;90(3):124–7.
21. Dore A, Glancy DL, Stone S, Menashe VD, Somerville J. Cardiac surgery for grown-up congenital heart patients: survey of 307 consecutive operations from 1991 to 1994. Am J Cardiol. 1997;80(7):906–13.
22. Betz CL. Approaches to transition in other chronic illnesses and conditions. Pediatr Clin N Am. 2010;57(4):983–96.

23. Boyle MP, Farukhi Z, Nosky ML. Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. Pediatr Pulmonol. 2001;32(6):428–36.
24. Tanaka ST, Kaufman MR, Brock JW III. The aging pediatric urology patient: obstacles and opportunities in transition care. J Urol. 2012;187(4):1159–60.
25. Viner RM. Transition of care from paediatric to adult services: one part of improved health services for adolescents. Arch Dis Child. 2008;93(2):160–3.
26. Cooley WC, Sagerman PJ. Clinical report—supporting the health care. Transition from adolescence to adulthood in the medical home. Pediatrics. 2011;128(1):182–200.
27. Okumura MJ, Kerr EA, Cabana MD, Davis MM, Demonner S, Heisler M. Physician views on barriers to primary care for young adults with childhood-onset chronic disease. Pediatrics. 2010;125(4):e748–54.
28. Szymanski KM, Misseri R, Whittam B, Large T, Cain MP. Current opinions regarding care of the mature pediatric urology patient. J Pediatr Urol. 2015;11(5):251.e1–4.
29. Shalaby MS, Gibson A, Granitsiotis P, Conn G, Cascio S. Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. J Pediatr Urol. 2015;11(2):89.e1–5.
30. Nakhla M, Daneman D, To T, Paradis G, Guttmann A. Transition to adult care for youths with diabetes mellitus: findings from a Universal Health Care System. Pediatrics. 2009;124(6):e1134–41.
31. Betz CL, Smith K, Macias K. Testing the transition preparation training program: a randomized controlled trial. Int J Child Adolesc Health. 2010;3(4):595–607.
32. Neild GH, Thomson G, Nitsch D, Woolfson RG, Connolly JO, Woodhouse CRJ. Renal outcome in adults with renal insufficiency and irregular asymmetric kidneys. BMC Nephrol. 2004;5:12–22.
33. Woodhouse CRJ, Neild GH, Yu RN, Bauer S. Adult care of children from pediatric urology. J Urol. 2012;187(4):1164–71.

3

Adolescence: An Overview

Joanna Begent, Jane Simpson, and Lara Gamper

Introduction

Adolescence is known to be a time of great change; from when a child starts puberty to when they become and adult (from Latin *adolescere*, meaning “to grow up”).

The precise definition and timings of adolescence are contested and probably differ for each young person as they have their own individual experience of this challenging time full of ups and downs. For the majority, it will be a largely positive time with more young people than ever contributing through volunteering and succeeding in education. However, it is also a time of immense change which can be hard enough in itself without the additional impact of ill health.

It is known that ill health significantly affects progression through the key tasks of adolescence—biological development (puberty), psychological development (complex abstract thinking, personal identity, impulse control), social development (emotional separation from parents, social autonomy, independence) and disruption in these tasks due to other factors such as mental ill health can cause a multitude of functional and physical problems.

Thus some awareness of these tasks and ability to spot problems with them is crucial. We will consider means of communicating well with young people and taking a brief additional history to pick up relevant issues.

At this time, a young person’s brain is changing faster than any time other than the first year of life—making them especially vulnerable. They may indulge in risk taking behaviour, especially when in groups (peer pressure) but are also susceptible

J. Begent (✉)
Department of Paediatric and Adolescent Medicine, University College London Hospitals, London, UK
e-mail: j.begent@nhs.net

J. Simpson · L. Gamper
Department of Adolescent Medicine, University College London Hospitals, London, UK
e-mail: jane.simpson12@nhs.net; lara.gamper@kispi.uzh.ch

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_3

to new risks. Some issues that arise may expose them to child safeguarding concerns as their vulnerabilities put them at risk of exploitation; not only sexually but from gangs, extremists etc.

Young people may create a risk to each other and themselves particularly through the use of the internet and social media—in many circumstances these are a wonderful resource facilitating communication with young people and, in healthcare, may help them understand and engage with treatment.

Adolescence can be a positive opportunity to transition young adults from paediatric to adult health care—by treating them thoughtfully and respectfully the aim is to truly engage young people in their health care. Developing their understanding of what is happening around them, alongside what they want from a service (respect, confidentiality, competence). In addition, the use of guidance and legal frameworks in place to protect and support them during transition to adult services results in a better experience, engagement and ultimately improved long term health outcomes.

Epidemiology

Data from the World Health Organisation show us that in 2012 adolescents have low mortality rates compared to other age groups and this rate continues to decline slowly. Across the world the main causes of death are trauma from road traffic accidents, HIV (rates have more than tripled since 2000), suicide, lower respiratory tract infections and interpersonal violence. Up to 35% of the global burden of disease starts in adolescence with depression, trauma, iron deficiency anaemia, HIV and suicide being the main cause of disability-adjusted life years lost in 10–19-year-olds.

Morbidity is a major public health priority for teenagers—many non-fatal diseases and conditions develop during this time with implications for the life-long health of the individual but also service provisions for the future. The most prevalent conditions causing significant disability worldwide have demonstrated little change from 2000 to 2012, and are consistent between low, middle and high income countries. Asthma, anxiety and back and neck pain feature for younger teenagers. In older males, alcohol use is a significant concern. Whilst major issues for teenagers include mental health and violence it is notable that they are not key health focuses. However, good health during adolescence is critical for lifelong wellbeing and investment in this age group has significant long-term benefits. Many of these health issues originate in the first decade, so clearly the whole life course is important. However, the transition from child to adulthood through adolescence and the impact of the very apparent developmental process make it a vital time to impact life-long health-related behaviours.

In the United Kingdom, 10–24-year-olds represent 20% (11.7 million) of the population. One in five is from an ethnic minority. The majority of under 18s live at home but greater numbers of 18–24-year-olds and beyond are living at home, causing a widening of the gap from physical maturity to financial independence (a postulated explanation for mental health and behavioural issues at this age).

The UK has a significant number of young people who are asylum seekers, homeless and looked after by the local authority who all have specific health care needs requiring consideration. Most young people stay in education until they are 18. 6.5% of 16–18-year-olds are not in education, employment or training. Forty percent of over-18s remain in education, unemployment for 18–24-year-olds is decreasing but the instability of this employment may disadvantage them.

Twenty percent of 11–15-year-olds are obese, and teenagers usually consume far over the recommended daily sugar intake—reduction in physical activity is seen throughout this age group. However, rates of smoking, drinking and drug use in the UK are all falling in this age group. At least a quarter of pupils in secondary school report getting too little sleep. This is multifactorial, but the Smartphone is a key issue.

Our understanding of adverse childhood experiences including: living with parental mental health issues, domestic violence, substance misuse etc has helped build a picture of the impact of an adolescent's day to day experience on their lifelong health outcomes. Young people living with low incomes are more likely to to be obese and have poor mental health. There are higher rates of sexually transmitted diseases and significant road traffic injuries in young people living in the most deprived areas. Looked after children (cared for by the local authority), young carers, children with learning disabilities and those from ethnic minorities or identifying as LGBT all have worse health outcomes. These effects start in adolescence but last throughout life [1].

Developmental Tasks of Adolescence

After the first year of life, adolescence is the time of greatest change for our bodies and minds. We change from children to adults both physically and emotionally. The psychological journey can be behaviourally challenging but may be widely influenced by social determinants of health, vulnerabilities and resilience influenced by genetic factors—our understanding of how these factors integrate is poor. Whilst we think of the period of adolescent development from 10 to 19 years evidence from neuroscience has shown that brain development goes on into the middle of the third decade.

Physical Development

The change from a child to an adult requires maturation of all the organs including significant change in the brain. Externally—the reproductive organs change most significantly. Population-wide the start of puberty has shifted to an earlier age (especially in association with obesity) but the end of puberty remains around the same. There is large individual variability but girls start between 12 and 13 years and boys between 13 and 14 years [2]. Thus in early adolescence girls with start their growth spurt, which will come later for boys. Girls will start breast bud development and pubic hair growth while boy's testes grow first followed by genital development. By mid-adolescence girls undergo menarche and develop an adult body shape with the associated fat deposition. Boys voices may 'break' and they start producing and emitting sperm. By the end of puberty boys will have developed a more muscular body shape and body hair.

Brain Development

One of the major developments in neuroscience over the last 20 years has been the understanding of the remarkable rate of brain development (in both cortical and subcortical structures) through adolescence [3]. The growth of the prefrontal cortex, which controls executive functioning along with its connectivity to the limbic system, improves enabling regulation of behaviour, emotion, reasoning, emotional intelligence, perception of risk and reward. The exact inter-relationships between brain changes seen on functional MRI and developmental changes are not fully understood but it is recognized that this is a time of significant vulnerability for risk taking and mental health issues when the emotional milieu of a young person is vital.

Cognitive and Behavioural Development

The way a young person thinks changes during adolescence as cognitive processing progresses from concrete thinking to develop the ability to allow and manage abstract thoughts, into complex thought processes. They learn from experience, developing their moral and ethical code and way of thinking, the incorporate political and religious ideology and learn to control impulses. The brain becomes more efficient and able to adapt.

However, there are periods of impulsivity when young people may see themselves as 'bullet proof'. These impulses lead to risk taking, especially when with peers, as the 'social brain' develops and young people learn to interact with others independently [4]. This period can present challenges when managing health care, requiring appropriate skill and resource to understand and manage this phase well—embedding good life-long health care behaviours.

Emotional and Social Development

In early adolescence brain development and puberty start to impact on sexuality, as sexual identity develops and sexual orientation matures, ultimately moving towards finding a partner. Sense of self, separated from family begins to create a personal identity and develop self-esteem as well as a move away from family, who whilst remaining important, are joined by friends, peer groups and ultimately a partner as key figures in young people's lives. This may include a period of experimentation with drugs and alcohol etc. This is at a time when they are also developing their independence (including with their healthcare) and sense of responsibility and moving towards a vocation and financial independence.

Communicating with Adolescents

Adolescence is a time when young people need to start taking control of their health care and as a result their medical care team needs to shift away from a focus dependent on communicating with parents and carers (adults) to communicating with the young person. This should include written communication as well as in consultation and indeed consideration must be given to using electronic communication as the most effective means of communicating with young people.

Communicating with young people can be problematic. Initially focusing conversations on them with adults in the room but quickly moving to seeing them alone for some of the consultation is crucial. This is an opportunity for them to develop autonomy and their own voice as well as discuss private issues that are relevant. It is important to reassure adults initially about the importance of this time, as this separation for them if they have been caring for a chronically ill young person can be challenging. Other members of staff can be used to help this process so a young person and adults can be seen separately but at the same time [5].

Young people place great value on confidentiality. It is important to let under 18s know that if they disclose any information that puts them or others at risk it will need to be shared with their responsible adults but the exact nature of what is shared may be negotiable (especially if 16–18 years). Generally, this does not reduce disclosure of important information.

Consultations for young people need time. A period of 'problem free talk' getting to know a young person can be a great investment as they value people taking an interest in them. Non-judgmental curious questioning to understand their views and decisions are important, for example around medication. Assessing their understanding of their condition and what they have remembered from previous consultations provides a basis to start the consultation.

Proxy presentations (i.e., presenting with a simple problem when another issue is paramount) are common in adolescent medicine and further questioning may be needed—to ascertain the problem that is most worrying them. An additional adolescent set of questions can be useful, including psychosocial questions checking strengths as well as risks are vital to understand all the factors discussed throughout the chapter that may be affecting a young person's life causing risky behaviours, ill health and impacting on chronic disease.

The 'HEADS' framework is helpful in exploring this history [6]. It can be covered quickly or explored in greater depth, it is a recognised psychosocial interview framework that allows a better understanding of the young person's situation and what their specific needs may be.

- Home
  Who is at home? How are they? what are your relationships like? What is home like? Do you have responsibilities? (chores)
- Education/Employment
  Are you in school? Employment? How is it going? What do you enjoy? What is your attendance like? Are you doing exams? What are your plans for the future?

- Activities
  What do enjoy doing? How do you spend your time? Do you do any sport? Tell me about your friends? Do you go out much?
- Drugs
  Smoking/Alcohol/Drugs? Amounts? How do you pay for it?
- Driving
  At 16 if disabled
- Diet
  What is your diet like? Do you ever restrict or binge eat? Or vomit? Do you drink caffeine/enough water?
- Sexuality
  Do you have a partner? Have you had one previously? Was it a boy or a girl? Have you been sexually active? Did you use contraception and protection?
- Sleep
  Do you get enough sleep?
- Screen time
  How many hours? What type/sites/apps? Any cyberbullying? Addictive behaviours? At night?
- Suicidal ideation
  Depression, anxiety, a more detailed history may be important.
- Safety
  Do you ever feel at risk of violence? If so from where?

For some of these questions it can be helpful to start in an abstract manner before asking personally about the issue for example:

> Around your age people sometimes start doing drugs, is this happening in your school? How about your friends? Have you ever tried any drugs? Which ones? How often? How did you find it?

By normalizing the behaviour, it can feel less judgmental.

When examining a young person, it is important to ensure they understand why this is important and to give them some control over how it happens. Would they like a doctor of the same sex (if possible)? Would they like their adult/friend with them? A chaperone is essential. Ensuring the minimal amount of their body is exposed is good practice.

Using straight forward, developmentally appropriately language (both verbally and in correspondence) is essential and checking back that the young person has fully understood both their diagnosis and treatment plan will increase adherence. It is normal for young people to be ambivalent and it may take a few sessions to establish trust so consistency where possible is important.

When young people are taking control of their own treatment it is also important to ensure there is agreement on taking medication or engaging in therapy. Some open questions such as ‘most people struggle to take all their medication; how do you manage?’ may lead to a more honest response. Understanding their motivation for taking a certain medication or their beliefs as to why they did not may help problem solving and explaining additional benefits, e.g., 'once you are well you will go into puberty.' It is vital to plan what is realistic with the young person and think about strategies to help them for example thinking through the practicalities of their day such as school. Approaches such as 'with teeth brushing' rather than twice a day, alarms on mobile phones and smaller more discrete devices for school may all help. It is helpful to understand from the young person what has helped them before and repeat it.

Health Problems in Adolescence

Adolescence is generally a time of good health however 10% of 10–24-year-olds have a disability that permanently affects their life and nearly 1 in 4 11–15 year olds have a long term illness or disability. It remains unusual for young people to die but the main causes of death, preventable injury and suicide are usually avoidable. Deaths from cancer are falling more slowly in this than other age groups.

The diagnoses of asthma and type 1 diabetes mellitus are most commonly made in teenagers. Prevalence of autoimmune conditions increases at puberty these include inflammatory bowel disease and inflammatory arthritis, age specific types of epilepsy emerge and migraine becomes more common especially in girls. The growth spurt of puberty leads to musculoskeletal pain and pain syndromes which can be challenging to manage.

Teenage pregnancy rates have fallen in the UK but remain relatively high for Europe. Between 15 and 24 there are higher rates of sexually transmitted disease than in any other age group, chlamydia being the most common.

The majority of young people report high or very high satisfaction with life. However, 50% of lifetime mental health disorders have started by age 14, and 75% by 24 years. Self-harm and eating disorders peak aged 15 years, hospitalisation is more common in girls; concerningly 25% of 16–24-year-old women show signs of anxiety or depression. Whilst 10% of this age group have significant mental health problems, only a small proportion of this number will receive support from mental health services.

Young people are significant users of health services with at least half visiting their general practitioner and a third attending the emergency department every year.

Education is a key determinant of long-term health, it appears engagement with secondary education improves mortality, mental health, fertility and reduces sexually transmitted diseases.

Chronic illness and biopsychosocial development are reciprocally affected during adolescence. Chronic illness can physically interrupt progress through puberty, affect growth (both height, weight and bone density) and have profound effects on body image and sexualisation. It also affects social development as a young person creating a more dependent relationship with their parents/carer and thus a patient struggles to gain autonomy. This in turn will impact on development of friendships, relationships, establishing independence and progression towards a vocation.

Adolescent development may have a deleterious effect on chronic disease management. The metabolic demands of puberty can affect diabetes management (due to increased growth hormone) and any condition where eating is a challenge. As young people go through the psychological changes of adolescence their disease management is often compromised with poor planning, ‘bullet-proof’ thinking, lack of adherence and rejection of the medical profession. Young people with chronic disease are more likely to indulge in risk taking behaviours and a chaotic life style which may compound poor disease management further.

Good disease management is key to progression through puberty as is addressing nutritional issues efficiently. Management of this challenging time may require a wider multidisciplinary team including mental health support (for the young person and family), social work input, dietetics and potentially a co-ordinating adolescent specialist. Endocrine input may be beneficial to oversee pubertal progression.

Safeguarding Adolescents

Adolescents are vulnerable, in many ways, throughout this complex period of life. Chronic illness compounds this vulnerability compounding low self-esteem, affecting peer support and increasing a tendency for risk taking and exploitation. Safeguarding is everybody’s responsibility but ensuring the safeguarding needs of this group is considered is a key role of their clinical team. Self-reported data from 2009 suggest that 18.6% of 11–17-year-olds have been the victim of some kind of severe maltreatment [7].

Young people are at risk from physical violence in the home from parents and siblings, within sexual relationships (domestic violence), and in the community with the prevalence of gang violence being widely reported. Unusual bruising and injuries should always be recorded and questioned—the medical consultation maybe a young person’s key moment to disclose if asked sensitively. Complex issues such as honour violence must be considered.

Up to 15% of young people report neglect. This often starts as young people move to secondary school and develop more independence. Whilst they are more practically independent the need for emotional support, boundaries and guidance remains crucial, especially if they are living with a chronic condition. This emotional maltreatment (abuse or neglect) can have life-long consequences on disease management, mental health, socialisation and lead to addiction. Emotional abuse maybe more specific and is more common in young people with chronic disability or illness. As the young person is part of the community this may come from peers and on line as well as from within the home. Issues such as trafficking and radicalisation must also be considered.

Since 2012 there has been a doubling of sexual offences against children under 18. Twenty-four percent of 10–18-year-olds have been contacted by an adult they do not know on-line; more than one in seven children aged 11–18 (15%) have been asked to send sexual messages or images of themselves. Many serious sexual assaults continue to be intra-familial but there has been an escalation of peer on peer abuse, including cyberbullying and ‘sexting’. The peak age for child sexual exploitation is 15 years old. Disclosure is rare but clues such as STIs, school absence, behavioural change and altered appearance may cause alert. The nature of relationships with unknown adults accompanying a young person should always be questioned. Sexual abuse and exploitation commonly cause a deterioration in mental health. In the UK health care professionals have a mandatory duty to report any suspicion that female genital mutilation is going to be or has been performed.

One of the most complex forms of abuse is factitious and induced illness. In young people with pre-existing health issues this can be additionally complicated. It is very unusual to see symptoms that are genuinely fabricated however exaggeration and misinterpretation of symptoms is more common and particularly challenging to unravel as the team is trying to help a young person develop an understanding of their illness and an independence from their parents. Addressing such issues early and with the support of a multidisciplinary team which may include social care and mental health support may be necessary.

Management of safeguarding issues in teenagers follows similar principles to younger children but is additionally complicated by their involvement in the process, as they get older they have a right to be involved in discussion about their safety and wellbeing. The range of potential perpetrators is wider. A young person who is scared may present with aggressive challenging behaviour or alternatively be very withdrawn. A comprehensive history, taken with the young person alone, a full examination and tools such as chronologies to determine the long-term impact of the abuse may be helpful. Whilst child protection legislation ends at 18 years of age, the effects of maltreatment can be felt into ‘legal’ adulthood and adult safeguarding processes can always be used. A multidisciplinary approach is usually needed [8, 9].

Legal and Ethical Issues

Adolescence is often a tricky time for those going through it, but can also prove challenging for doctors, particularly from a legal and ethical perspective. Consider the 4 year old girl brought by her parents because of abdominal pain. Her history will be openly discussed in the consultation; she will be examined even if she doesn’t want to be; bloods tests will be performed despite the tears; and if she needs an operation, her mother or father will be asked to give consent.

But what if she is 14 years old? What then?

Adolescence describes the period during which an individual makes the gradual transition from childhood to adulthood. It is not a legal term, therefore its meaning, and in particular the age range to which it applies, varies widely.

The WHO classifies adolescents as young people between the ages of 10 and 19 years [10], but for legal purposes, adulthood in the UK usually starts at 18 years of age. This is in keeping with guidance from the UN [11] which defines a child as everyone below the age of 18 unless specific laws have granted majority below this age. In the UK there are a number of laws which specify age limits under different circumstances. So, for the purposes of child protection, a child is anyone under

18 years of age, whereas the age of consent (the legal age to have sex) is 16 and the age of criminal responsibility is 10.

Doctors caring for young people must be aware of the legal framework that supports their practice, in particular with regards to consent and confidentiality.

When can a young person give consent?

In most cases, a doctor must obtain consent before treating a patient. For this consent to be valid, the individual consenting must have all the relevant information, have the capacity to make an informed decision, and be free from coercion.

Young people aged 18 and above are legally adults and are therefore assumed to have the capacity to make their own decisions about medical treatment. No-one else can therefore make these decisions unless it can be demonstrated that the person lacks capacity. This might be because of serious physical or mental illness. Treatment can then be provided if necessary and considered in the individual's 'best interests', or if agreed to by a previously nominated decision-maker or under mental health legislation.

Young people aged 16 and 17 years are also considered to have the capacity to *consent* for medical treatment, unless there are other factors affecting their capacity, such as a mental health problem.

Children below the age of 16 years can give consent if they are deemed 'Gillick competent', in reference to a case brought by Victoria Gillick, a mother of five daughters, over the legality of providing them with contraception under 16 without her knowledge [12]. The eventual House of Lord's judgement is specific to contraceptive advice or treatment for under 16s (the Fraser guidelines), but the name has been applied more widely to refer to the assessment of a young person's capacity to consent to all medical care. This capacity to consent will depend on the young person's emotional and intellectual maturity, and the nature of the treatment to which they are consenting.

If a child is judged not to have capacity, then consent should be sought from a person with parental responsibility (PR). This will be the mother and usually the father if he is married to the mother or was named on the birth certificate (for further information on PR see Box 3.1).

Box 3.1 Parental Responsibility (PR)

PR describes the legal rights and responsibilities of a parent, which include the basic provision of a home to choosing their education to ensuring their protection. Mothers automatically have PR for their children from birth whilst fathers will have PR if married to the mother, or listed on the birth certificate, or through a specific PR agreement with the mother or a PR order from the court. Same sex partners will both have PR if they were civil partners at the time of treatment, or if they have a PR agreement or jointly registered the birth. PR is shared with the local authority if the child is under a care order. PR can only be removed from the birth mother when a child is adopted.

For more information see https://www.gov.uk/parental-rights-responsibilities

However, for children and young people under 18 years, *refusing* treatment is different to consenting to treatment. Whilst the decision of a young person with capacity cannot be overridden by their parents, in the case of life-saving treatment, an application can be made to the court to make a decision in the young person's best interests. The court has the power to override the decisions of both the parents and a young person with capacity.

Occasionally, providing treatment to a young person might require their restraint. For children under 16 years who lack capacity, restraint is lawful given parental consent, provided that it is necessary to provide clinical care, proportionate and involves the least restrictive measures possible. For young people aged 16 and 17 years who lack capacity, guidance on restraint is provided by the mental capacity act 2005 [13] which states that a young person can be restrained if it is reasonably believed to be necessary to prevent harm to the individual being restrained. Again, it must be proportionate and involve the least restrictive measures. A child with capacity may also be restrained if the treatment being provided is immediately life-saving or if their capacity may be temporarily suspended due to fear or distress, and their parents have provided consent. Physical restraint is also legally justified if it is required to prevent self-injury, significant injury to staff or others, serious damage to property or an offence from being committed.

A child or young person of any age may be detained under the Mental Health Act 1983 to enable treatment of their mental illness, or manifestations of that illness, such as administering NAC in the case of paracetamol overdose.

Further information can be found at Child Law Advice [14].

What Are the Rules Around Confidentiality?

Confidentiality is a fundamental principle of medical care and underpins the trust which is essential for the doctor-patient relationship. Doctors have a duty of confidentiality towards their patients, which is the same for children and young people as it is for adults. This means that young people have the right to have their personal information remain confidential unless they give consent or there is a legal justification for its disclosure, such as in the context of child protection or in the prevention of a serious crime. For the purposes of providing direct care or local clinical audit, *implicit* consent can be assumed provided certain criteria are met, such as the young person is aware of how their personal information might be used within the clinical team. Without a legal justification, information sharing for all other purposes requires *explicit* consent, from either the young person with capacity or an individual with parental responsibility if the child lacks capacity. A parent may only see their child's health records if it is in the child's best interests and the child has consented or lacks capacity to consent. More information can be found on the General Medical Council website [15].

Transition

It is inevitable that young people will need to progress through paediatric services to adult carers. This can be challenging as paediatric services often see patients more frequently and have easy access, adult services are more likely to expect patients to function independently between less frequent and maybe less well coordinated appointments. The management of this process of transition is crucial to ensure ongoing engagement in their healthcare with good long-term outcomes.

Discussion about transition should start at an early age. The paediatric team should prepare the young person to have more responsibility for their condition, seeing them alone and directing the consultation to them, asking them to explain plans to their parents/carers etc. Exact timings will depend on the young person's developmental readiness rather than rigid timings dictated by the service. Ideal times may include coinciding with other transitions such as move to higher education, however it is evidently less likely to work well during a flare of illness.

Information about the transfer process should be given to the young person and adults with time to discuss and question. The anxieties of adults can provide a significant barrier to successful transition. A GP may be another important resource as a more robust relationship with them may become necessary. Joint creation of a 'passport' documenting a young person's health, history, likes and dislikes etc can be an empowering tool for them and useful for future services as well as in emergencies.

There are different models of transition depending on the condition and available resources. Direct transfer from paediatric to adult care should involve prior visits to the adult clinic and ideally joint appointments with both teams to transfer care. An adolescent/young people's service that bridges this age group and runs for several years with paediatric and adolescent teams working together is an excellent model. Key staff should be identified to support young people through this process, a clinical nurse specialist is ideal.

Guidance has been published to make services young people friendly – these discuss environment, methods of communication, accessibility, staff training etc. The involvement of young people is vital in designing any service for them [16, 17].

In Summary

- Adolescence is a time of rapid brain and body growth with psychosocial development as a child becomes an adult.
- Communicating with teenagers requires time and thought, an additional psychosocial history is important to understand the interaction between adolescent development and their health condition.
- There are many diseases that start in adolescence including most mental health issues. However, teenagers can have paediatric and adult conditions.
- Safeguarding teenagers is vital as they are exposed to, and often take, many new risks and are especially vulnerable to neglect.

- Issues of consent and confidentiality in young people can be complex but there is clear guidance.
- Supporting young people as they transition from paediatric to adult services improves long term health outcomes.

With thanks to Dr. Terry Segal for her input and support.

References

1. Hagell A, Shah R, Coleman J. Key data on young people 2017. London: Association for Young People's Health; 2017. http://www.ayph.org.uk/keydata2017/FullVersion2017. Accessed 30 Oct 2018.
2. Patton GC, Viner R. Pubertal transitions in health. Lancet. 2007;369:1130–9.
3. Goddings AL, Burnett Heyes S, Bird G, Viner RM, Blakemore SJ. The relationship between puberty and social emotion processing. Dev Sci. 2012;15(6):801–11.
4. Blakemore SJ. Development of the social brain in adolescence. J R Soc Med. 2012;105(3):111–6.
5. White B, Viner RM. Improving communication with adolescents. Arch Dis Child Educ Pract Ed. 2012;97(3):93–7.
6. Doukrou M, Segal TY. Fifteen-minute consultation: communicating with young people-how to use HEEADSSS, a psychosocial interview for adolescents. Arch Dis Child Educ Pract Ed. 2018;103(1):15–9.
7. Bentley H, Burrows A, Clarke L, Gillgan A, Glen J, Hafizi M, et al. How safe are our children? NSPCC; 2018. https://learning.nspcc.org.uk/media/1067/how-safe-are-our-children-2018.pdf. Accessed 30 Oct 2018.
8. James DR, Sargant NN, Bostock N, Khadr S. New challenges in adolescent safeguarding. Postgrad Med J. 2017;93(1096):96–102.
9. Khadr SN, Viner RM, Goddard A. Safeguarding in adolescence: under-recognised and poorly addressed. Arch Dis Child. 2011;96(11):991–4.
10. World Health Organization. Health topics: adolescent health. http://www.who.int/topics/adolescent_health/en/. Accessed 30 Oct 2018.
11. The United Nations Convention on the Rights of the Child. https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.156926908.608784734.1512042654-652719693.1512042654. Accessed 30 Oct 2018.
12. E-lawresources.co.uk. Case summaries: Gillick v West Norfolk and Wisbeck Area Health Authority [1986]. http://e-lawresources.co.uk/cases/Gillick-v-West-Norfolk.php. Accessed 30 Oct 2018.
13. Legislation.gov.uk. Mental Capacity Act 2005. http://www.legislation.gov.uk/ukpga/2005/9/notes. Accessed 30 Oct 2018.
14. Child Law Advice. Young people and medical treatment. http://childlawadvice.org.uk/information-pages/young-people-and-medical-treatment/. Accessed 30 Oct 2018.
15. General Medical Council. Ethical guidance for doctors. https://www.gmc-uk.org/guidance/ethical_guidance.asp. Accessed 30 Oct 2018.
16. Department of Health. Transition: moving on well. London; 2008. https://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf. Accessed 30 Oct 2018.
17. Department of Health. You're Welcome quality criteria. London; 2007. https://www.ouh.nhs.uk/paediatricorthopaedics/information/documents/youre-welcome.pdf. Accessed 30 Oct 2018.

Metrics and Guidelines

4

Alun Williams and Abigail Jenkins

Overview

The landscape of transition is complex and variable. There is variability at the level of individuals (whose transition needs may be quite different), at the level of service provision, and in the type of health and social care system. The ability to understand and measure these variables in the process of transition, and how that may relate to the outcome for individuals is important. Such metrics will begin to inform how best to tackle complexity and variation in all these areas. The direction of travel for many adults with long term childhood conditions is largely unknown.

The evidence base for current practice is weak but growing. Guidance needs to be widely applicable—to support a range of individual conditions and circumstances without being so vague as to be unhelpful. Key to informing guidance are outcomes reported by service users (whether patients, their families or others). We must remember that transition from paediatric to adult care needs to include health and social care, psychosocial development, and education. Trying to find a way of measuring process and outcomes will guide the further development of transition planning.

A. Williams (✉)
Department of Paediatric Urology, Queen's Medical Centre, Nottingham, UK
e-mail: alun.williams@nuh.nhs.uk

A. Jenkins
School of Medicine, University of Leicester, George Davies Centre, Leicester, UK
e-mail: abi.jones@doctors.org.uk

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_4

Transition: The Period Between Two Inconsistently Defined Times

Transition between childhood and adulthood is a somewhat arbitrary period since, as already described (see Chap. 3), development is variable. This is even more so when children have developmental delay or conditions that impact on their physical or psychosocial development. Most healthcare systems have drawn an arbitrary distinction between healthcare in children and healthcare in adults; these have become divergent as sub-specialization has evolved. The law, likewise recognizes a distinction on the basis of age, and transition between, for example social care infrastructure between childhood and adulthood, can be enshrined in law—in the UK, the Children and Families Act 2014 [1]. The same caveats in terms of development apply in these situations. It is worth reiterating again that transition represents a process over time rather than a discrete event. Transfer is one event within this process.

The Challenge of Guidelines and Metrics for Transition

An increasing number of children with long term conditions will live into adulthood—their life expectancy continues to rise. There are numerous examples—including cystic fibrosis [2, 3], organ transplantation [4, 5], spina bifida [6, 7]. There are many factors that have led to these improvements. Poor or lacking transition appears to increase the risk for a child disengaging with or becoming lost to healthcare. This, coupled with the 'effect' of adolescence creates a considerable challenge. Accounting for this in any metric is complex.

As an exemplar, the creation of selection criteria for and against early operative intervention dramatically improved survival beyond the newborn period for spina bifida infants, in the era before antenatal diagnosis [8]. Improvements in surveillance, multidisciplinary care (including orthopedic, neurosurgical, urological) incorporating therapists, orthotics and aggressive treatment of complications (e.g. urinary infection) has led to improve care. The characterisation of 'hostile' urinary tracts [9] allowed drainage strategies to be applied—such as intermittent bladder catheterization [10]. Surveillance imaging and functional testing have allowed renal function to be accurately monitored. Contemporary assessments have suggested the incidence of renal failure in conditions with neurogenic urinary tracts has decreased to single figure percentages [11].

From the example above, it is clear that a number of transitions will have taken place in any individual's life up to the point at which they reach their 20s, namely—the transition into primary education, into secondary education, puberty, transition into adulthood (from a legal as well as healthcare perspective), higher education and employment. Each of these may influence the next stage, and the long-term outlook. The multifactorial nature of this makes it difficult to study—a randomized study would be unethical and impossible, comparison with historical cohorts would be skewed and of little or no value.

This makes useful guidance very difficult to generate. The risk is that a myriad of guidelines ensue to deal with specific conditions and/or different healthcare systems. A generic guideline runs the risk of being so general that it becomes vague and unhelpful. Disease-specific or specialty-specific guidance runs the risk of being so limited that it cannot be transferred, and the transition of individuals with multiple system problems becomes impossible to manage effectively.

Guidelines

The purpose of guidelines, in any health or social care sphere, is to provide a standard of care, ensuring equitable provision in any setting. Guidelines inform good practice, and provide a benchmark against which to measure outcomes. A further aspiration is to minimise any differences in care as a consequence of geography—the so-called ‘postcode lottery’. The myriad of chronic conditions with improving survival some of which were referred to above, as well as increasing numbers of young people with multisystem disease, have led to a need for more general guidance to be available for both health and social care.

There have been a number of guidance documents generated nationally and internationally since the recognition in published literature of the need to assess and guide the transition process for young people. Interestingly the focus on education and psychosocial development is a significant feature [12–14]. It is worthy of note that the age at which transition was proposed is higher than might have been expected—at 17–20 years [13] but with subsequent recognition that planning and preparation should be undertaken earlier [14].

In the 1990s a study in the UK [15] recognized a number of gaps not mandated by legislation. These included

- multi-system problems cannot be catered for within a single service,
- transfer should be flexible and
- some specific conditions fared less well—cerebral palsy in particular.

The latter point represented an unintended consequence of legislation.

NICE Guidance

The UK’s National Institute for Health and Care Excellence (NICE) has generated evidence-based guidance on a plethora of issues since its inception in 1999, with a rigorous approach to gathering and synthesizing evidence, stakeholder involvement (including patient and carer) and expert consensus.

The assent of the Children and Families Act in UK law in 2014 saw transition planning for those youngsters with an Education and Health Care plan (EHC) mandated at the age of 13–14. This was the basis of setting the time for transition planning from paediatric to adult healthcare within NICE guidance [16].

Elements of NICE Guidance

The guideline development group found the overall evidence base to be poor overall. Perhaps as predicted there is a lack of rigorous quantitative research powered adequately to describe different outcomes (see Table 4.1).

It is clear that these factors can be documented, measured and audited [17]—providing the foundations of metrics to plan transition in an overarching way.

Table 4.1 Some of the highlights of NICE guidance, as a foundation to plan a service

Person-centered	Moving away from the family centered approach for pediatric care
Strength based	Rather than based on a 'problem list' that highlighted deficiencies or weaknesses
Developmentally appropriate	Recognition of wide variance in the scope of a patient's readiness and/or ability. For example, transition planning processes must cater both for the young person going to university with insulin-dependent diabetes, as well as the young person with profound developmental delay requiring round-the-clock care
Named worker	Each young person must have a key person to coordinate transition and be a first point of contact. This may be a doctor, nurse, social worker or any other nominee
Involvement of parents and carers	According to the wishes of the young person and their developmental needs
Peer and mentor support	Potential for involvement with youth services, social media and special events
Advocates	May be any of, or a combination of individuals above, or another
The use of mobile technology	Reflecting increasing use in this population—for organization (e.g. SMS based reminders for hospital appointments) and information
Documents for support	Formal documentation of transition plans and process, to include patient-held summary of care. 'Ready Steady Go' program commended (see below)
Strategies for non-engagement	In healthcare to ensure consistent appointments with an individual, and to ensure communication without loss to follow-up
Ownership of responsibility for guidance implementation	Falls to institutional executive committee and management, not just individual clinicians—that is, to name a champion to oversee strategy
Gaps in service	These need to be identified and addressed at institutional levels
Review of transition planning	On at least an annual basis (and may be more frequent if required)

Cross-Cutting Metrics for Transition: Making the Important Measurable

Measurable outcomes (i.e., metrics) seem to be very heterogeneous. As described below, individual disease-related, or treatment-related outcomes are necessarily specific, but NICE guidance provides a set of metrics reflecting cross-cutting themes in transition for paediatric to adult care. Consequent to the NICE guidance was the development of quality standards to measure aspects of the process of transition [18], namely:

1. Planning of transition to commence by age 13–14 years—or as soon as possible thereafter if the individual entered a care system later
2. A documented annual meeting to review planning
3. A named worker
4. Evidence of a meeting with a defined adult practitioner
5. Engagement/non-engagement with services and strategies

In addition, gap analyses of service provision are measurable entities. The Sheffield study [15] proposed that transition plans must reflect service availability. The subsequent approach of the NICE guidelines was to propose assessing the gap in provision. This addresses some of the concerns about groups of young people who had been identified as being served poorly [16]—such as those with cerebral palsy, neurodevelopmental delay, challenging behaviours and those with a need for palliative care support.

The supporting documentation suggested for use by young people in transition allows an additional opportunity to assess transition readiness in a semi-quantitative way. In the UK and internationally, the ‘Ready, Steady, Go’ programme [19] (and ‘Hello’ when transferred to adult services) has an increasing uptake of use, and consequently is evolving an evidence base [20].

Disease-Specific Metrics

To reiterate, it is evident that metrics can be highly condition-specific—for example organ transplant rejection rates, glycosylated hemoglobin fraction in diabetes, or echocardiogram parameters in heart disease. Disease specific metrics may allow one to measure the adequacy or effectiveness of a transition process for a particular disease as surrogate markers—this would suggest an improvement in disease or treatment specific outcomes. For example, in patients with neurogenic bladder secondary to spinal dysraphism, a ‘panel’ of outcomes might be: estimated glomerular filtration rate (eGFR), upper tract appearance on ultrasound, urinary tract infection (UTI) frequency, and use of additional appliances for continence (e.g. pads). A good transition process should support a young person such that their adherence with treatment remains steady or even improves. In the absence of a new insult, estimated glomerular filtration rate (eGFR), appearance of the pelvicalyceal systems and frequency of UTIs should remain stable throughout transition. These specific metrics may be used for individual patients in a cohort i.e. to look at patient-level outcomes of a particular service.

Two studies previously mentioned are revealing examples of the importance of measurement, support of young people, coordinated transition and supporting documentation during transition. Graft failure during transition of kidney transplant patients has been observed to be a concern [4, 5]. In the latter study, the graft loss rate fell dramatically during the period of observation with supported transition. Importantly the higher rates of graft loss were in historical cohorts, and therefore will likely have been multifactorial. Nonetheless the drop in graft failure is impressive.

Each clinician should think carefully about which disease-specific measures could be utilized in their own, and institutional practice, applied specifically to the transition process. These may now be set in the context of the general requirements of a transition process as defined by the NICE guidance.

Planning for Services

Information about transition continues to evolve for all services. Some have developed requirements and service planning for particular conditions, or groups of patients (e.g. cardiology, rheumatology, gastroenterological or hepatological disease) [21]. There are some conditions where there is a clear adult team to care for a patient and therefore a diabetic or asthmatic youngster will pass from the pediatric team to their respective adult equivalent. This requires engagement in transition and a specific accommodation within an existing service. The bigger challenge may come when there is no specific adult service for some conditions, especially if they are rare and/or complex—e.g., there is no ready-made adult urological service to deal with conditions such as the bladder exstrophy—epispadias complex.

There is a range of challenges in the group of patients with complex conditions. Many conditions are rare, treatment is bespoke and the understanding of long-term outcomes is still developing. Pediatric care is highly specialized and still developing. Adult care needs to mirror that and although there are differences in service design the level of care needs to be as good and as expert. These conditions will require multidisciplinary care—for example the VACTERL association (an association of vertebral, anorectal cardiac, tracheo-oesophageal, renal and limb anomalies) will require the input of thoracic surgery, general surgery, neurosurgery, orthopedics, respiratory medicine, cardiology/cardiac surgery, nephrology, urology along with other allied professionals (such as orthotics, physiotherapy) and psychology. The contribution of both pediatric and adult carers to shared meetings is required in order to develop a better understanding of the condition, the treatment and long-term outcomes. Registries for rare diseases may have an important role to play in amalgamating knowledge. Developing services need to accommodate these elements.

One UK paediatric surgical study showed that an increasing number of children with such conditions are needing care in adult life—highlighting the need for an infrastructure (including transition) to provide this care [22].

A questionnaire study of patients with esophageal atresia (unpublished but presented [23]) revealed that only a minority (18%) had positive views on their transition. The patient views were that their preferred transition care model was a combined adult and pediatric 'transition clinic'. There are, however, other models of transition which may be more appropriate for specific local settings or conditions and there is some evidence for the utility of other models [24].

The 'transition clinic' with both adult and paediatric practitioners co-located is very common but there may be local constraints that mandate local solutions. For example would this be situated in a dedicated children's hospital or in the adult unit? Many local and logistic factors will influence the way a particular transition service develops. There is no 'right' model. Patient-related experience measures (PREMS) as well as outcome measures (PROMS) may help with service development.

Other disease-specific 'known unknowns' may play a part in planning services and the infrastructure needed to support those services. For example, ageing in the setting of a congenital disease [25] where the long-term outcomes are simply unpredictable, long term fertility issues after the treatment of childhood cancer, or after extensive pelvic surgery, long term malignancy risks, and heritability of disease or disease-modifying factors. The incidence of these problems will only be understood as we care for more of these patients in the long-term.

A further consideration is which elements of care can be delivered locally and which will need a specialist center. One aim of standardizing care with the development of guidelines is to allow uniform standard of care irrespective of the environment. The assumption of this is the availability of expertise in a local healthcare setting. The reality is that some conditions are rare and expertise can only develop in a centre where a high volume of patients can be seen and treated. This is exemplified by the contrast between adult care for Barrett's esophagus and cloacal anomalies. In adults found to have had Barrett's in childhood care can be delivered within the majority of gastrointestinal units. The management of long-term concerns in an adult having had a cloacal anomaly, will require multidisciplinary input. In conditions which have already been designated as 'centralised' in childhood (for example the exstrophy/epispadias complex), expertise in adult follow up will grow up around the children's specialist centers—in order to maintain a high volume unit in adulthood.

Commissioning

NICE guidelines signpost some issues—in particular, gap analysis—and the measurable responsibilities of individuals within organisations for the provision of commissioning and management of services.

In privately funded, or insurance-based systems there are different challenges for funding services compared with a nationally funded service. It is clear that a 'one size fits all' approach will not work. Legislation will help highlight some groups but must be carefully designed to avoid unintentionally excluding others as previously exemplified (e.g., cerebral palsy services in adulthood).

As yet, there is no specific process for commissioning transition services. In an interview study [26] common themes were clear as necessary for transition: these included both personalized (i.e., person-centered) and broadly focused themes. The authors of the study highlighted the need for a core set of transition outcomes. The complexity and variability in addressing these is a concern. The NICE Quality Standards [18] go some way to addressing measurable indices but more will emerge.

Conclusion

Transition care is complex—providing comparable standards in wide-ranging healthcare systems and patient groups is a significant challenge. The growing recognition of the need for structured and robust transition has led to the development of transition principles for the UK, in the form of NICE guidelines. These provide some measurable outcomes, which must co-exist with condition-specific metrics. Enmeshing these principles and assessments of transition into current practice is important for continued development and success. Development is the shared responsibility of clinicians, managers and commissioners alike—and patients need to kept at the center of this and ideally part of that process. Established guidance gives a foundation for planning and building services for the future.

Declaration Both ARW and ARJ have had formal roles with NICE relating to transition. ARW is a current member of a NICE standing committee.

References

1. The Children and Families Act. http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted. Accessed 31 Aug 2018.
2. Dodge JA, Lewis PA, Stanton M, Wilsher J. Cystic fibrosis mortality and survival in the UK: 1947–2003. Eur Respir J. 2007;29(3):522–6.
3. MacKenzie T, Gifford AH, Sabadosa K. Longevity of patients with cystic fibrosis in 2000 to 2010 and beyond: survival analysis of the cystic fibrosis foundation patient registry. Ann Intern Med. 2014;161(4):233–41.
4. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. Pediatr Nephrol. 2000;14:469–72.
5. Harden PN, Walsh G, Bandler N, et al. Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. BMJ. 2012;344:e3718.
6. Oakeshott P, Hunt GM, Poulton A, Reid F. Open spina bifida: birth findings predict long-term outcome. Arch Dis Child. 2012;97(5):474–6.
7. Oakeshott P, Reid F, Poulton A, et al. Neurological level at birth predicts survival to the mid-40s and urological deaths in open spina bifida: a complete prospective cohort study. Dev Med Child Neurol. 2015;57(7):634–8.
8. Lorber J, Salfield SA. Results of selective treatment of spina bifida cystica. Arch Dis Child. 1981;56(11):822–30.

9. McGuire EJ, Woodside JR, Borden TA, Weiss RM. Prognostic value of urodynamic testing in myelodysplastic patients. J Urol. 1981;126(2):205–9.
10. Lapides J, Diokno AC, Silber SJ, Lowe BS. Clean, intermittent self-catheterization in the treatment of urinary tract disease. J Urol. 1972;107(3):458–61.
11. Malakounides G, Lee F, Murphy F, Boddy SA. Single centre experience: long term outcomes in spina bifida patients. J Pediatr Urol. 2013;9(5):585–9.
12. Stadler D. What has become of them? The careers of the physically handicapped—a model study (German). Rehabilitation (Stuttgart). 1984;23(3):120–3.
13. Court JM. Outpatient-based transition services for youth. Pediatrician. 1991;18(2):150–6.
14. American Academy of Pediatrics. Transition of care provided for adolescents with special health care needs. Pediatrics. 1996;98:1203.
15. Fiorentino L, Datta D, Gentle S, et al. Transition from school to adult life for physically disabled young people. Arch Dis Child. 1998;79:306–51.
16. Transition from children's to adults' services for young people using health or social care services. https://www.nice.org.uk/guidance/ng43. Accessed 31 Aug 2018.
17. Developing and implementing the newcastle adolescent and young adult transitional care service. https://www.nice.org.uk/sharedlearning/developing-and-implementing-the-newcastle-adolescent-and-young-adult-transitional-care-service. Accessed 31 Aug 2018.
18. Transition from children's to adults' services. https://www.nice.org.uk/guidance/qs140. Accessed 31 Aug 2018.
19. Nagra A, McGinnity PM, Davis N, Salmon AP. Implementing transition: ready steady go. Arch Dis Child Educ Pract Ed. 2015;100:313–20.
20. Implementing transition care locally and nationally using the 'Ready Steady Go' programme. https://www.nice.org.uk/sharedlearning/implementing-transition-care-locally-and-nationally-using-the-ready-steady-go-programme. Accessed 31 Aug 2018.
21. Brooks AJ, Smith PJ, Cohen R, et al. UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care. Gut. 2017;66(6):988–1000.
22. Jones AR, John M, Singh SJ, Williams AR. Transition from paediatric surgery: how many patients do we need to plan for? Ann R Coll Surg Engl. 2016;98(8):586–8.
23. Jones AR, Williams AR, de Coppi P, Hannon E. Transition in oesophageal atresia. Presented at the annual congress of the British association of paediatric surgeons; 2017.
24. While A, Forbes A, Ullman R, et al. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. Child Care Health Dev. 2004;30(5):439–52.
25. Schrander-Stumpei C, Sinnema M, van den Hout L, et al. Healthcare transition in persons with intellectual disabilities: General issues, the Maastricht model, and Prader-Willi syndrome. Am J Med Genet C Semin Med Genet. 2007;145C(3):241–7.
26. Kolhmainen N, McCafferty S, Maniatopoulous G, et al. What constitutes successful commissioning of transition from children's to adults' services for young people with long-term conditions and what are the challenges? An interview Study. BMJ Paediatr Open. 2017;1:e000085.

Information Transfer

5

Dan Wood

Introduction

There are many aspects to patient care, but continuity sits at the heart of them all. Many of the chapters in this book discuss the challenges of caring for patients who have complex healthcare needs. Experience tells us that there is a very important relationship that forms between the patient, their family and the paediatric healthcare team. The knowledge of the patient's condition and the complete understanding of treatment delivered is, clearly, very important in this. When a patient moves from paediatric care in to an adult environment, they will set their standards based on experiences so far. In short, they (not unreasonably) will expect the same standard of care.

With the above in mind there are two important points. The first, each professional that undertakes this work in adolescence and adulthood has to ensure they are well trained. This includes a complete understanding of the paediatric conditions that will come under their care. It is also important that they understand the treatment delivered in paediatric care. This allows explanation to patients about what they have and has happened to them—when they ask questions in later life. If there is to be a long-term healthcare relationship these elements are essential to success. These patients and their parents are usually expert in their condition and their treatment—and if they are not, they are certainly very well acquainted with the medical profession and how it has managed them, so far. They will quickly compare a new carer with their previous experiences—if the new team appears to fall short, it will be very difficult to gain trust going forward.

D. Wood (✉)
Department of Urology, University College London Hospitals,
London, UK
e-mail: dan.wood1@nhs.net

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_5

The second component is that the information given is accurate and reliably transferred from the previous team to the new team. This chapter aims to examine the importance of this, potential methods of transfer and some of the challenges in data transfer.

Patient Role

At the core of transition is the development of the patient's own ability to contribute an increasing role and responsibility in their own healthcare. As their own understanding of what has happened to them grows their role in communicating information to doctors both present and future expands alongside this. The purpose is not to suggest that a patient becomes responsible for all medical information, but their position is greatly empowered the more information they have and the better they learn to use it.

Many of us working in fields that require transition have encountered patients with a rare diagnosis or specialist forms of treatment. These may be much less familiar to healthcare professionals outside of specialist centres. There are three ways patients can help with their own healthcare in this setting, on understanding that a doctor does not know about their condition—the patient can become their own expert and explain what they have and (if possible) how the current problem has been managed before. Most sensible professionals will respond positively to this and at least use the information given to support their own enquiries. The second way is to bring written information with them when meeting a new healthcare professional. This might be hospital letters, their own summary report, a health passport (where they exist), some form of electronic record—or a combination of the above. The third, most common, way is for the patient to direct the doctor—either to their own (existing) healthcare team or to other electronic resources that offer information about their diagnosis or care. We have all listened to anecdotes where this has not gone well—often (from a patient perspective) because a doctor has appeared not to listen or to be reluctant to take on board the guidance that is being offered. This creates friction, a loss of trust and the relationship quickly deteriorates. The converse is also true—I have encountered very good doctors who have tried to treat such complex patients, but they are met with a wall of resistance often on grounds that are unreasonable, e.g., their own doctor not being available (during weekends, leave, etc.) or not agreeing with a diagnosis despite good evidence for it. It goes without saying that when patients are reacting in such a way the doctor has to do their best to establish why and to try and support the patient—after all, they are the professional and this is their job. Patients may be unwell and frightened and therefore less able to manage themselves than normal. Perspective is very important as both sides can get it wrong—the importance is to maintain an open mind—this is the probably the easiest path to the best outcome.

Health Passport

There have been many examples and attempts to achieve this and it meets with vocal enthusiasm when suggested. There is even an example using the acronym HEALTH (Helping Everyone Achieve Long Term Health; https://www.nice.org.uk/sharedlearning/the-health-passport-helping-everyone-achieve-long-term-health).

Despite apparent enthusiasm, this has not yet gained widespread adoption or acceptance. Some healthcare systems in Europe have adopted a 'smartcard' which can be inserted into a computer—allowing immediate access to a patient's records.

There are a range of potential opportunities for a health passport. The most obvious is the portability of information—allowing a patient to carry their own record with them. This means whoever sees them will have immediate access to their medical charts. It also allows the healthcare team currently seeing the patient to contact other teams involved either historic or present day.

Above and beyond historic medical information the ideal passport will allow the patient to interact with it. During the approach to transition part of the preparation could be staged. First, for the parent to agree with their child questions that might be asked at an upcoming appointment. As the child understands this and develops—they may begin to discuss things with their parents and then write their own questions in the passport—the development to them raising their own concerns and asking their own questions would ideally follow, with the passport playing a part in that process.

There have been attempts to produce electronic applications (apps) to facilitate information transfer between patients and their healthcare teams. Assuming the technology exists to allow this and maintain the security of patient data and thus strict confidentiality—this may be a very good way to facilitate immediate communication with a patient's medical team. These avenues will, no doubt develop. This appears to create an excellent resource for patients—with the intention of obtaining immediate advice and potential treatment advice. Indeed, as I write this chapter it is likely that this aspect will become outdated almost as soon as I finish this sentence!

Whilst electronic communication is an excellent ideal it opens a healthcare team up to a much wider pool of potential enquiries in the front line of healthcare. In order to fulfill the expectations of patients that will, in turn, become more immediate and the healthcare team must be adequately resourced. There are two fundamental aspects—the first centres on personnel, how different health systems deliver such a service will vary. The development of technology to bring the patient closer to healthcare is, almost certainly, inevitable. There must be staff availability and training to take on this work—a range of models could be designed—and additional staff time may be required. Systems may, for instance, decide to allocate specific times of the day or week for answering or responding to enquiries through these means—even then they have to ensure there is specific staff time to do so. We all need to understand that simply because we have sent a message, we cannot assume it has been received or actioned. Therefore, the message sender retains a degree of responsibility for pursuing an enquiry until the information needed has been obtained.

The portability and availability of information is an important part of modern healthcare and is an area that is likely to develop. It will develop as a specific part of this area of healthcare—the transition from one healthcare environment to another under these circumstances or others. It will also develop because it can, and we are, to a degree, subject to the expectations of patients in delivering care. It will be our job to deliver it and regulate it.

Hospital Record

Ideally, the paediatric record should be open to the team that are going to look after the patient in adolescence and adulthood. This is important at the point of first meeting and if there are subsequent joint meetings. It is useful to have a summary of the overall information, if the patient is due to move to another team or location. It remains important that the full record is available to the adult team.

Data Protection

Data protection laws will vary across the world. Each practitioner needs to be mindful of those that relate to their own country and healthcare and environment.

As a set of principles, the information must be kept in a secure place and should be shared only with those people who need access to it.

Geography

It is obvious that if a patient remains within the same hospital the information from previous care will remain will be readily available to all teams involved. Indeed, the paediatric team also have access to the long-term data that allow them to examine progress after they have handed over care. This will facilitate their understanding of the long-term outcomes of their treatment. If a child has to move facility of their adolescent and adult care both aspects are more difficult. Each system will need to establish its own approach. The entire healthcare record can be copied and transferred. A good summary may be enough. Either way the team assuming care should not have their ability to look after a patient compromised through a lack of information. The reciprocal is that the adult team needs to find a way of feeding back information on long-term care to the paediatric team. This may be on a case-by-case basis—if individual or complex problems arise. The additional component should be the examination of cohorts of patients and a broader look at their outcomes. This will be designed to give a better perspective to the paediatric team of their long-term outcomes.

Summary

It is clear that good care for these patients relies on full and coherent information being available to all teams involved in looking after them. This information will rely on clear documentation throughout paediatric care and secure but accessible transfer to the adolescent and adult team. Data protection must be preserved.

Patients can play a very important role in this with their own expertise and account of their condition and treatment. It may be that with time more patients are given some form of personal and portable record to carry for themselves and give to professionals as they meet them.

The development of electronic records may improve the portability of information. As technology develops healthcare teams are called upon to respond appropriately to electronic requests from patients and other healthcare professionals. Expectations need to be managed to ensure that where immediate responses are required the resources are available to provide this and when the need is less urgent the enquiry is managed proportionately.

In the long-term paediatric teams must be given access to their long-term data. This allows them to assess the outcomes of the diseases they care for and the treatment they have delivered. This may be on an individual basis or from reporting of datasets to inform a particular team or the paediatric community as a whole.

Further Reading

IT Governance. GDPR compliance checklist for health and social care. https://www.itgovernance.co.uk/healthcare/gdpr?gclid=EAIaIQobChMIn9vUwrPA3gIVjrDtCh1cHgdCEAAYASAAEgKciPD_BwE. Accessed 7 Nov 2018.

National Institute for Health and Care Excellence. The HEALTH passport: Helping Everyone Achieve Long Term Health. https://www.nice.org.uk/sharedlearning/the-health-passport-helping-everyone-achieve-long-term-health. Accessed 7 Nov 2018.

6

Managing the Parents

William G. Reiner and Dominic Frimberger

Introduction

It is obvious but important: Birth initiates parenting, rather abruptly, with all of the inherent mysteries of who and what this baby will grow to become. For any parent preparation for this moment will include a mix of hope, excitement, fear, uncertainty, deep thought and delusion. Nothing quite prepares a parent for that amazing, precipitous, emotional and humbling event. However, a newborn with any major anomaly naturally enshrouds new parents in heightened anxiety and even greater uncertainty about the future. Parenting such a child impacts the child's health and development throughout young life. Thus, managing the parents throughout the child's life becomes an important part of clinical strategy; this is no less apparent during the clinical transition from adolescence to adulthood. There are no recipes, no real guidelines, for managing parents during this period. To be sure, parent management is part of the art of practicing medicine. The research literature is nearly nonexistent; the few studies available generally describe only parent perceptions of transitional care, parent-child relations or the overall transition processes. There are, however, important insights to be offered about managing parents of adolescents affected by urological anomalies.

W. G. Reiner (✉)
Section of Pediatric Urology, Department of Urology, University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA

Division of Child and Adolescent Psychiatry, Department of Psychiatry (Adjunct), University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA
e-mail: William-reiner@ouhsc.edu

D. Frimberger
Section of Pediatric Urology, Department of Urology, University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA
e-mail: Dominic-frimberger@ouhsc.edu

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_6

Parents will evolve their strategies slowly during the child's early years. The approach to adolescence presents a new frontier for parents, a reality often requiring new rules—or at the least an adjustment of old approaches. In the clinical setting an adolescent is a new patient to the clinic, designing management strategies for both child and parent may be difficult and time-consuming. Managing the parents of any affected adolescent often requires more focused direction than managing the parents of an affected prepubertal child and may benefit from an interdisciplinary team for several reasons. First, parents are likely to differ (father from mother) in emotional and behavioral reaction to clinical and behavioral realities, care, or problems [1]—this is not necessarily new. Second, adolescents gradually become more active participants in their own healthcare and development—this is new and presents an additional dimension to the differences (already mentioned) between parents. Third, parents attend to their child, to their child's needs, sometimes to the exclusion of their own needs—especially when they experience simultaneous competition for their time and emotional commitment from the needs and demands of others within or outside of the family. Fourth, typical parents feel that they know their child. But younger children do not verbally express or even comprehend their self interest well, while the adolescent has achieved far greater expressive and receptive verbal skills. Still, the adolescent typically verbalizes only a small portion of their inner thoughts and may not even direct such verbalizing to their parents. Managing the parents, then, becomes a broad-based clinical challenge.

Naturally, parents have a strong influence over the relationship with their child, and indeed, over all family relationships. Thus, abusive or neglectful parents can impede or otherwise damage their child's development and health. With more typical parents, however, "good enough" parents or with parents and child who are a "good enough fit" for each other, the child is likely to develop and adapt well enough. In fact, each child has to adapt to nonfamily social situations and milieux, parental involvement notwithstanding. In other words, children learn to adapt and sometimes to maladapt to their social situations and also to their parents. Away from their parents, adolescents' behavioral and emotional states, their activity and reactivity, tend to reflect more programmatic interactions of their genetics, epigenetics, and environmental or external experiences.

Such interactions are, for the most part, continual just as they are difficult to tease apart, one from the other. High levels of child-reactivity, and especially negative reactivity, correlate to a higher risk for the development of anxiety disorders—in later life. This is true for children as well as for adolescents and parents [2]. From the perspective of parent management goals, however, it is important to realize that behavioral research increasingly demonstrates that children (like their parents) have temperament-associated emotional reactivity that has strong genetic correlations. For example, in a very large study of twins from two different continents, differences between negative, neutral, or positive reactivity correlated more strongly with genetic than with environmental (including parent-input) differences [3].

This is not to say that parents are not important. Many of the developing child's early social situations and much of their emotional development occur within the context of the family. More to the point, when children are young, parents possess and wield the executive functions of the family—that is, those critical social functions that control attention, organizational and planning skills, working memory, emotional regulation, and other critical cognitive social functions. Child and adolescent brains progressively develop these executive functioning skills over more than two decades. Studies of these developmental processes are well represented in research literature.

Unfortunately, only limited studies and scarce data are available to reflect such adolescent development in those with chronic urological conditions. Nonetheless, their experiences of repeated surgery, anesthetics, and multiple hospitalizations in infancy and later childhood likely impact and may render negative vulnerabilities for these cognitive developmental processes. Parents, moreover, have no experience or innate social supports in dealing with children with such chronic maladies. This combination of voids limits our ability to standardize parent management and education for urological disorders even as parental anxiety is typically increasing over time [4].

A discussion of family therapy, systems therapy, or other behavioral interventions—for father, mother, adolescent, or the family unit—is beyond the scope of this paper. But these clinical realities become increasingly complex from a management standpoint, as the child moves into adolescence, and demand a team approach. To adapt to a progressing adolescent development in the face of urological anomalies, and with little help from experience or their own social milieu, parents do need assistance. Add to the mix a set of complex parents, and the clinical approach can become at times almost overwhelming.

Therefore, active and appropriate management of the parents while encouraging their participation demands a multidisciplinary team. The team requires varying members depending on the clinical status of the patient and on the social status and emotional and cognitive states of the parents. Adolescent and adult mental health care professionals who are likely to enhance the clinical team should include: (1) a clinical social worker experienced in family and social and ecological needs of adolescents with complex urological disorders; (2) a psychologist skilled in assessing cognitive as well as emotional variables in parents and in adolescents; and (3) a psychiatrist skilled in treating family as well as adolescent psychopathology. These professionals may often meet or work as a subunit of the team. Each can have a clinically significant impact depending on clinical variables at a given time.

Clearly in the adolescent with urological disorders, the development of the parental role in care will be complex. To be able to assess, treat, and support the parents and the family, the urologist and the team need to master and apply several skills:

1. Engaging and educating the parents as clinical and social situations evolve;
2. Helping parents manage boundaries between their adolescent and themselves;
3. Recognizing when and how parents should be included, excluded, or simply encouraged to retreat to the background from patient discussions and physical examinations;

4. Maximizing the privacy and ultimately the confidentiality of the adolescent and the adolescent in transition to adulthood.

These should be regarded as "moving targets" both in terms of adolescent as well as of parental development and require flexibility from the team.

Engaging and Educating the Parents Through the Transition

Information is critical to parents, as it will be to the adolescent. In the information age clinical education requires accuracy, appropriate knowledge and understanding if the urologist is to help direct parents toward their future roles in parenting. As with most people, parents learn best with repetition of important points over time accompanied by written educational materials. For accuracy and for reference basic condition-specific developmental processes can be outlined and provided early and intermittently in printed form. A printed summary every year or so, specific to the adolescent, keeps parents up-to-date and can include insights about likely future clinical directions. The urologist can help parents compare and contrast the clinical educational materials to information or misinformation gleaned from the Internet.

Nothing, however, is likely to be as useful as the formal encounter between the urological team and the parents (or the patients) who are perplexed. First, the team must educate the parents about the importance of the clinical transition itself—the "why" and the "how" of transition. Second, the urologist and other team members will need to re-engage parents periodically when clinical complications arise, as well as when adolescent needs (as opposed to those in childhood) and desires begin to prevail. Being familiar with the social and emotional states of the parents over time is quite useful, especially when the urologist must discuss new or troubling clinical information. The team may have to manage the overly involved parent—the so-called hovering or "helicopter" parent. Managing the hovering parent early and regularly can help prevent emotional enmeshment between parent and child and, later, between parent and adolescent. The team can gradually redirect hovering behaviors towards a more useful, involved healthcare focus.

A major part of the team, the clinical social worker can direct parents to appropriate groups for support, including local or regional groups or national or international support group websites. Managing parental expectations is also important in managing adolescent health care. The social worker along with support groups can augment appropriate parental management. However, managing expectations of the parents depends on their cultural perspective, cognitive function, educational background, emotional state and how they adapt to those parameters [5]. Having a rough understanding of the parents' gross executive functioning skills (including reading level) will enhance clinical communication as well as the adolescent's healthcare and transition. Educating the parents about the adolescent's likely developmental potential and vulnerabilities enhances managing the parents and therefore managing the adolescent. After all, it is the parents who must understand and master the clinical care responsibilities and requirements, such as clean intermittent catheterization, bladder washouts, and so forth. It will be up to the parents to re-enforce the urologist's teaching of these responsibilities to the adolescent. Generally, the team's psychologist can best assess parents' (and the adolescent's) cognitive and learning potentials and how to address the clinical implications. (An example of an excellent screening tool would be the BRIEF, or Behavior Rating Inventory of Executive Function [6]. Available from the PAR website, there is a version for parents, teachers, and the patient, with an excellent explanatory guide book with definitions of the executive functions.)

Parents will likely recognize some of their adolescent's developmental vulnerabilities. However, they are not likely to be sophisticated about the implications of urinary incontinence, genital anomalies or disease-chronicity likely to be associated with adolescent anxieties—or the realities—about potential sexual function, reproduction, romantic relationships and even peer relationships. These developmental vulnerabilities are atypical if compared to vulnerabilities in adolescents with chronic but non-urological disorders and will be mostly foreign to the parents. Parents are also likely to be ill-prepared for boundary issues inherent to these developing vulnerabilities. The psychiatrist can provide appropriate assessment and treatment for developing adolescent or parent psychopathology, or appropriate referral if desired.

Helping Parents Manage Boundaries with Their Adolescent

Boundary issues are common between most parents and adolescents. While there is a growing behavioral literature debunking any major parental influence on developing personality, temperament, cognition, and even outcomes, boundary issues between parents and the affected adolescent often impact short-term behaviors and emotions and sometimes long-term parent-child relationships. Boundary issues inherent to most chronic adolescent urological disorders often create stresses and even long-term conflict that may impact adolescent autonomy and health care. Therefore, helping parents manage boundaries is important to the entire team.

Although specific details of clinical strategies will relate to the urologist's approach to parents of the adolescent with a specific urological condition, certain parent management strategies need to be emphasized:

- Begin early—establish clinical "rules" as part of the educational processes for the parents
- Re-enforce these early rules by repetition as the child develops into adolescence
- Modify the rules as the adolescent grows and develops, i.e., as needs transform
- Establish which rules are strict and which can be adapted to or by the parents
- Distinguish between the specific needs of adolescent autonomy and the variability of parenting styles as the adolescent develops—and as the parent develops.

Adolescents are inherently sexual. Chronic urological disorders influence and impact sexuality. As might be expected, many affected adolescents questioned their sexual potential well before they entered puberty; in fact, anxieties about future sexual function often begin during school-age [7]. Therefore, the early education of the parents should be formatted to include sex education of the child during development specific to the underlying urological disorder and well before adolescence begins.

A trusted professional, the urologist is also “an outsider”: the intimacy of a discussion about sexuality is therefore diffused and in some ways sublimated when conducted between the patient and urologist. Therefore, it is important early in the management of parents to establish the rules and roles for the urologist and for the parents in terms of adolescent discussions and adolescent education. The urologist will educate the parents early in the child’s development about sexual potential and sexual function. As the child nears adolescence and especially after puberty begins, the urologist should be the mainstay of the sex education of the adolescent patient. Printed tables or flowcharts outlining relative roles can be especially useful when provided early in parents’ education and again several times as the child matures (see Table 6.1). The urologist and the parents can refer to such a flowchart repeatedly, as necessary.

When parents are asked to step out, or at least to retreat to the background, the adolescent can begin to comprehend the nature and importance of privacy and the confidentiality of the subject matter. Once a set of rules for a given set of parents or for a given adolescent are established, they should be largely maintained unless clinical exigencies (such as pregnancy or illness) intervene. Reifying the relative roles of educator begins to create an almost formal if initially unrecognized separation between urologist and parents, at least in terms of the adolescent’s sexuality, while augmenting the clinical relationship between urologist and adolescent. This is the initial transition for the adolescent and for the parents—when the adolescent begins to look to the urologist for critical information rather than to the parents. This process is often the beginning of establishing the ultimate autonomy of the emerging adult.

Our own REACH Clinic at the Oklahoma Children’s Hospital, University of Oklahoma Health Sciences Center in Oklahoma City (Oklahoma, USA) is an example of a model of an adolescent- transition clinic. With a focus on adolescents with neurogenic bladders, the clinic provides interdisciplinary healthcare, local and regional support group access, and direct participation in community social and sporting groups for the adolescents and their families—with healthcare providers often participating. It also provides materials explaining available participatory

Table 6.1 Example of a simple flowchart, here providing suggestions for who the educator should be, and during which ages of the patient

Child’s age	Educator
Birth to 7–8 years old	Parents, with urologist providing needed background information
9–11 years	Parents, with urologist present
12–14 years	Urologist, parents not present but informed
15 years–emerging adulthood	Urologist, parents not present, not informed

community programs, national and international support groups, and website information for participation. These approaches focus on ultimate adolescent independence but also on providing healthcare settings as well as social access that encourage a sense of comfort for parents and for adolescents alike.

Recognizing When and How Parents Should Be Excluded

The process of moving the adolescent from dependence gradually to autonomy, therefore, is initiated with the parents well before adolescence even begins. However, a specific set of clinical rules may be modified based on parents' temperament and disposition as well as on an adolescent's own cognitive and personality realities. For example, an adolescent with myelomeningocele, hydrocephalus, and a ventriculoperitoneal shunt may have reduced cognitive and executive functions when compared to an adolescent with bladder exstrophy—establishing rules allows the urologist to work with the parents while working with the adolescent. In establishing such rules, it is important to recognize that parenting is in a sense "an institution" of Human Nature—with legal and ethical aspects for the parents of protecting, nurturing, decision-making, and so on [8].

There is an art to the manipulation of the clinical situation such that the parents gradually and adequately transfer their control to the adolescent under the scrutiny of the team. To be sure, legal and ethical aspects also envelop the clinical team. In other words, boundaries exist for all parties involved. Decision-making must evolve into a mixed process between parents and adolescent. The ultimate aim, clearly, is independence as possible for these adolescents when they reach adulthood.

Along this line, relevant and material themes for the adolescent include more than simply having discussions in private. Indeed, the physical examination can provide an additional avenue for educating the parents about child and adolescent development with increasing stress on patient privacy. For the majority of parents and for social and cultural appropriateness, when the child is young the parents should not only be present, but it is probably best if at least one parent is near to the child during physical examinations. For school-age children clinical situations tend to be emotional and high anxiety even with an otherwise calm child. Anxious situations are not conducive to learning or listening. Therefore, parents should be present and encouraged to take notes or be provided with printed materials. As the child nears adolescence, however, emotional and anxious reactions of the adolescent or between adolescent and parents may be problematic and are likely to intensify: heightened anxiety may relate at least partly to the presence of the parents and the fabric of the family dynamics. It is often best, therefore, to usher the parents out or at least to the background.

Adolescents generally do best with parental distance or absence. This is especially true when the substantive matters involve mastery and self-care. Adolescents generally learn better and listen better when they are alone with an educating member of the team. Once the adolescent is alone any uncomfortable family dynamics are absent, anxiety diminishes, emotions tend to stabilize. The adolescent can be encouraged to take notes. Notetaking will be novel, to the young adolescent, in the clinical setting, as will autonomy. These are learned traits. Educating the adolescent begins simply and progresses through the more complex. This is the best approach for the parents as well. The adolescent, of course, can inform the parents about anything discussed. At the first few meetings it may be sensible to offer (to the adolescent) a further, joint conversation with the parent to support wider communication. They may or may not consent to this but it (importantly) gives them the choice.

Therefore, depending on the child's age and level of development, the parents should be close but not necessarily present in the exam room. As the child moves into adolescence and truly begins to grasp an understanding of their diagnosis, treatment and their own responsibilities, the urologist can ask the parents to step out and can provide the printed materials to the adolescent, then separately to the parents. The process of moving the parents towards a recognition of the magnitude of necessary autonomy is usually gradual. Again, printed materials that outline this transformation are most useful, especially if the materials are initially provided before the child begins adolescence. Discussions that necessarily require both parties can be modified accordingly at any time, with major modifications in the case of an adolescent with significant cognitive or executive function deficiencies, who may not be able to achieve much independence.

However, some adolescents need or feel they need more parenting than others. An adolescent who requests parental presence may indeed be signifying their own specific autonomy. Here again the team approach is valuable in helping guide the adolescent and the parents, as well as the team itself, in an appropriate even if idiosyncratic clinical approach.

Maximizing the Confidentiality of the Adolescent Through the Parents

By emphasizing the need to move towards adolescent autonomy, the urological team encourages and teaches the importance of privacy. Managing the parents requires educating them about necessary privacy issues for their adolescent; educating them about privacy encourages adolescent confidentiality. In other words, early education about the importance of privacy becomes a springboard to later education about the importance of confidentiality.

Privacy is an issue the child will likely grasp fairly early in school-age years, as anxieties arise and gradually intensify about the possibility of discovery by peers—discovery of urinary incontinence, genital abnormalities, or a stoma. This risk or the fear of discovery can lead the family toward secrecy for parents and for the child. In managing parents, preventing or eliminating secrecy by instruction on the nature of privacy when the child is young can help reduce stressful life events or anxieties both within the family dynamics and within the child's external social milieux. Eventually, this sense of privacy can transform into a recognition of the need for confidentiality for the adolescent. Gently but firmly helping parents to step out when necessary patient discussions or queries are likely to impinge on patient emotions helps the early adolescent grasp the potential of their impending independence as well. A growing sense of independence enhances learning as it empowers and augments adolescent development.

A parent management approach that fosters adolescent independence can easily begin with the childhood physical exam. Such an early strategy is likely to be successful long-term. Young adolescents often do not mind if their parents are present during physical examinations. To prepare both parties for privacy issues, having the parents step out or at least to step into the background when the genital exam is to begin can be initiated in late prepubescence, well before adolescence begins. In this way, the urologist begins to prepare parents and patient for the gradual transition regarding privacy, especially in terms of the young adolescent's burgeoning if somewhat vulnerable sexuality. This preparation also augments the boundary rules established earlier in the parent-urologist relationship. By mid adolescence, the parents can be encouraged to step out for the entire physical examination if this is okay with the adolescent. This approach emphasizes privacy for the adolescent but begins the process of establishing confidentiality.

Privacy is necessary for the child's protection within any social milieu. Confidentiality allows the adolescent similar protection—the sense of the sexual self relates not only to one's romantic relationships but also to peer relationships—while allowing and encouraging the adolescent to explore questions of social and sexual intimacy. Exploring these themes, adolescents can deal with their own urological realities relating to sexual function, fertility, relationships, and peer interactions. Initially, some of these topics can be broached with the parents present. Most of these questions should be encouraged after the parents step out, however. Developing this sense of confidentiality allows protection within the adolescent's social circle, then, as well as the broader external environment.

Confidentiality along with self-confidence of the adolescent can be engendered within the context of increasing the sense of privacy, integrity, and autonomy initially within the family. Parents can and should be informed early in their adolescent's development of the nature of present and likely future discussions between the child or adolescent and urologist. As the adolescent develops further, however, the parents might not be included, even after the fact—although the adolescent of course can tell them everything. Parents' understanding of this unfolding process is part of the urologist's engaging and educating the parents as it simultaneously prepares them (and the adolescent) for the developmental attainment of adolescent confidentiality.

Conclusion

The practice of adolescent urology includes sensitive issues. Sexual matters are indeed private; complicated urinary functions can be embarrassing. Parents will understand this clinical emphasis on privacy. However, matters of urinary incontinence, intermittent serious illness, recurrent stone disease, urgent hospital admissions or reoperations also require privacy and confidentiality. Peers may not honor or understand the adolescent's need for privacy. The adolescent may feel or may fear a need to explain to friends or peers. Adolescent sensitivity may not be obvious to the parents, who may be in need of emotional and social support themselves. Parent management processes, then, often require an emphasis on the privacy of the family, beginning when the child is an infant. Early emphasis on family privacy can then evolve towards a re-emphasis on the privacy of the child in particular, a privacy with respect to the family initially but ultimately leading to a sense of overall confidentiality. The privacy of the young adolescent, then, merges with the need for confidentiality as part of the increasing autonomy of the emerging adult.

Parents are likely always to be a part of their adolescent's developing and adult life. Managing the parents while treating the adolescent enhances this development while minimizing the risk of exacerbation or exploitation of vulnerabilities—of both adolescent and parents. By focusing on the processes, the urologist sponsors and emphasizes a gradually diminishing course of parental involvement, albeit specific to a given adolescent's needs and grasp of the clinical demands and realities. This sense of autonomy empowers integrity and confidentiality for adolescent as well as for parental development and transition. Healthy parental development encourages healthy adolescent development—this is an important two-way process.

References

1. Malm-Buatsi E, Aston CE, Ryan J, Tao Y, Palmer BW, Kropp BP, Klein J, Wisniewski AB, Frimberger D. Mental health and parenting characteristics of caregivers of children with spina bifida. J Pediatr Urol. 2014;11:65.e1–7.
2. Craske MG, Waters AM. Panic disorder, phobias, and generalized anxiety disorder. Annu Rev Clin Psychol. 2005;1:197–225. Nolen-Hoeksema S, Cannon TD, Widiger T (eds.). Palo Alto, CA: Annual Reviews.
3. Lake RIE, Eaves EJ, Maes HHM, Heath AC, Martin NG. Further evidence against the environmental transmission of individual differences in neuroticism from a collaborative study of 45,850 twins and relatives of two continents. Behav Genet. 2000;30:223–33.
4. Friedman D, Holmbeck GN, DeLucia C, Jandasek B, Zebracki K. Parent functioning in families of pre-adolescents with spina bifida: longitudinal implications for child adjustment. J Fam Psychol. 2004;18:609–19.
5. Mathews A, MacLeod C. Cognitive vulnerability to emotional disorders. Annu Rev Clin Psychol. 2005;1:167–97. Nolen-Hoeksema S, Cannon TD, Widiger T (eds.). Palo Alto, CA: Annual Review Use.
6. Gioia G, Isquith P, Guy S, Kenworthy L. Behavior rating inventory of executive function; 1999. https://www.parinc.com/Products/Pkey/23. Accessed 8 June 2018.
7. Reiner WG, Gearhart JP, Jeffs R. Psychosexual dysfunction in males with genital anomalies: late adolescence, tanner stages IV to VI. J Am Acad Child Adolesc Psychiatry. 1999;38:865–72.
8. Engelhardt HT, Jr. Chapter 4: the context of healthcare: persons, possessions, and states. In: The foundations of bioethics. Oxford: Oxford University Process; 1996. p. 135–88.

The Importance of the Specialist Nurse Role as Part of the Lifelong Care of Congenital Conditions

7

Winnie Nugent

Introduction

Young Onset Urology (YOU), the acronym for the service in which the author works, describes patients with childhood long-term, complex urological conditions. This may include patients with congenital conditions such as bladder exstrophy, cloacal anomalies, spina bifida, posterior urethral valves, hypospadias, and patients with neurogenic bladders. A number of these children will have had reconstructive surgery, and are at risk of urinary infection, stones, bladder dysfunction, metabolic disorders, neoplastic changes and potential deterioration in their renal function. These young people with long-term complex conditions require ongoing care as they move on from children services. During this time, it is recommended that their continued care should be delivered by a specialist team. This team should have specific knowledge about their conditions and previous treatments with adequate skills to provide lifelong care. Careful consideration must be given to the most appropriate place for their long-term care, and who will support them and their families during and after this period [1].

The recognition that patients will move from pediatric healthcare to adult services has become more significant during the past 20 years [2] as care delivery has become more complex and advances in pediatric medical and surgical management, with greater availability of treatment options have increased life expectancy for this group. As such, roles have developed to proactively manage the period of transition during which a young adult will assume more responsibility and autonomy in their own healthcare and to facilitate the transfer of care from pediatric to adult services. Therefore, central to this is a recognition that encouraging the development of patients' independence and involving patient in their treatment options and decision

---

W. Nugent (✉)
Urology Centre, Guys Hospital, Guys and St Thomas NHS Trust, London, UK
e-mail: winifred.nugent@gstt.nhs.uk

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_7

making are vital component in maintaining treatment compliance and providing ongoing support [3].

This chapter will describe the clinical nurse specialist (CNS) role within such a service, illustrate the introduction and use of a transition pathway and demonstrate how the role of the CNS provides support to this group of patients. This will include education, management, accountability and peer support for the CNS. The clinical care pathway will be outlined, with reference to the identified age of transition, its implication for care and treatment options.

Transition

It is recognized that morbidity and mortality rates increase for young people after moving from pediatric to adult services [4, 5]. This evidence has resulted in a plethora of publications, guidelines and reports aimed at a reduction in risk linked with the move to adult services [6–8]. Essential to this process is the concept of transition. Studies show that effective transition between paediatric and adult care can improve long-term outcomes [9, 10]. On-going communication between the paediatric and the adult clinicians facilitates the transition process even after the transfer of care has occurred [1].

The goal of transition is to provide uninterrupted, developmentally appropriate transfer of medical care from a pediatric service to an adult care model [11]. Transitional care is not purely a move from one healthcare team to another or from one hospital to another, it is multi-dimensional and multidisciplinary. Consideration should be given to health, psychosocial, educational and vocational needs [12].

Young people with long term conditions across a variety of subspecialties share similar issues as they prepare for transition to adult services. Barriers to the transition process have been identified by Binks et al. [13]. These include:

- an unwillingness of pediatric healthcare providers to discharge patients
- the patient’s reluctance to leave the familiar pediatric environment
- a lack of interest by adult care providers.

A key aim of transitioning patients with complex urological conditions is to facilitate the transferring of care from the parent to the patient. This should include preparing the adolescent for adult life by addressing their development, both physically and psychologically as well as encouraging their overall independence. Inadequate transition can have serious health consequences [3]. In YOU patients these may include bladder dysfunction, metabolic disturbances, neoplastic changes and deterioration in their renal function.

Failure to engage properly with adult services is shown to result in increased levels of morbidity [7]. Early identification of transitioning young adults is paramount, in order to allow adequate time and preparation for all involved in the process to ensure a smooth, timely and individualized referral to adult services. In the United Kingdom Department of Health expects the standards laid out in the national guideline entitled Your Welcome [6] to be led locally. This quality measure facilitates the improvement in local practice and assists in giving evidence regarding improvements in the healthcare journey and outcomes for young people. The use of this document should aid young people to become involved in making decisions pertinent to their health [14]. It also optimizes the ability of the patient to assume adult roles and responsibility.

In current health care systems, delivery processes involve numerous interfaces. Patients may need regular contact with their healthcare team—as part of this and other interactions they will come into contact with multiple health care practitioners with varying levels of knowledge about the underlying condition and its treatment. A health care professional who becomes a single point of contact, often described as a patient advocate or key worker, is beneficial in particular to support young adults prior to and during their transition to adult services [15].

The Key Worker Role

The key worker role was initially developed primarily within cancer services and is defined as a person who, with the patient's consent and agreement, takes a key role in coordinating care, promoting continuity and ensuring the patient knows who to contact for information and advice [16]. This key worker role can be successfully used within a transition service within the remit of the transitional CNS. The CNS acts as the facilitator to assist a smooth transition of patients to adult services. This role ensures there is no reduction in the standard of care for patients as they move to adult services and aims to offer some continuity at a time of change. The role supports the patient during transition to help reduce anxiety at a time when it is likely young adults are experiencing several other life changing events such as starting college, university, work or leaving home for the first time. They may also be exploring their sexuality and integrating more with friends. It is important to ensure that transition experiences are positive for young adults and that the service is one that young people want to use. It is believed that the availability and access to a key worker may improve both the patient experience and concordance with treatment regimes.

The CNS Role

The Royal College of Nursing (RCN) [17] has called for commissioners, health care providers and governments to commit to the following:

- All patients with long term conditions should have access to a specialist nurse.
- Specialist nurses should be allowed time to care and accomplish the vital aspects of their role
- Increasing funding for specialist nurses' roles and supporting other providers and commissioners to understand the wider cost implications and health improvements to be gained in continued investments in both medium to long term.

In UK Healthcare clinical nurse specialists work in a variety of acute and community settings, specializing in particular areas of practice such as general practice, mental health, children's nursing, learning disability nursing and district nursing. Specialist nurses can work independently or as part of a multidisciplinary team to provide high quality, patient-centered, timely and cost-effective care. All specialist nurses provide tailored care depending on the patient's level of need. They also provide education and support for patients to manage their symptoms, particularly patients with long term conditions and multiple morbidities [18].

The quality of care and support that specialist nurses offer has been instrumental in reducing unnecessary hospital admissions and re-admissions and reducing waiting times. It enables consultants spend quality time with patients, improves access to care, educating, health and social care and supporting patients in the community [17, 19].

The key worker function and facilitating transition are key elements of the YOU CNS role. The clinical nurse specialist may also:

- carry out specialist nursing procedures
- assess patients, plan, implement, and evaluate evidence-based care
- provide specialist advice to patients, families and carers, and the wider multidisciplinary team
- contribute to the development of the workforce through developing and delivering education and training
- contribute to the development of services
- participate in and lead research activity and clinical audits in own specialist area
- work collaboratively with the multidisciplinary team to ensure the cohesive management of patients

The CNS Role in Facilitating and Supporting Transition

Within a service that incorporates transition the CNS's goals are is to facilitate a gradual process of empowering the patients to move to adult services, with the ultimate aim of providing continued support by a team familiar with their conditions, treatments and future care needs. The ultimate aim is to create an environment and a system that will ensure effective transition. The CNS forms the link and bridge between pediatric and adult services, thereby facilitating a smooth transition pathway for the patients to access. Transition should not be viewed as a single event or treated as the transfer of care. For a young adult with complex healthcare needs it becomes a very important period in adolescent life. It should be viewed a process supported by a multidisciplinary approach.

Within the authors service transition is managed by identifying appropriate patients early in their teenage years—approximately 13 years of age. It is an important stage in adolescent life. It sees a gradual but dramatic change in the relationship between the patient and their medical team. There is currently no consensus on the 'correct' age for transition—this should allow an individual approach both for the design of a service and its patients. Some healthcare professionals consider that transition should begin a year or two prior to moving to adult services. Studies conclude that the optimum transition age for commencement of the transition process should be around 11 or 12 years of age as this result in better knowledge and skills [20]. The author's practice is to become formally involved in patients care from the age of 16 years. Joint consultation with pediatric colleagues occur regularly prior to this.

Throughout early pediatric care the medical team's primary interaction is with the parents with regular reference to the child. In adolescence, there is a shift where the interaction gradually becomes between the medical team and the patient, including as necessary, support from the parents. Joint working relationships and strong links between pediatric and adult teams are pivotal in order for patients to develop relationship and trust with adult services. Poor relationships with clinicians can have negative consequences in both immediate and long term [3]. When health care professionals are not communicating effectively, patient safety is at risk for several reasons including lack of critical information, misinterpretation of information, unclear orders over the telephone and overlooked changes may occur [21]. Multi-Disciplinary Team (MDT) transition meetings are crucial to guarantee patients receive the most appropriate care prior before, during and after transition. The MDT approach also ensures more effective documentation and formalizing of pathways, this enhances joint care planning in complex cases.

The Practicalities of Establishing the CNS Role Within a Transition Service

A new CNS post was established in a South East London Trust, prompted by the recognition of the complexities around the transition from pediatrics to adult care. The post was supported with charitable funding for 2 years. Stakeholders included patients and families, pediatric and adult urologists, commissioners and senior nursing and management teams. Priorities for the CNS and stakeholders included:

- Scoping existing pathways and service
- Understanding issues around transition
- Understanding patient and parent's concerns and priorities
- Identifying necessary skills and training and education needs for the CNS
- Identifying key performance indicators
- Agreeing new clinical pathways and developing patient information
- Securing permanent funding

Scoping Existing Pathways and Services and Understanding Issues Around Transition

When establishing a service, it is important to identify existing local services, understand the geographical catchment area and understand the needs of the young population. Networking with other CNSs and medical colleagues is also useful to help shape the future of the service. It is important for the CNS to have an understanding of their patient group and care received during the pediatric phase, in order to successfully deliver a robust, clinically sound and supportive service to this group of patients.

This was achieved by arranging a supernumerary period to support the development and induction period of the CNS. The objective during this period was to meet and develop a professional relationship with both nursing and consultant colleagues. It also enabled the CNS to visit other urology units, network with other services and key personnel and identify evidence based best practice and pathways. This collaborative working and formulation of ideas also facilitated an understanding of the challenges in some services. The CNS was encouraged to work with colleagues within pediatrics and adult urology services and a period of involvement and engagement in ward duties was actively encouraged to gain a good understating the existing patient pathway.

Two months after commencing post the CNS presented the aims and objectives of her role to the wider stakeholders. This allowed the CNS to raise her profile, explain her role and remit and encouraged discussion from other newly developed services in order to share best practice. In addition, it proved beneficial in raising awareness and the profile of the new service.

Understanding Patient and Parent Concerns and Priorities

Engaging patients and potential users of the service is essential both when setting up a service and when evaluating its effectiveness. Services are planned and evaluated with patient input including tools such as questionnaires to ensure that patient views help shape the service

During the establishment of the service it is vital to take into consideration the differences between pediatric and adult health services, these include:

- Age range
- Culture of care
- Growth and development
- Consultation dynamics
- Communication skills
- Generic health issues
- Confidentiality issues
- Role of parents/family/peers
- Education/Vocation
- Tolerance of immaturity Service Provision.
- Appointment duration
- Extent of physical examination
- Provision of continuity of care
- Consultant accessibility and peer support [2]

An understanding of these differences is beneficial in establishing a realistic job plan incorporating pediatric and adult services. This helped the CNS to forge a robust clinical presence within pediatric and adult urology services. This included attendance at the MDT which facilitated the early identification of transition patients and allowed ongoing learning.

Identifying Necessary Skills and Training and Education Needs for the CNS

When initially setting up a service, the CNS needs to conduct a scoping exercise, aimed to identify and address gaps in knowledge and skill in collaboration with the medical team, nursing colleagues and management. A tailored education plan was then developed within the performance and development review process.

Identifying Key Performance Indicators

Developing benchmarking strategies is crucial, as they facilitate the auditing of practice to help shape the future of the service.

Some of the quality and key performance indicators identified for this service include:

- Reduction in readmission rates
- Reduction in infection rates
- Increase in self-directed management programs
- Reduced complication in catheter care
- And reduce requirement for antibiotic therapy

Agreeing New Clinical Pathways and Developing Patient Information

It was recognized that a pathway to guide transition for the patient group was a key requirement of the role and service. The aim of this pathway was to provide Clinical Standards which could provide benchmarking data and identify Key Performance Indicators for reporting to commissioners and clinical leads. In developing the pathway, the CNS built on the evidence-based practice in the Good2Go Transition Program [22]. This formalized an appropriate seamless transition to adult service, whilst raising the profile of the service by ensuring all stakeholders were aware of the process and subsequent progress involved.

Recent research advocates the use of a validated questionnaire referred to as the CTM-15 questionnaire to assess the introduction of transition clinics [1]. This latest evidence can be incorporated into the service assessment documentation and the validated tool will help to prepare young adults to move to adult services. The assessment protocol's aim is to introduce the CNS as a consistent member of the team providing ongoing care, introduce the concept of transition, assess the patient's knowledge of their condition, support their development of independence by offering opportunity to be reviewed independent of carer for part of consultation and to help the patient develop an understanding of the issues surrounding healthy lifestyles. Other service developments include introducing Health Passports for young people.

The CNS has developed and works within an abstract clinical care model that was devised as part of the YOU service (Table 7.1). Having a **presence** within both paediatric and adult urology has the benefit of early identification of transition patients. This abstract model fosters good working relationships with cohesive working. It enables shared practice and promotes development within the service.

The PRESENCE concept was positively evaluated and supported by service users as demonstrated by a satisfaction survey conducted by the CNS after 6 months in post. The aim of this survey was to gain patient centered, service user feedback and provide information to help shape the future in response to patient needs. Pediatric colleagues stated the positive benefits of presence included an enhancement of working relationships.

As part of the survey, patients were asked what would make their transition easier. Sixty-five percent felt that they would have liked to "meet the CNS prior to transition" and 80% stated they wanted more information about their condition. Results of the survey were used to enhance young people's patient experience. The CNS developed patient information leaflets on the most common presenting conditions of patients and treatments offered. Other suggested information topics service user identified including an understanding the concept of transition, explaining the provision of continued care in an adult environment. These patient information leaflets are now sent to all new patients prior to review in CNS led clinic in pediatrics and when required. The provision of patient information particularly related to medical conditions helps to empower patients, promote patient autonomy and develops independence. Providing written information to patients may also improve their overall satisfaction and facilitate the transition process [1].

The CNS maintains traditional nursing roles as a patient advocate within the MDT team, providing information and support for patients and their families, during the assessment, planning, implementations and evaluation of care utilising high level communication skills. This supports the view that clinical nurse specialists provide essential resource for an effective NHS [23].

A transition pathway (Fig. 7.1) was also developed, combining the good2go [22] transition program. This has been useful in terms of formalizing the approach, gaining consensus and reinforcing the importance of early identification and referral to the transition service.

In practice, patients are referred to the transition CNS from pediatric CNS colleagues and other Urology Consultants within the pediatric team. Patients care pathways are discussed at MDT meeting. The CNS then contacts the family introduces self while explains role in ongoing care and support prior to and during the

Table 7.1 PRESENCE

Patient-focused	Care is patient-centred, planned and evaluated with service users
Responsive	CNS must be responsive to different and changing needs and priorities as patients move between services
Engagement	The CNS practices and promotes engagement with colleagues and with patients providing a seamless transition to adult urology. Continuity of care and facilitation of service users is provided
Sharing	Sharing knowledge with other member of the MDT facilitates developments in the service and advances in practice
Encouragement	The CNS encourages staff, patients and carers to see the benefit of the role by transitioning patients, updating teams with changes and provides continuity of care
Negotiation	Negotiation both with patients, families and colleagues is vital to plan care and improve the service
Collaboration	Collaboration with patients, carers and colleagues is essential to provide best outcomes
Evaluation	Continuous service evaluation is essential to ensure the service is effective and responsive to patient needs

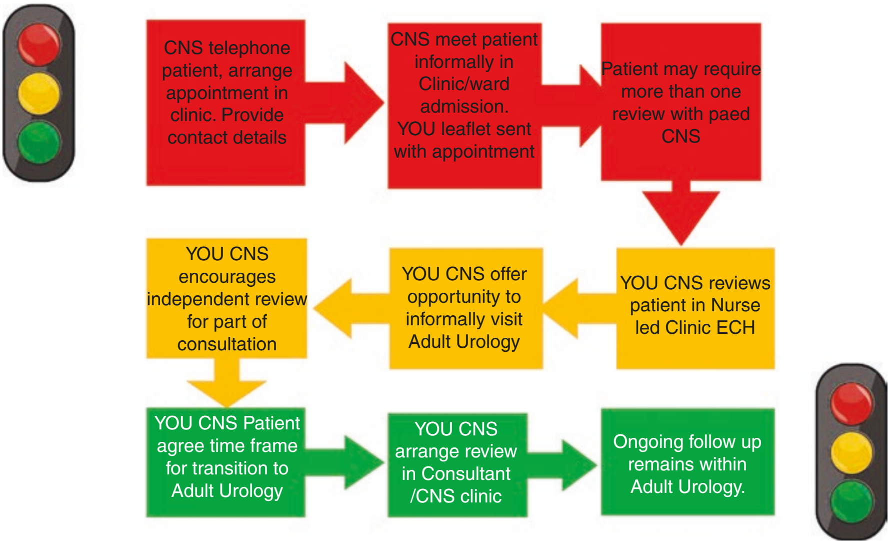


Fig. 7.1 YOU transition pathway

transition phase. An agreed appointment date in the pediatric environment is arranged. The CNS runs monthly clinic, however a flexible approach is adopted with availability to review patients at other times, depending on patient and family commitments. During the review process where appropriate the need for ongoing care and transition is discussed. Allowance is made for the possibility that some patients require more than one review in pediatric care. A timely appropriate seamless transition to adult service is facilitated. Patients are informed of the opportunity to be reviewed for part of the consultation independent from their carers. It is believed this review encourages patients to become responsible for accessing health care providers with an understanding to act upon health care plans. It also aims to facilitate patients' ability to openly discuss any change in their health conditions. This is promoted and encouraged further once reviewed in the adult service. Patients are encouraged to become involved in all further decisions relating to their care. It is believed this inclusive approach increases patient compliance.

Securing Permanent Funding

The post was initially created on a fixed term contract for 2 years. Funding for the post was obtained from the Trust charity. During this period, it allowed the team to understand the need for the role, plan the service and perform an evaluation of its effectiveness. This was also supported by the Department of Health guidelines relating to the You're Welcome quality criteria [24]. There was also a recognition that the Trust did not have any support service available for this group of patients. Following the 2-year period, the CNS produced results on income generated as a result of CNS clinic review and procedures carried out. This proved positive and after formal application, the trust assumed funding responsibility and the post was granted as substantive.

The RCN highlights evidence indicating that specialist nurses can improve the lives of their patients and deliver value for money. This body of evidence is growing as nursing stakeholders and frontline nurses continue to make the economic case for specialist nurses in both community and hospital settings. This evidence indicated that investing in Rheumatology Nurse Specialist to perform routine follow-up consultant's time are freed up to see new patients, saving an additional £175,168. There is growing evidence that CNS make a considerable difference to patient care, and that an investment in the role can generate efficiencies and even cost savings for the health service [25].

Nurses working in these advanced and specialist roles spend approximately 65% of their time in clinical activity, 17% of time in education, 14% in management activity and 4% in research [18]. The quality of care and support that specialist nurses offer has been instrumental in reducing unnecessary hospital admissions and re-admissions, reducing waiting times, freeing up the consultant's time to treat other patients, improving access to care, educating health and social care professionals and supporting patients in the community.

Management and Accountability

Legal accountability relates to the obligation of citizens to obey the laws of the country and to be able to defend their actions through the court if required to do so. Legal responsibility encompasses civil law (e.g., the duty of care), criminal law (duty towards the public) and employment law (duty towards the employer).

Professional accountability relates to the additional obligation of the professions not to abuse trust and to be able to justify their professional actions. In the United

Kingdom, nurses and midwives are professionally accountable to the Nursing and Midwifery Council (NMC). The current revalidation required by nursing statutory body ensures up to date relevant care is delivered and evidenced. Nursing practice should adhere to the principle of the NMC Code found at http://www.nmc.org.uk/code:

- Prioritize people
- Practice effectively
- Preserve safety
- Promote professionalism and trust

The CNS is accountable for all actions with a social, ethical, legal and contractual accountability and responsibility for any tasks undertaken [26]. In order to be accountable, the post holder must:

- Have ability knowledge and skills to carry out the action or intervention
- Admit responsibility for doing the task
- Have the authority to perform the task within their role, through delegation and the policies and protocols of the organization [27].

The Nursing and Midwifery Council (NMC) Code [28] states that nurses should recognize and work within the limits of their competence which includes completing the necessary training before carrying out a new role. Identifying knowledge and skill gaps, education and assessment of competency can be part of the performance and development review process; reflecting on learning and practice will also be an essential element of the revalidation process for nurses.

Accountability for team working includes a commitment that team members make to themselves and their team members to demonstrate attitudes, behaviors and actions that promote team effectiveness and therefore high standards of care [28].

Education and Training and Qualifications

In the UK, there is no title protection for specialist nurses leading to the creation of multiple professional titles and roles. This has made it difficult to collect accurate data on numbers, and role requirements. This has also led to inconsistencies in scope of practice, education and training across hospital providers and higher education institutions, and career progression for clinical nurse specialists [23].

However, CNS post holder requirements may include:

- Diploma or degree in nursing
- Master's level education related to specialist area
- Qualification in teaching and learning in clinical practice
- Leadership skills training
- Additional qualifications related to specialist area
- Research training
- Counseling skills [29]

An important facet of this role is need for highly developed influencing and negotiation skills. A large part of the role includes advanced communication and negotiation skills with colleagues, children, young adults and carers. Anecdotally it has been suggested that nurses with experiences within other disciplines such as oncology, community pediatric services and mental health bring valued experiences to the CNS role. Experience and experiential learning should not be underestimated and can bring additionally qualities to the role and to the service. Nurses may bring transferable skills which are of great benefit in liaising with stakeholders, patients, families and carers at what can be a challenging time for all involved.

Ongoing education within the specialty for the CNS is necessary in order to continue providing evidence-based care. The CNS should continue to network with colleagues within the specialty availing of any opportunities to attend meetings and seminars relevant to practice. This will enable expansion of knowledge and in turn allow for sharing of best practice.

The RCN suggest CNS spend 17% of their time in education [30], this includes education of juniors and colleagues. In practice, the presence of the CNS on the wards assists in demonstrating the value of the role and provides specialist knowledge, informal education and expertise to ward staff. It is essential that the CNS does not lose the essence of nursing as they take on increasing and highly specialist workload [23].

E-learning tools such as the Adolescent Health e-learning project are available. This aims to ensure that all health professionals have essential youth communication skills and understand a young person's right to consent and confidentiality [31].

Users of the service also have training and learning needs. Patient training can be delivered using several methods. Results of a patient survey carried out by the CNS indicated that 80% of patients required more information and education. This led to the development of patient information on common conditions and treatment of patients using the service. Information on the transition service offered was also developed. Education of the patient includes providing them with tools, knowledge and skills to manage their healthcare independently. This may consist of ordering of medical supplies, medication management to include any interaction with contraceptive management. Educating patients on prevention of deterioration in renal function, importance on recognizing factors affecting this is also of utmost importance. In the patient group with bladder reconstruction where part of the bowel is used, it is essential to educate and clarify the need to perform a serum HCG to confirm pregnancy when it is suspected [32].

A model of training for our service is illustrated as an example, in Fig. 7.2 [2].

Conclusion

Pediatric patients with complex conditions need long term care as they move on from children's services. Long term care is required to prevent deterioration and detect later problems and complications related to both condition and treatment. Their transition from pediatrics to adult services should be considered a gradual process, empowering the young people with skills and knowledge necessary to independently manage their healthcare. It should be multidisciplinary with

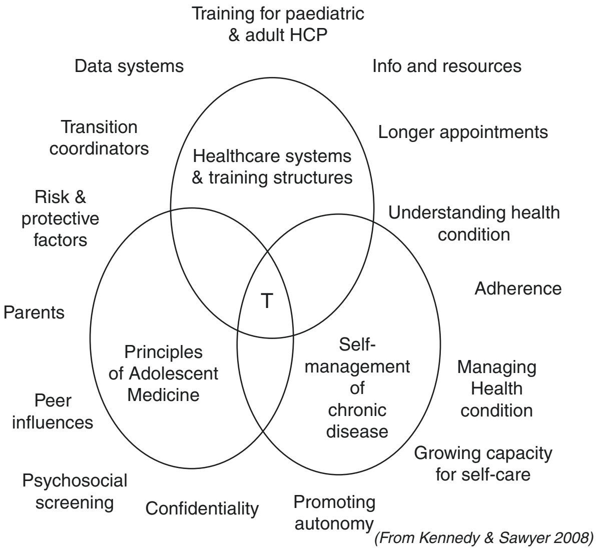


Fig. 7.2 A model of training for YOU services

pathways in place to ensure a smooth seamless appropriate transition to adult services is facilitated. The role of the Clinical Nurse Specialist is instrumental in providing key worker support, education, and information to patients and their families prior to and during the transition period. This support enables the patient to be prepared and empowered to take responsibility for their care. The CNS is an essential bridge between pediatric and adult services.

Engagement and investment from both pediatric and adult services is paramount to the success of a service. The CNS is ideally placed to connect both services. Surveys of young people with various chronic conditions have highlighted the need for transition services, this has been supported by policy documents in the UK [33] the call to support patients and caregivers during this time has never been greater.

References

1. Shalby MS, Gibson A, Granitiotis P, Conn G, Casio S. Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. J Pediatr Urol. 2015;11(2):89.e1–5.
2. Kennedy A, Sawyer S. Transition from pediatric to adult service: are we getting it right. Curr Opin Pediatr. 2008;20(4):403–9.
3. Creighton SM, Wood D. Complex gynaecological and urological problems in adolescents: challenges and transition. Postgrad Med J. 2013;89(1047):34–8.
4. Nagra A, McGinnity PM, Davis N, Salmon AP. Implementing transition: ready steady go. Arch Dis Child Educ Pract Ed. 2015;100(6):313–20.
5. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. Paediatr Nephrol. 2000;14:469–72.
6. Department of Health. Your welcome quality criteria self-assessment toolkit. London: DH; 2011.
7. Department of Health. Transition getting it right for young people. London: DH; 2006.

8. Department of Health. Transition: moving on well. London: DH; 2008.
9. Harden PN, Walsh G, Bandler N, et al. Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. BMJ. 2012;344:e3718.
10. Shaw KL, Watanabe A, Rankin E, et al. Walking the talk. Implementation of transitional care guidance in a UK paediatric and neighbouring adult facility. Child Care Health Dev. 2014;40:663–70.
11. Wood HM, Yerkes EB. The transition process: initial assessment and development of a treatment plan. In: Wood HM, Wood D, editors. Transition and lifelong care in congenital urology, current clinical urology. Switzerland: Springer International Publishing; 2015. p. 3–10.
12. McDonagh J, Viner RM. Lost in transition? Between paediatrics and adult services. BMJ. 2006;332(7539):435–6.
13. Binks JA, Barden WS, Burke TA, Young NL. What do we really know about the transition to adult centred healthcare? A focus on cerebral palsy and spina bifida. Arch Phys Med Rehabil. 2007;88:1064–73.
14. Glasper A. Are young people welcome in the health service? Br J Nurs. 2011;20(12):762–3.
15. RCN Lost in transition. Moving young people between child and adult services. 2013. Publication code 003-227. ISBN 978-1-908782-70-0 RCN 2013.
16. Improving supportive and Palliative Care for adults with cancer guidance (2004). NICE; 2004.
17. RCN. Specialist nurses: changing lives, saving money; 2010. http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf.
18. Ball. Maxi nurses: advanced and specialist nursing roles. RCN; 2005.
19. Fletcher M. Assessing the value of specialist nurses. Nurs Times. 2011;107:12–4.
20. Shaw KL, Southwood TR, McDonagh JE. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. Child Care Health Dev. 2007;33:368–79.
21. Chatman IJ. The joint commission guide to improving staff communication. Oakbrook Terrace, IL: Joint Commission Resources; 2009.
22. Good2Go Transition program. www.sickkids.ca/good2Go.
23. Vidall C, Barlow H, Crowe M, Harrison I, Young A. Clinical nurse specialists: essential resource for an effective NHS. Br J Nurs. 2011;20(17):S23–7.
24. Department of Health. Your Welcome quality criteria: making health service young people friendly. DH London; 2007.
25. RCN. Clinical nurse specialist: adding value to care. 2012. http://www.rcn.org.uk/data.assets/pdf file/0008/317780/003598.pdf.
26. Hamric AB. Creating our future: challenges and opportunities for the clinical nurse specialist. Oncol Nurs Forum. 1992;19(Suppl 1):11–5.
27. RCN. Accountability and delegation, code for the nursing team; 2015.
28. Nursing and Midwifery Council. The code: professional standards of practice and behaviour for nurses and midwives. 2015. https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf. Accessed 2 Aug 2017.
29. NHS Career Planner for Nurses. Clinical Nurse Specialist NHS; 2010.
30. RCN. Factsheet: specialist nursing in the UK February 2013 (last updated December 2014).
31. Department of Health. Adolescent health (online resource). 2011. http://tinyurl.com/6jmbc8g. Accessed 10 Oct 2015.
32. Nakhal RS, Wood D, Woodhouse C, et al. False-positive pregnancy tests following enterocystoplasty. BJOG. 2012;167:300–4.
33. While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. Good practices that address continuity during transition from child to adult care; synthesis of the evidence. Child Care Health Dev. 2004;30:439–52.

Barriers to Transition

8

Wendy F. Bower, D. Michael Whishaw, Caroline Dowling,
and Yves Heloury

Children with complex health problems require multi-disciplinary care. Using the case of congenital urological disorders as an example, children and adolescents with urinary tract involvement require care by multidisciplinary teams. At some point as adolescents or young adults they are moved to an adult service. This is a transfer from a multiple intervention health model to a single clinician environment during a time coinciding with other major life changing events.

Failed transition from pediatric to adult care negatively affects health outcomes, as it is associated with non-adherence to treatment recommendations and increased hospital admissions [1]. Surrogate markers of the efficacy of transition include the proportion of patients lost to follow-up, inappropriate or preventable hospital admissions and medication or self-management non-adherence rates [2].

W. F. Bower (✉)
Continence Service, Department of Medicine and Community Care, Royal Melbourne Hospital,
Parkville, VIC, Australia

Faculty Medicine, Dentistry and Health Sciences, University of Melbourne,
Parkville, VIC, Australia
e-mail: wendy.bower@mh.org.au

D. M. Whishaw
Continence Service, Department of Medicine and Community Care, Royal Melbourne Hospital,
Parkville, VIC, Australia

Department of Urology, Royal Melbourne Hospital, Parkville, VIC, Australia
e-mail: Michael.Whishaw@mh.org.au

C. Dowling
Department of Urology, Eastern Health, Box Hill, VIC, Australia
e-mail: caroline.dowling@easternhealth.org.au

Y. Heloury
Department of Urology, Royal Children's Hospital, Parkville, VIC, Australia

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_8

This chapter outlines the issues facing the pediatric care team, the adult services receiving the young person and the adolescent and their family during the transition of care. The aim is to identify current or potential roadblocks that limit healthcare systems successfully addressing the medical, psychosocial, educational and vocational needs of adolescents who live with their lifelong condition. Instead of a process focused on service transition and transfer, the intention is to support a holistic concept of moving young people with congenital disorders into adulthood and independence.

Pediatric Team

Members of the young person's pediatric care team develop longstanding relationships with patients and their families. Clinicians from different disciplines have steered the child through medical and other issues, often since infancy. During childhood the young person was unlikely to have fully engaged in their own care, meaning the parents and clinicians jointly managed the condition. As the child grows this can create reluctance by the pediatric team and the parents to give autonomy to the adolescent. At transfer of care, the pediatric team may have reservations about the developmental readiness of the young person to co-ordinate and prioritize self-management or to advocate for themselves. The pediatric team may wait to organize transition until the medical situation is perfectly stable, which, in some cases may never be realistic. Furthermore, fear about often unfounded but critical judgement of the pediatric management may delay transition.

In childhood, comprehensive multisystem developmental medical care can be likened to a hub and spokes principle, where the child sits at the convergence of various disciplines. Although there is a specific focus on the anomaly, education, social care, family support and other aspects are routinely addressed. Pediatric team members may be reluctant to initiate moving the young person into an adult care model, because of concerns there is no equivalent of an "adult pediatrician" to oversee both therapeutic and holistic issues. Additionally, reluctance in transferring young people may be associated with the perception that the adult service is unfamiliar with pro-actively managing complex congenital conditions (in some, but not all, environments, this is true).

The pediatric team is ultimately responsible for effective transfer of young people to an adult service. Ideally, team members should start preparing their patients and caregivers at an early age for transfer of care into the adult environment. Readiness programs that sequentially build skills around self-evaluation, reporting, questioning clinicians, articulating needs and engagement in self-management have been described [3]. This takes the form of systematically building skills itemized in a readiness checklist at regular allied health appointments and subsequent practice during medical consultation. The aim of readiness programs is to enable young patients to become effective partners in their own care, in whichever health system they are managed. Engaging a child in self-management optimizes treatment compliance. The readiness process can be limited by participation in risk-taking behaviors and an adolescent mindset or developmental issues that limit the level of responsibility that a young person can assume for their own wellbeing.

Transition is problematic when the pediatric team has limited contact with adult primary provider(s). Communication issues are likely to arise when services are on different sites or do not share a medical record system. It is challenging to summarize life-long care and management to a clinician whose specialized education has targeted only adults. Purposefully built links between adult and child services, shared consultation and staff common to both environments facilitates transition between care teams [4].

Adult Urology Team

Adult urological teams are hampered by a lack of training in the management of rare, complex malformations and the management of an adolescent or young adult population. Urology training does not always include a rotation in a pediatric center with significant malformation surgery. Clinical information, particularly imaging and operation records of earlier surgeries, may be lacking or inaccurate.

The general practitioner plays a larger role in care of young people and adults with on-going urology needs than during childhood. The young person will commonly need help to self-advocate the timely care they need from a family doctor, who in turn requires clear communication channels with the overseeing adult care team.

Whilst adults who attend urological appointments are generally able to self-report important aspects and concerns related to their condition, young people are new to this kind of consultation. Their childhood experience is care-giver directed with consultation being family-oriented. Clinicians in the adult service thus require additional time to gain pertinent information and to develop effective strategies to manage young people. Collaborative and reactive relationships with young people represent a new care model for adolescents. Building trust with a new clinician may take several visits to establish, suggesting that annual review models of care may be sub-optimal in adolescents. Unless specifically questioned, unmet psychosocial needs that influence self-management may be missed.

Young people often worry about their most intimate body parts, about how they look and function. Such worries can lead to withdrawal, low self-esteem, depressed moods and anxiety [4]. Psychological difficulties are intimately related to physical condition. Young people with limited mobility and altered employment prospects may perceive themselves as unequal to their peers. Childhood services provide a degree of psychological support; however, adult services often deal only with the urological issues and are generally resource poor in terms of mental health intervention, social support and psychological assistance.

Individuals who have urinary tract dysfunction commonly report co-existing sexual issues and impaired continence, all of which impact on self-esteem and sexuality. Using the Spina Bifida population as an example, erectile dysfunction occurs in up to 25% and can be multifactorial in nature. Those with higher level lesions (higher than T10) may have fertility issues [5].

Adult services will need to discuss sexual issues, including fertility and safe sex practices. These conversations need to be introduced at a developmentally appropriate age and time and are unlikely to have been raised in the pediatric environment. Many transitioning adolescents with congenital anomalies haven't had the exposure to sex-education either formally or informally. Many parents choose not to think that their child is developing into an adult and this includes "sexuality." In the past sexual information has been prioritized only if the client has a "partner." However, safe sex, family planning, and ensuring that sexual activity includes more than just penetrative sex are areas that are now more routinely discussed. Some services advise on what to look for in a professional organization and alternatives such as virtual reality sex and specialized sex toys for both men and women.

Most successful services will have nursing and ancillary support staff to bridge the transition gap. These team members often know the young adult from the pediatric setting and attend the adult consultations with the young person on several occasions. Without this team- member-in-common, transition services may lack communication, troubleshooting, product advice, appointment follow-up and a familiar person for the adolescent to contact. Transition nurses, in particular, ensure a youth-friendly environment by preparing relevant education material, resourcing clinics with appropriate products and devices and offering care for a range of unplanned needs. As transition is a process, joint services between the pediatric and adult specialist will extend for 2 or 3 years with clinics initially in the pediatric hospital and later in the adult service.

Adult clinicians accepting young people with on-going complex needs may be disincentivized by lack of financial support to undertake complex and time-consuming work which comparative to other sub-specialist areas is less well funded. Funding models are country specific, but in general funding for these complex patients tends to be less than for some other less complex or higher turnover specialties. Along with the challenging nature of the physical and psychological issues in transitioning young adults, there appear to be vocational and financial disincentive for some adult practitioners to assume transfer of care.

Young Adult

Young adults living with chronic disease are establishing independence and autonomy, often making changes in living arrangements and moving from full time-education to work, vocational or higher education. This may occur against a backdrop of neurodevelopment or mobility limited by the underlying condition. During this period patients commonly prioritize "normal" behaviors and body image above appropriate care for their medical condition. As consumers of health care, they commonly choose to attend review consultations only if they see immediate benefit. Unfortunately, long-term regular surveillance for early markers of potential complications may not fit this mindset.

During childhood, the family and pediatric team have likely driven care and adherence to intervention and management strategies. With early adulthood comes the need to self-advocate and react appropriately to signs of significance or deterioration. Families are reluctant to withdraw oversight until the young person is able to assume responsibility for taking these steps in managing their disorder. In reality, families have a lifelong role as “second in command,” but need to facilitate the patient assuming as much accountability as they are able for self-management of their condition.

Some individuals have difficulty prioritizing or implementing treatment regimens. This may coincide with poor health literacy, perception of conflicting information or differences in service provision between pediatric and adult environments. With little or no relationship between a transitioning adolescent and the adult care team it becomes easy for young patients to opt out of surveillance programs and to be lost to follow-up by the new service. This may be compounded by geographical distance from adult service clinicians, difficulty with transport and business hours appointments offered by the relevant medical teams.

Family

Families, usually parents, will probably have had a direct relationship with clinicians throughout their child’s life, potentially across several medical disciplines, but often within one health facility. Although the objectives of care remain similar the adult care model is more likely to be fragmented, and often spread over a number of care centers, making service provision more difficult to co-ordinate. Responsibility for this co-ordination is more likely to fall upon the parents/young adult.

In some countries allied health services may have been provided and funded through the Education Department at schools. This service co-ordination and funding ceases on entry to adult services. Information handover is often poor. One common strategy is to encourage parents to gather as much documented information as possible to take to their new adult service.

The obligatory transfer of patient care from a unit with whom the family has established trust and understanding means new relationships must be established. In many cases clinicians in the adult services will have less experience of working with families.

There is a need to prepare children for assuming whatever level of self-care their condition allows, from as early as possible. Most parents will be keen to consider future financial independence and vocational experiences for their child, but will often be in need of guidance in these areas. Then, as the young person moves into adulthood parents are relegated to a less prominent role. Probably for most, this is a complex and emotional transition.

There may be conflicts between life-long care-giving and advocating for their child versus potentially impeding an adolescent’s developing autonomy, independent decision-making and self-care [6]. Parents may have difficulty relinquishing responsibility for oversight of care, particularly when adult team and safety net practices are poorly understood or unknown. This concept becomes more challenging where the transitioning young person has an intellectual difficulty or border-line competency making decisions.

Placing the young person, not their disorder, at the center of transition will assist families in progressively relinquishing certain tasks and responsibilities. However, some patients will continue to have significant dependency for certain care needs previously catered for by a parent, such as catheter and bowel management. At least for a while parents will continue this responsibility, but for many young adults, parental care will become socially challenging, at times unacceptable; this will create a demand to explore alternative strategies.

The transition from being a "minor" to being an adult also has legal consequences for the parents. Indeed, there may be limited recognition of their changed legal status within the doctor-patient relationship and the threat of violating patient confidentiality may become an issue. Parents often feel that they still have a 'right' to know what is going on with their child and whilst it may helpful to have them informed (as they can support their child) the young adult can block this and needs to know that they are the one who has the 'right' to information and confidentiality. This can be very uncomfortable for a parent when they encounter it for the first time.

Transition is a time when the emotional needs of families may change. This may revolve around many fears, including potential consequences of relinquishing control, and even a fear that their child might be the subject of exploitation, e.g., socially, financially or vocationally. A good transition process will address these issues.

Facilitating Successful Transition

Table 8.1 summarizes key aspects of service provision that will optimize success of transition and transfer. Recommendations are listed chronologically, and it can be seen that a positive expectation of transfer of care can be developed from an early age.

Summary

The ongoing care of a young person with lifelong needs extends beyond the just their diagnosis or the organ(s) directly affected.

Complex medical, psychosocial, educational and vocational needs co-exist and impact treatment adherence and efficacy. The move from a childhood to adult health service can be optimized by focusing on what matters to the young person and their family. The aim is to support a level of independence in adulthood that the underlying condition permits.

Attention to building systems that closely link pediatric with adult care teams will improve communication, build knowledge and surveillance skills, allow the young person to build new health care relationships and support the natural progression to greater self-monitoring and timely help-seeking.

Table 8.1 Identifying and solving the common barriers to successful transition

Problem	Prevention
Transfer comes as a surprise	Eventual transfer of care to an adult team presented as a normal expectation during childhood
Transfer induces fear	Care by an adult team presented as a positive progression for best long-term management from an early age
No transition before transfer	Providing time for the young person to adjust expectations of style of care; creating the opportunity to develop new relationships
Young person not ready to move from pediatric care model	Childhood readiness programs being part of allied health care from early years
No familiar face in adult service	Appointment of a specific person in adult service to coordinate the transition process and to attend appointments jointly with young person prior to actual transition
Different service location	Consider age appropriate environment, with optimal access by public transport, flexible consultation hours, use of telemedicine and electronic communication
No multi-disciplinary teams	Co-opt nurses, psychologists, social workers, and transition coordinators to assist patients to optimise eligibility and access to community services.
Communication between teams	Transition service delivered jointly by members of both the pediatric and adult teams. Full access to complete medical records. Individual case discussion with childhood caregivers.
Reactive consultations new to young person	Begin to teach patient how to self-report important aspects of their condition from teenage years or earlier
Adult care model requires autonomy	Families to empower children to be able to take on aspects of organizing themselves to attend appointments, notice early complications or when medication is needed, plan ahead to order supplies of consumables etc.
Isolation; different to peers	Link young people into support networks of similar disorders or across conditions
Primary care under utilized	Ensure GP access to relevant information about the young person's condition and care plan

References

1. Goodhand J, Hedin CR, Croft NM, et al. Adolescents with IBD: the importance of structured transition care. J Crohns Colitis. 2011;5(6):509–19.
2. Wysocki T, et al. Diabetes mellitus in the transition to adulthood: adjustment, self-care, and health status. J Dev Behav Pediatr. 1992;13(3):194–201.
3. Schwartz LA, et al. Stakeholder validation of a model of readiness for transition to adult care. JAMA Pediatr. 2013;167(10):939–46.
4. Bower WF, Christie D, DeGennaro M, Latthe P, Raes A, Romao RL, et al. The transition of young adults with lifelong urological needs from pediatric to adult services: an International Children's Continence Society position statement. Neurourol Urodyn. 2017;36(3):811–9.
5. Bong GW, Rovner ES. Sexual health in adult men with spina bifida. Sci World J. 2007;7:1466–9.
6. Kovacs AH, McCrindle BW. So hard to say goodbye: transition from paediatric to adult cardiology care. Nat Rev Cardiol. 2014;11(1):51–62.

9

Developmentally Appropriate Adolescent Health Care: An Essential Prerequisite for Positive Transition Experiences

Deborah Christie and Gail Dovey-Pearce

Introduction

As a direct result of improvements in medical care, therapy regimens, and advances in medical technology the number of young people with chronic illness and/or disabilities surviving into adulthood is increasing [1, 2].

The organizational boundary between children's and adult services remains the starting point for many clinicians, managers and researchers focusing on structural boundaries and the changing landscape associated with adult services. There is a common assumption that transition should start around 16. For example, in the UK National Service Framework for children, young people and maternity services the emphasis is for pediatric services to retain responsibility for young people until their 16th birthday, if not till 18 years [3].

The majority of current transitional care models are located within disease specific specialist teams based in hospital-based clinics [4]. Professional guidelines from the UK [5–8], USA [9], Canada [10], and the World Health Organization [11] address the need for transition in adolescence and adolescent health and

D. Christie (✉)
Department of Child and Adolescent Psychological Services,
University College London Hospital NHS Foundation Trust,
London, UK
e-mail: Deborah.christie@uclh.nhs.uk

G. Dovey-Pearce
Department of Child Health (c/o Health Psychology, DRC),
North Tyneside General Hospital, Northumbria Healthcare NHS Foundation Trust,
North Shields, UK
e-mail: gail.dovey-pearce@nhct.nhs.uk

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_9

propose parameters for what transition programs could and should look like. The UK Department of Health published guidance that is freely available on the internet [12], whilst McDonagh [13] reviewed 232 papers summarizing the literature and producing a toolkit to enable the planning and implementation of transition services.

However, this traditional focus on 'healthcare transition', as the 2–3 years around the move between child and adult services, offers a limited and unhelpful perspective. It is essential to see transition as a key component of overarching, developmentally appropriate healthcare (DAH) for adolescents and young adults. DAH requires an approach by healthcare professionals who understand and respond to the changing biopsychosocial and developmental needs of young people, embedding individualized healthcare, health education and health promotion, by engaging effectively with each young person and their carers [14].

Within the literature and chapters of this volume, DAH is closely linked to the concept of transition and in providing DAH, transition and transfer will be addressed as these needs arise.

> …if we had true age and developmentally appropriate adolescent health services, incorporating all facets of adolescent health, transition would flow naturally. As this is not yet the case, it is important to understand concurrent adolescent developmental issues in conjunction with chronic health issues [15].

DAH is the "key principle underpinning the practice of adolescent medicine" [16] supporting the care of young people from early adolescence through to young adulthood, with transition and transfer as distinct aspects of this more broad conceptualization and process. Whilst there will be some specific needs—related to diagnosis and treatment—in order to better understand, define and operationalize DAH, researchers and clinicians must consider the existing and emerging evidence about adolescent development, looking to fields such as psychology, sociology and neurobiology.

Within the field of developmental psychology, for example, "emerging adulthood" has been described as a developmental phase in Western societies between late teens and early 20s. It is characterized by feelings of ambiguity and experimentation as young people strive towards abstract goals, such as responsibility and independence. Concrete markers that once delineated adulthood such as marriage and childbirth, now tend to happen later in life. Within neurobiology, new evidence relating to the development of brain areas associated with social behaviors might support openness to social stimulation and the importance of peer acceptance as key components if young people are to "strike out" from their family of origin. This evidence may also underpin risk-taking and reward-seeking behaviors that can enable adolescents to try different experiences and explore the costs and consequences; necessary for their development of self-determination and identity. Such theories help to contextualize young people's thoughts about illness, well-being and self-care behaviors as much as other cognitive and behavioral domains. Experimentation and oscillation in social behavior is also observed in patterns of self-care. The ambiguity for young people around what marks the boundary between childhood to adulthood is mirrored by a perception of one's self as a young, vital being balanced against the challenges of a long-term health condition more in keeping with "old age." The importance of peers and social referencing has been explored as a useful intervention for health teams (e.g., peer mentoring) but also means that young people often wish their condition 'away' in their desire to be "normal."

Adolescence through into young adulthood is, therefore, a unique and critical period of development when specific prevention and intervention strategies may still alter trajectories and decrease threats to health along the adult life course. However, unmet health needs and disparities in access to appropriate care, health status and mortality rates are high. Young adults between 18 and 25 years of age experience higher rates of mortality and unplanned pregnancy, and lower access to health care compared to those immediately younger (10–17 years of age) and those immediately older (26–30 years of age). As the disparate health status and the biological development has become known, young adulthood is increasingly seen by international and United States adolescent and young adult health researchers as a vulnerable developmental period, and therefore, in need of specific focus and attention [17, 18]. The change of emphasis in relation to health condition focuses on greater resilience, self-care, integrated support from services and embedded social support [17, 19]. These factors mean that the time when young adults move away from their parental home to independent living can be fraught with challenges. Evidence suggests that those young adults that do the worst are those who have not had attention paid to the complex balancing act between medication demands, hospital appointments, work and social activities, nutrition and key tasks of development [18]. This chapter provides an overview of the better evidenced approaches and interventions within "adolescent medicine," including some specific to the process of transition. These approaches include how to think about and assess whether a young person is ready to cope with the multiple and changing healthcare challenges as they move from adolescence to adulthood.

Approaches and Interventions to Support the Provision of DAH

There remains a lack of evidence for 'what works' in adolescent medicine, DAH and transition, which continues to create a challenge for those tasked with putting policy into practice. Despite the constant flow of reviews, articles and commentaries on transition, in the last decade, the body of evidence describing service development has not grown at anything like the same rate as the number of young people who are now 10 years older and ready to transfer to adult services. It is suggested that the field remains constrained by a reliance on descriptive rather than evaluative studies and poor research design. A key weakness is the continued focus on a 2–3-year window around transfer and the lack of debate about what constitutes successful, long-term outcomes for young people managing their health condition in the context of their daily life.

A recent 5-year, UK study of health service provision and healthcare outcomes for young people aged 14–18, with LTHCs attempted to address some of these research design issues [20–22]. The authors concluded that 'healthcare providers working with YP should understand their individual needs and coping strategies allowing a personalized approach to their clinical care.'

In looking to provide such a person-centred approach, they found initial evidence to support a focus on three aspects of service provision for young people:

- promoting the young person's confidence in their ability to manage their health and wellbeing,
- supporting appropriate parental involvement (i.e., that meets the needs of both the parent and the YP), and;
- facilitating a meeting with the adult team before the transfer between services.

Developing Confidence in Self-Management and Healthcare Self-Efficacy

The development of self-management skills is associated with positive medical outcomes e.g. metabolic control, self-efficacy, and quality of life is improved in adolescents with diabetes taking part in self-management, education and coping skills training programs [23–26]. A key component of self-management is to ensure that young people have

(a) an awareness and knowledge of their medical condition
(b) an understanding of the rationale behind the recommended therapeutic regimen and
(c) consequences of selecting to follow a regimen of their own choosing.

Perceived self-efficacy rests upon the beliefs that a person has about their ability to manage the impacts of the events affecting their lives. It shifts and changes over the course of life, and is influenced by personal experience of managing events, seeing (at close hand) others coping with tasks, encouragement from peers and others in their social network and the awareness of internal responses (such as emotions) that can reinforce a sense of achievement or highlight potential vulnerabilities [27].

In order to help young people develop self-efficacy in relation to their health and wellbeing, the working relationship between the HCP and the YP is key. YP want their HCP to be interested in them as a person and not just in their medical need(s) above all, they must be perceived as approachable and trustworthy by the YP [28]. With such a rapport in place, the HCP is then in a position to be one of the people helping the YP develop the knowledge and skills they need to self-manage their care. This will include being able to identify signs and symptoms of emotional or physical health need, in addition—developing their confidence (in their own ability) to manage those needs—i.e., their healthcare self-efficacy. As part of this the YP will come to understand their own coping skills and strengths. Permission and partnership will allow a YP to have some trial-and-error experiences, knowing that they are able to ask for support when required. The HCP needs to consider that a YP will have competing priorities, such as academic and social pressures—this will help to contextualize the YPs decisions and responses, including the ones that are seemingly at odds with optimal self-care.

The HCP is only one person that the YP draws upon for support. Family members are the most central source of support and advice, including for health issues; peers also feature strongly in an adolescent’s network [29].

Appropriate Parental Involvement

An earlier study found that one in three health professionals identified parental difficulties during transition, with successful transition influenced by parental and family factors [30]. Taking a step backward and encouraging independence is a challenge for many parents of adolescents that is made much more challenging by chronic illness and/or disability. This is certainly a view held by many adolescents. In a survey, 44% of adolescents with sickle cell disease stated that transition programs should offer “ways to help parents let their adolescents grow up!” [31].

A DAH approach would require HCPs to steadily encourage young people to take time and develop the skills to take an active part in consultations, independently of their parents. This will include practices such as: speaking directly to adolescents during the consultation, ensuring that their questions are ascertained, as well as those of the parents; having a small amount of time alone with younger adolescents, with this time increasing as they get older and more confident; and staff having the confidence to talk to young people about issues of increasing relevance, such as managing risks of experimental behaviors, exploring relationships and sexuality, discussing social media pressures etc. HCPS need to have the confidence to do this and may require support and training. They will need to have an awareness of other available services locally, to be able to signpost a YP to. The healthcare team cannot be specialist in their medical area and know all about issues of housing, sexuality, or education, for example, but will need to know who to contact or where information can be found. As well as individual HCPs having skills, information and confidence, managerial and organizational factors can also support the delivery of DAH, with practices such as offering all YP the opportunity to be seen alone usefully becoming part of the cultural norm within whole teams or departments, rather than being viewed as specialist practice. The parameters around confidentiality and consent need to be clearly understood by staff and explained to families, so that YP and parents can feel reassured about this steady change in emphasis and practice. Sometimes, young people will need support and encouragement to manage this shift and sometimes the parents will need to be reassured. This approach does not mean that parents are excluded from their young person's care. Some 15-year-olds will come to their consultations alone and some 21-year-olds will want their parent with them, even when transferred to adult services—healthcare teams need to create an individualized feel to care that makes either situation feel right for a patient.

Meeting the Adult Team

For those YP moving from child to adult services, the Paediatric health care teams are ideally placed to introduce ideas of independence and confidence. This will be best achieved by not asking how a single transition point should be managed but how best to meet the needs of the young person at each stage of development. Young people who have close working relationships with team(s) have less anxiety about the move to adult services, increased perception of improved coping and as a result they need less formalized support. As part of the transition process the team should enable the development of self-management skills which should parallel the psychological, emotional and cognitive development of the young person. The team should also take into account the family and social situation [32].

Even if the team completely changes when pediatric and adult services are culturally aligned, families can still experience a smoother and manageable transfer. Joint working and structural integration alone do not guarantee this alignment and it has been reported that clinical leadership and a commitment to adolescent health appear to be the additional active ingredients in services exhibiting highest levels of cultural continuity. Enabling families to manage the move and negotiate the cultural differences between teams is also central [33].

Having a Key Worker

Liaison personnel in both pediatric and adult teams, one of whom could usefully be a key worker/named worker throughout transition, should be identified for each individual and remain available to the YP until transition is successfully completed [34]. This kind of service development will have resource implications in terms of clinic space and/or time in addition to staffing levels, particularly for those practitioners not working within a multidisciplinary team. There is a requirement for multi-disciplinary and/or multi agency involvement especially for complex cases and teams.

Clinical Tools to Support the Provision of DAH

Young people are clear that they don't wake up one day feeling "ready" and even if they did, they may well change their mind the next day. Assessment of 'readiness' is not a unitary construct but rather requires an ongoing process over time. A recent systematic review [35] reported on ten tools specifically designed to "assess readiness." Seven were disease specific and three generic. Only the TRAQ (Transition Readiness Assessment Questionnaire) demonstrated adequate content and construct validity as well as internal consistency. The TRAQ is only designed to assess the concept of self-management and self-efficacy as described above and does not address the role of parental involvement or the development of a relationship with the adult team and its members. The authors would argue, strongly, that completing this as a one-off exercise at a predetermined age can only provide 'snapshot' view and thus violates good adolescent health principles. Questions about self-management and efficacy must be explored on a regular basis—and at the very least yearly from the point at which the young person starts to see themselves or be seen by others as a young adolescent.

Health Passports

There is enthusiasm for young people to be provided with a health planner (often described as a health passport) to record medications, treatments, school, activities and healthcare appointments, which serves as a portable and accessible health summary for the young person to take with them when they meet new teams. A relatively recent study of 50 young people found that young people said their 'health passport' was "helpful", especially with planning and organizing their healthcare [36]. However, they did not use it all of the time. The most frequent use was just before and after their move to the adult service. A combination of being busy in other areas of life and feeling that the HP was too big, meant that people thought it was hard work and didn't always use it. Young people seemed to use the HP in short but useful bursts and only used the sections relevant to them. Support to use it was key: e.g. help filling it in; the doctor asking to see it in clinic. Overall, young people showed a 'modest use' of the HP and to be useful it needs to be built into the consultation with the doctor rather than it just being left to the young person to complete. This is mirrored by the young people's work within the Transition research in the UK [37]. In a small-scale, exploratory survey, they elicited the views YP who had co-developed health passports for use within their service. Even having co-designed these tools, the YP said that they were "sometimes" useful but that they rarely remembered to take them to clinic, and that maybe the HCP and parents had more use for them. The emerging published findings and anecdotal evidence suggest that a wider investigation of the use and utility of hand held health records for YP is needed.

The Department of Health's "You're Welcome" self-assessment framework is another useful resource for all health services looking to be acceptable and accessible to young people [38].

There also standardized screening tools such as HEADSS [39] or the more current SSHADESS, which emphasizes strengths [40, 41]:

The SSHADESS Screen

- **S**trength
- **S**chool
- **H**ome
- **A**ctivities
- **D**rug/substance use
- **E**motions/eating/depression
- **S**uicidality
- **S**afety

Psychosocial Interventions

There is also limited evidence relating to the positive effects of psychosocial interventions designed to support transition. Data suggest benefit is only sustained for as long as interventions are provided and that the small number of studies, carried out in a number of different countries, make it difficult to ascertain the general applicability of any findings. Another challenge is that, to date, studies focus on narrow health outcomes rather than outcomes reflecting a holistic definition of transition, or (importantly) outcomes defined by young people. What an adolescent defines as a ‘health outcome’ may bear no relation to the outcomes defined by health care professionals.

More comprehensive and conceptually clear research is required. Also needed is a focus on the organizational and commissioning approaches that are central in underpinning long-term improvements within the field.

The Importance of Organizational and Commissioning Structures to Support Clinical Work

In a scoping review of studies reporting ‘transition interventions’, current evidence for practice was evaluated alongside how these practices become embedded within healthcare systems. Normalization Process Theory (NPT) is an evidence-based theory approach to evaluating how complex healthcare interventions become part of routine practice (i.e. normalized). Original studies were evaluated as to how far they showed consideration of four elements of NPT: (1) coherence (is the service perceived as valuable by service users and useful by the providers?); (2) cognitive participation (do staff think the work is a legitimate part of their role and do they support it over time?); (3) collective action (how does the work get done in the clinical context?); and (4) reflexive monitoring (how is the work formally evaluated and informally reflected upon). Most studies gave descriptions of interventions they were evaluating but reported little information about these aspects of service sustainability. Studies gave some account of the perceived value of interventions but there was little description of how staff incorporated the work into their existing roles. The focus was on individual champions and coordinators, with clear risks around sustainability and equity of provision.

The Colver et al. study [20] also concluded that there are important organizational and commissioning approaches that are required, to underpin the fundamental, clinical work. In terms of commissioning structures, YP's healthcare provision should involve fundholders (e.g., insurers or health commissioners (UK) of both child and adult services and that they should be commissioning a framework to provide DAH across healthcare organizations). Organizationally, institutions should adopt a wide approach to implementation of transition and young people's healthcare. A Transition Steering Committee—or similar set up, chaired by a Transition Coordinator, is one suggested means by which to facilitate this. Further, pediatric clinicians should plan Transition procedures jointly with the relevant named adult clinicians and general practitioners.

Prioritizing adolescent health training and incorporating it into all aspects of professional healthcare training is essential and long overdue. Good examples of training resources exist—(e.g., European training in effective adolescent care and health (EuTeach [42]) and E-learning for Health, adolescent health module)—but more needs to be done to ensure widespread access to training for healthcare professionals across child and adult services [14].

Current training in adolescent health and transition, in pediatrics and adult medicine, is still not fit for purpose in the UK and many other countries. For example, just under half of health professionals working in rheumatology clinics are unclear about transitional care issues, are ambivalent about their role and identify significant training needs [30, 43, 44]. Lack of training in adolescent development and health care has been reported as a major barrier to the implementation of transition [32]. Whilst specific health needs of adolescents have been clearly acknowledged and extensively documented [45–49] few pediatricians have received specific training in adolescent health.

Conclusion

Reid et al. have pointed out that the issues of transition are "discussed frequently … [but] studied rarely" [50].

Even though a number of chapters in this book attempt to do so, it is time that instead of trying to provide a good 'transition' we concentrate on ensuring that pediatricians and adult physicians improve their understanding of adolescent and young adult development and provide "good adolescent and young adult healthcare." There have been attempts to make this happen. The Children and Young People's Health Outcomes Forum is an independent group of experts from local government, the NHS and charities helping to develop a new strategy for improving care. In July 2012, they recommended four new indicators for inclusion within the NHS Outcomes Framework. Two of these are: (1) effective transition from children

Table 9.1 Basic principles of Adolescent Health and Medicine

Provide developmentally appropriate care
Enhance patient autonomy
Ensure collaboration between healthcare providers
Teach skills of negotiation
Gradation of responsibility to the adolescent
Provide community resources
Designated professional who takes responsibility for transition
Provide patient a portable summary of their healthcare needs
Have current transition plan documented

to adult services and; (2) age-appropriate services, with particular reference to teenagers.

More recently in 2014 the Care Quality Commission (CQC) published a report on transition with a key quote:

> … good transition arrangements may raise a provider's rating, and poor practice may reduce it. We may take action in cases where arrangements are so poor that they pose a risk to the quality of care experienced by people who use services [51].

Rather than continually reviewing transition we should encouraging young people to become "independent managers of their health care personal mastery!!" [52].

Numerous guidance documents contain suggestions for addressing the developmental needs of young people that have been overlooked by focusing on the organizational matters of transfer. We agree that all young people should know well in advance that the location of their care will change and preparation for this should happen. However, we propose that this should occur as a matter of course, embedded within a framework of quality adolescent and young adult healthcare. The way in which we do this is enshrined in the Society for Adolescent Health and Medicine [53] (Table 9.1).

What Needs to Be Done

Adolescent Healthcare Provision: Key Practice Points

- Professionals working with young people (aged 11–25) should seek additional training in adolescent health and development (e.g., http://www.e-lfh.org.uk/projects/adolescent-health/. and http://www.unil.ch/euteach)
- Making Healthcare Work for Young People: A Toolkit to support delivery of developmentally appropriate healthcare in the NHS (https://www.northumbria.nhs.uk/sites/default/files/nhs-making-healthcare-work-web.pdf)
- Young people will want to discuss their health condition in the context of their daily life

- Individual time within the consultation separate from parent(s)/carer(s) should be offered to young people, based on their readiness and preference.
- The parameters of confidentiality should be discussed with young people in the first consultation, with reminders at periodic points throughout adolescence.
- Parent(s)/carer(s) will continue to need to be involved to support the young person.
- Skills in facilitating this triad of communication (young person-parent(s)/carer(s)-professional) are required by health care professionals, in order to co-create the agenda of the consultation.
- Future research needs to capture the detail and complexity of interventions pertaining to the more nuanced, developmental aspects of young people's healthcare. There has been a call [54] for future research to be led by staff trained to work with young people and with a nuanced knowledge of the barriers that impact negatively on their care.

References

1. Nelson KE, Hexem KR, Feudtner C. Inpatient hospital care of children with trisomy 13 and trisomy 18 in the United States. Pediatrics. 2012;129(5):869–76.
2. Stoll BJ, Hansen NI, Bell EF, Shankaran S, Laptook AR, Walsh MC, et al. Neonatal outcomes of extremely preterm infants from the NICHD Neonatal Research Network. Pediatrics. 2010;126(3):443–56.
3. Department of Health. National Service framework: children, young people and maternity services. 2004. https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services. Accessed 18 May 2018.
4. Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. J Adolesc Health. 1999;24(4):259–64.
5. British Medical Association, Board of Science and Education. Adolescent health. 2003. http://image.guardian.co.uk/sys-files/Society/documents/2003/12/08/BMA_AdolescentHealth.pdf. Accessed 18 May 2018.
6. Royal College of Nursing and Royal College of General Practitioners. Getting it right for young people in your practice. 2014. https://www.rcn.org.uk/professional-development/publications/pub-004509. Accessed 18 May 2018.
7. Royal College of Nursing. Adolescent transition care: RCN guidance for nursing staff. 2013. https://www.rcn.org.uk/professional-development/publications/pub-004510. Accessed 18 May 2018.
8. Royal College of Paediatrics and Child Health. Bridging the gaps: health care for adolescents. 2003. http://rcpch.adlibhosting.com/files/Bridging%20the%20Gaps%20-%20Health%20Care%20for%20Adolescents%202003-06.pdf. Accessed 18 May 2018.
9. American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics. 2002;110(Supplement 3):1304–6.
10. Pinzon J, Harvey J, Canadian Paediatric Society and Adolescent Health Committee. Care of adolescents with chronic conditions. Paediatr Child Health. 2006;11(1):43–8.
11. World Health Organization Europe. Young people's health in context. Health behaviour in school-aged children (HBSC) study: international report from the 2001/2002 survey. 2004. http://www.euro.who.int/__data/assets/pdf_file/0008/110231/e82923.pdf. Accessed 18 May 2018.

12. Department of Health/Child Health and Maternity Services Branch. Transition: getting it right for young people. 2006. http://webarchive.nationalarchives.gov.uk/20130123205838/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145. Accessed 21 May 2018.
13. McDonagh JE, Minnaar G, Kelly K, O'Connor D, Shaw KL. Unmet education and training needs in adolescent health of health professionals in a UK children's hospital. Acta Paediatr. 2006;95(6):715–9.
14. Northumbria Healthcare. Making healthcare work for young people: a toolkit to support delivery of developmentally appropriate healthcare in the NHS. 2017. https://www.northumbria.nhs.uk/sites/default/files/nhs-making-healthcare-work-web.pdf. Accessed 21 May 2018.
15. Khadr S, Kelnar C. Transition care—between a rock and a hard place? J R Coll Physicians Edinb. 2008;38:194–5.
16. Sawyer SM, Aroni RA. Self-management in adolescents with chronic illness. What does it mean and how can it be achieved. Med J Aust. 2005;183(8):405–9.
17. Hagell A, Shah R, Coleman J. Key data on young people 2017. London: Association for Young People's Health; 2017. http://www.ayph.org.uk/keydata2017/FullVersion2017.pdf. Accessed 21 May 2018
18. Walker-Harding LR, Christie D, Joffe A, Lau JS, Neinstein L. Young Adult Health and Well-Being: A Position Statement of the Society for Adolescent Health and Medicine. J Adolesc Health. 2017;60(6):758–9. https://doi.org/10.1016/j.jadohealth.2017.03.021. Accessed 21 May 2018.
19. Public Health England. Improving young people's health and wellbeing: a framework for public health. 2015. http://www.youngpeopleshealth.org.uk/wp-content/uploads/2015/07/PHE-Improving-young-peoples-health-and-wellbeing.pdf. Accessed 21 May 2018.
20. Colver AF, Merrick H, Deverill M, Le Couteur A, Parr J, Pearce MS, et al. Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. BMC Public Health. 2013;13(1):675.
21. Merrick H, McConachie H, Le Couteur A, Mann K, Parr JR, Pearce MS, et al. Characteristics of young people with long term conditions close to transfer to adult health services. BMC Health Serv Res. 2015;15(1):435.
22. Kmietowicz Z. Five minutes with … Allan Colver. BMJ. 2017;359:j4903.
23. Anderson BJ, Wolf FM, Burkhart MT, Cornell RG, Bacon GE. Effects of peer-group intervention on metabolic control of adolescents with IDDM: randomized outpatient study. Diabetes Care. 1989;12(3):179–83.
24. Grey M, Boland EA, Davidson M, Li J, Tamborlane WV. Coping skills training for youth with diabetes mellitus has long-lasting effects on metabolic control and quality of life. J Pediatr. 2000;137(1):107–13.
25. Grey M, Davidson M, Boland EA, Tamborlane WV. Clinical and psychosocial factors associated with achievement of treatment goals in adolescents with diabetes mellitus. J Adolesc Health. 2001;28(5):377–85.
26. Østbye T, Yarnall KS, Krause KM, Pollak KI, Gradison M, Michener JL. Is there time for management of patients with chronic diseases in primary care? Ann Fam Med. 2005;3(3):209–14.
27. Urdan T, Pajares F, editors. Self-efficacy beliefs of adolescents. Greenwich: IAP; 2005.
28. Dovey-Pearce G, Doherty Y, May C. The influence of diabetes upon adolescent and young adult development: a qualitative study. Br J Health Psychol. 2007;12(1):75–91.
29. Hagell A. Promoting young people's health literacy and understanding their help-seeking behaviour. Association for Young People's Health; 2015. http://www.youngpeopleshealth.org.uk/wp-content/uploads/2015/07/628_Health-literacy-EE-format-Updated-by-AH-march.pdf. Accessed 21 May 2018.
30. Shaw KL, Southwood TR, McDonagh JE. Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a postal survey. Rheumatology. 2003;43(2):211–9.

31. Telfair J, Myers J, Drezner S. Transfer as a component of the transition of adolescents with sickle cell disease to adult care: adolescent, adult, and parent perspectives. J Adolesc Health. 1994;15(7):558–65.
32. Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. J Adolesc Health. 2003;32(3):225–33.
33. Beresford B, Stuttard L. Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions. Clin Med. 2014;14(4):404–8.
34. White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. Lancet Child Adolesc Health. 2017;1(4):274–83.
35. Zhang LF, Ho JS, Kennedy SE. A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. BMC Pediatr. 2014;14(1):4.
36. Gorter JW, Stewart D, Cohen E, Hlyva O, Morrison A, Galuppi B, et al. Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: a mixed-methods longitudinal prospective cohort study. BMJ Open. 2015;5(5):e007553.
37. Northumbria Healthcare. Transition. 2017. https://research.ncl.ac.uk/transition/. Accessed 21 May 2018.
38. Department of Health. Self-review tool for quality criteria for young people friendly health services. 2011. https://www.gov.uk/government/publications/self-review-tool-for-quality-criteria-for-young-people-friendly-health-services. Accessed 21 May 2018.
39. Wilkes MS, Anderson M. Topics in review: a primary care approach to adolescent health care. West J Med. 2000;172(3):177–82.
40. Tomescu O, Ginsburg KR. Interviewing the adolescent: strategies that promote communication and foster resilience. In: Emans SJ, Laufer MR, editors. Emans, Laufer, Goldstein's pediatric and adolescent gynecology. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins; 2012. p. 21–8.
41. Ginsburg KR. The SSHADESS screen: a strength-based psychosocial assessment. In: Ginsburg KR, Kinsman SB, editors. Reaching teens strength-based communication strategies to build resilience and support healthy adolescent development. American Academy of Pediatrics; 2014. p. 139–64.
42. EuTeach. European training in effective adolescent care and health. http://www.unil.ch/euteach. Accessed 21 May 2018.
43. McDonagh JE. Growing up ready for emerging adulthood. Department of Health. 2006. http://webarchive.nationalarchives.gov.uk/20130124073547/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4137428.pdf. Accessed 21 May 2018.
44. Sawyer SM, Tully MAM, Colin AA. Reproductive and sexual health in males with cystic fibrosis: a case for health professional education and training. J Adolesc Health. 2001;28(1):36–40.
45. British Paediatric Association. Report of the working party on the needs and care of adolescents. 1985.
46. Court SDM. Fit for the future: report of the Committee on Child Health Services. London: HMSO; 1976.
47. House of Commons Select Committee on Health. Fifth report: hospital services for children and young people. London: HMSO; 1997.
48. Platt H. The welfare of children in hospital. BMJ. 1959;1(5115):166–9.
49. Keane M, Viner RM. Youth matters: evidence-based best practice for the care of young people in hospital. London: Caring for Children in the Health Services; 1998.
50. Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Siu SC, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. Pediatrics. 2004;113(3):e197–205.

51. Care Quality Commission. From the pond into the sea: children's transition to adult health services. 2014. https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf. Accessed 21 May 2018.
52. Anderson BJ, Wolpert HA. A developmental perspective on the challenges of diabetes education and care during the young adult period. Patient Educ Couns. 2004;53(3):347–52.
53. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. J Adolesc Health. 2003;33(4):309–11.
54. Watson R, Parr JR, Joyce C, May C, Le Couteur AS. Models of transitional care for young people with complex health needs: a scoping review. Child Care Health Dev. 2011;37(6):780–91.

10

Quality and Safety in Transitional Urologic Care

Jessica H. Hannick and Martin A. Koyle

Introduction: Managing Complex Patients Well

In 2002, the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians—American Society of Internal Medicine (ACP-ASIM) published a consensus statement in the United States defining the need for transitional care for pediatric patients with special health care needs. They acknowledged that this process should be fluid and ever-changing depending on the individual's unique needs and evolving maturity level. Most importantly, they outlined that "the goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination" [1]. This statement was mirrored by the *Healthy People 2010* goal that all young people with special health care needs would receive the services needed to make necessary transitions to all aspects of adult life, including health care, work, and independent living [2]. Based on 2005–2006 data from the National Survey of Children with Special Health Care Needs, only 13.8% of children with special health care needs aged 12–17 years received their care in family-centered, comprehensive, and coordinated systems, a goal which *Healthy People 2020* strives to increase to 15.1%, still a far cry from ideal [3, 4].

J. H. Hannick
Division of Pediatric Urology, McMaster University Children's Hospital,
Hamilton, ON, Canada
e-mail: hannickj@mcmaster.ca

M. A. Koyle (✉)
Division of Pediatric Urology, The Hospital for Sick Children, Toronto, ON, Canada
e-mail: martin.koyle@sickkids.ca

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_10

How Are We Doing in General?

Recent data estimates that among US youth population aged 12–18 years, the special health care subset comprises 4.5 million or 18.4% of their age group. Unfortunately, of those youth, only about 40% met the national transition outcome based on the 2009–2010 National Survey of Children with Special Health Care Needs [5]. The survey also found that those youth whose activities are significantly affected by their condition have a higher likelihood of not meeting their transition outcome (OR: 1.90, 95% CI: 1.59–2.26) and a higher likelihood of not being usually or always encouraged to take greater responsibility for care. Additional subgroups lagging in successful transition were males, blacks and Hispanics, patients from low-income backgrounds, patients with mental, behavioral or developmental conditions, patients who did not live in a medical home, and patients lacking insurance coverage. The study also revealed that many parents did not see the need for beginning transition preparations until their child was a long way into adolescence, this probably hinders successful transition.

Acknowledging these gaps in care, the AAP published their report entitled "Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home" [6]. The report incorporates expert and consensus opinion to educate and train health care teams on how to develop, support, and sustain an effective transitional care plan. They advocate that transition from child- to adult-centric care should optimally occur between the ages of 18 and 21, depending on the individual patient and institutional guidelines. Their transition process begins at 12 years of age and focuses on four specific necessary components to effective transition: (1) discussing the medical home transition policy, (2) initiating a transition plan, (3) reviewing/updating the transition plan, and (4) implementing an adult care model. The report provides a timeline as well as an algorithm for managing as well as implementing the transition process to be used by the health care practitioner, while also informing and setting expectations for patients and their families.

How Are We Doing in Urology?

Urology patients with special long-term care needs may struggle throughout the spectrum of transition. Many of the time these patients have very intimate or private and less visually apparent chronic medical concerns such as bladder exstrophy, prune belly syndrome, and disorders of sexual development. There are also those patients with spina bifida or intestinal reservoirs, who may have ambulatory limitations and/or require medical supplies for continent or incontinent urinary and/or bowel management. Many of these patients will be nearly to completely independent with their care by the time they reach adulthood. Despite this, the new environment of an adult hospital, the challenges of acquiring medical supplies, and the confusion of navigating the health insurance maze require education and assistance, which the transition process should provide. The previously foreshortened lifespan of many of these patients also poses its own challenge, as few adult urologists are equipped and comfortable managing these patients as they transition from childhood. Medical records including prior operative reports for these patients can be challenging to access, and patients may be unfamiliar with the specifics of their operations. In addition to inconsistent medical histories and lack of comfort with these patients, adult urologists are often ill-compensated for the lengthy clinic visits this patient population often requires, posing a challenge for patients to find a 'willing' adult urologist and establish a lasting rapport.

Reacting to the lack of introspection and research on the transitional process for children with congenital genitourinary conditions, the National Institute of Diabetes and Digestive and Kidney Disease sponsored a workshop to assess the current models being employed and the need for research on these models within urologic transitional care [7]. As a framework for quality improvement of transitional urologic care, they identified six areas of opportunity for improvement, as published by GotTransition.org (Table 10.1): (1) create a transition policy, (2) track and monitor the progress of transition, (3) assess readiness for transition, (4) plan for transition to adult care, (5) transfer to adult care, and finally (6) integrate into adult care [8]. The workshop convened experts from all fields interacting with patients with congenital genitourinary conditions, as well as the patients themselves, and asked the attendees to identify areas where they had seen barriers to care. Again, limited access due to health insurance coverage and healthcare financing was seen as an impediment to care. Physical access, either due to remote locations or limited mobility status, was also seen as a concern in some practice environments. Despite the recommendations from the AAP and Got Transition, only 68% of patients were found to have a written transition policy, with only half of those regularly assessing and modifying those processes [7]. In addition to the aforementioned barriers, the workshop identified psycho-emotional barriers, such as resistance on the patient or provider's part to relinquish the relationship, and educational or training barriers, such as limited expertise amongst adult care practitioners. Furthermore, as the World Health Organization's International Classification of Functioning, Disability and Health model, the Healthy People 2020 initiative, and Woodhouse acknowledge, high-quality care does not stop at healthcare, but rather should also extend to the activities, social participation, and environmental factors that need to be addressed to aid an individual's transition into a fully functional adult in society [4, 9, 10].

Ideas for Improvement

When striving for improvement, change agents must conceptualize an ideal state to work towards. In their consensus statement on Healthcare Transitions, the AAP, AAFP, and ACP-ASIM identified six critical steps essential to a successful transition:

Table 10.1 Six core elements of Health Care Transition 2.0

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Transition. [a]Sample clinical tools and measurement resources are available for quality improvement purposes at www.GotTransition.org

Transitioning youth to adult health-care providers (pediatric, family medicine, and med-peds providers)	Transitioning to an adult approach to health care without changing providers (family medicine and med-peds providers)	Integrating young adults into adult health care (internal medicine, family medicine, and med-peds providers)
1. Transition policy • Develop a transition policy/statement with input from youth and families that describes the practice's approach to transition, including privacy and consent information • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements*, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences • Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care	**1. Transition policy** • Develop a transition policy/statement with input from youth/young adults and families that describes the practice's approach to transitioning to an adult approach to care at 18, including privacy and consent information • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements,* and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences • Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care	**1. Young adult transition and care policy** • Develop a transition policy/statement with input from young adults that describes the practice's approach to accepting and partnering with new young adults, including privacy and consent information • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements* and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences • Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care

2. Transition tracking and monitoring • Establish criteria and process for identifying transitioning youth and enter their data into a registry • Utilize individual flow sheet or registry to track youth's transition progress with the *Six Core Elements* • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible	**2. Transition tracking and monitoring** • Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry • Utilize individual flow sheet or registry to track youth/young adults' transition progress with the *Six Core Elements* • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible	**2. Young adult tracking and monitoring** • Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry • Utilize individual flow sheet or registry to track young adults' completion of the *Six Core Elements* • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible
3. Transition readiness • Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care • Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care	**3. Transition readiness** • Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care • Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care	**3. Transition readiness/orientation to adult practice** • Identify and list adult providers within your practice interested in caring for young adults • Establish a process to welcome and orient new young adults into practice, including a description of available services • Provide youth-friendly online or written information about the practice and offer a "get-acquainted" appointment, if feasible

(continued)

Table 10.1 (continued)

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Transition. [a]Sample clinical tools and measurement resources are available for quality improvement purposes at www.GotTransition.org

Transitioning youth to adult health-care providers (pediatric, family medicine, and med-peds providers)	Transitioning to an adult approach to health care without changing providers (family medicine and med-peds providers)	Integrating young adults into adult health care (internal medicine, family medicine, and med-peds providers)
4. Transition planning • Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents • Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information • Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources • Plan with youth/parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each • Obtain consent from youth/guardian for release of medical information • Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care • Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports	**4. Transitionplanning/integration into adult approach to care** • Develop and regularly update a plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents • Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information • Determine of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources • Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult specialty care • Obtain consent from youth/guardian for release of medical information • Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports	**4. Transition planning/integration into adult practice** • Communicate with young adult's pediatric provider(s) and arrange for consultation assistance, if needed • Prior to first visit, ensure receipt of transfer package (final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records) • Make pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences • Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports

5. Transfer of care • Confirm date of first adult provider appointment • Transfer young adult when his/her condition is stable • Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records • Prepare letter with transfer package, send to adult practice, and confirm adult practice's receipt of transfer package • Confirm with adult provider the pediatric provider's responsibility for care until young adult is seen in adult setting	**5. Transfer to adult approach to care** • Address any concerns that young adult has about transferring to adult approach to care. Clarify adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs • Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss needed self-care skills • Review young adult's health priorities as part of ongoing plan of care • Continue to update and share portable medical summary and emergency care plan	**5. Transfer of care/initial visit** • Prepare for initial visit by reviewing transfer package with appropriate team members • Address any concerns that young adult has about transferring to adult approach to care. Clarify approach to adult care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs • Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss the young adult's needs and goals in self-care • Review young adult's health priorities as part of their plan of care • Update and share portable medical summary and emergency care plan

(continued)

Table 10.1 (continued)

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Transition. [a]Sample clinical tools and measurement resources are available for quality improvement purposes at www.GotTransition.org

Transitioning youth to adult health-care providers (pediatric, family medicine, and med-peds providers)	Transitioning to an adult approach to health care without changing providers (family medicine and med-peds providers)	Integrating young adults into adult health care (internal medicine, family medicine, and med-peds providers)
6. Transfer completion • Contact young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process • Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed • Build ongoing and collaborative partnerships with adult primary and specialty care providers	**6. Transfer completion/ongoing care** • Assist young adult to connect with adult specialists and other support services, as needed • Continue with ongoing care management tailored to each young adult • Elicit feedback from young adult to assess experience with adult health care • Build ongoing and collaborative partnerships with specialty care providers	**6. Transfer completion/ongoing care** • Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed • Assist young adult to connect with adult specialists and other support services, as needed • Continue with ongoing care management tailored to each young adult • Elicit feedback from young adult to assess experience with adult health care • Build ongoing and collaborative partnerships with pediatric primary and specialty care providers

Used with permission from © Got Transition™/Center for Health Care Transition Improvement, 01/2014. Got Transition™ is a program of The National Alliance to Advance Adolescent Health supported by U39MC25729 HRSA/MCHB. www.GotTransition.org

[a] American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011;128:182

1. identification of a healthcare professional responsible for the continuous transitional process,
2. developmentally appropriate healthcare transitional services,
3. an accessible, portable, and up-to-date healthcare summary,
4. a comprehensive, written transitional care plan collaboratively developed and updated by the youth and their caregivers, including required services and financing,
5. equitable guideline-based primary and preventative care, and
6. affordable, continuous health insurance coverage throughout the transition process and beyond [1].

The timing of when transition should be initiated is unclear. Though the consensus statement proposes the age of 14, individuals may have varying levels of maturity and cognitive development, thus criteria have been developed to attempt to assess when this process may begin. The refined "Am I ON TRAC for Adult Care questionnaire" assesses readiness of adolescents with special healthcare needs for transition from pediatric to adult health care [11]. Am I ON TRAC can be used at initiation of transition, as well as, during the transition to evaluate appropriateness to progress further along the transitional journey and to both predict and determine successful transition.

From a broader health-care transitions scope, Vaks and colleagues healthcare delivery innovation lab sought to answer the problem of delivering more affordable and effective transitional care [12]. Combining an extensive literature review with observations and interviews of successful transition programs, the group developed an evidence-based prototype of an ideal transitional care model which was then iteratively reviewed by researchers, clinicians, and adolescent patients. Three main pillars of coordinated care were identified as:

1. Building and Supporting Transition-Specific Self-Management Skills,
2. Engaging the receiving team, and
3. Guiding patients and families through the transition.

The team then provided solutions, such as the use of coaching, web-based therapy and telemedicine, along with a pre- and post-transfer checklist (Tables 10.2 and 10.3). Additional research is needed to validate this concept in larger populations, as it lacks elements such as addressing insurance coverage, however, it does provide a thorough model with which to begin to manage the youth to adult transition.

Prior et al. propose using the "Triple Aim" framework for evaluating transitional care models to determine their efficacy [13]. As this realm of healthcare is relatively new and ripe for innovation and reform, using the "Triple Aim" model offers a unique opportunity to both optimize and examine patient outcomes in regard to population health, patient experience, and cost. Prior's work illustrates, however, that many existing interventions and evaluative instruments neglect to address all three of the "Triple Aim" healthcare domains. The need to prioritize patient experience and population health is mirrored in a consensus statement on what constitutes

Table 10.2 High value care during transition from pediatric to adult healthcare systems

	Challenges	Solution	Predicted impact[a]
Building and supporting self-management	Tumultuous developmental period → decreased treatment adherence	Coaching for self-management	↑ Treatment adherence ↑ Self-efficacy for disease management ↑ Health status ↓ Hospitalizations ↓ED use ↓ Health expenditures
	Parents and young adults are unclear who is “in charge” of self-management		
	Parents may have difficulty stepping back from manager role when appropriate		
	Depression and anxiety are common, undertreated, and associated with decreased treatment adherence	Web-based cognitive behavioral therapy	↓ Anxiety and depression ↓ Health expenditures[b]
Engaging the receiving team	Care team composition and roles differ between pediatrics and adult medicine	Mobilize the receiving team	↑ Patient quality of life ↑ Patient and family experience ↓ Health expenditures
	Appropriate adult providers can be challenging to locate		
	Typical primary care appointment timeslots inadequate for complex patients		
	Adult specialists may lack expertise in childhood conditions	Telemedicine specialty support for adult PCPs	↑ Provider experience
	Pediatric providers are often anxious about sending patients to adult healthcare		
Guiding patients and families through the transition	Transition coincides with age-related service changes (e.g., insurance, PT, OT, durable medical equipment)	Patient guidance using a transition team and checklist	↓ Hospitalizations ↓ Health expenditures ↑ Patient satisfaction ↑ Patient quality of life ↑ Clinical decision-making ↑ Provider experience
	No point-of-contact for health-related crises		
	Important details of care are overlooked		
	New providers do not receive relevant patient history		

[a] Where available, research relevant to adolescents and/or young adults with chronic illness is cited. Where unavailable, literature from other populations is cited

[b] Meta-analysis for in-person CBT

Table 10.3 Pre- and post-transfer checklists

Pre-Transfer checklist
• The young adult and family are aware of the upcoming need to transition to adult-oriented care
• The young adult and family have agreed on their respective roles in the patient's care going forward
• Potential insurance changes and their implications have been discussed
• The young adult and/or family has appropriate self-management capability including:
– Activation and confidence for disease management
– Knowledge: e.g., understanding of diagnosis, medications, treatment plan, understanding of what symptoms to watch out for and who to call if they arise, understanding of the impact of high-risk behaviors on their health in the context of their chronic illness
– Skills: Able to make appointments, fill prescriptions, communicate with the healthcare team, etc.
• Comorbid anxiety and depression are not present or, if present, the young adult is stable and receiving appropriate treatment
• The young adult has a concise and up-to-date complete medical summary including an active problem list, technology settings, medications, and plans for next steps of care
• Goals of care have been reviewed
• Pertinent legal issues have been addressed (e.g., guardianship, authorization for parents/others to have access to medical information, durable power of attorney)
• Other needs/services have been addressed (e.g., for help with ADLs, Durable Medical Equipment needs, education/vocational needs, housing, etc.)
• A plan is in place for obtaining adult-oriented primary care including:
– If transfer to a new provider is needed:
An initial appointment has been scheduled
Information has been provided to the new provider
A warm handoff has been done if indicated
Or
– The young adult will be continuing with his/her current primary care provider who is able to provide ongoing age-appropriate care
• A plan is in place for obtaining adult-oriented specialty care including:
– If transfer to a new provider is needed:
An initial appointment has been scheduled
Information has been provided to the new provider
A warm handoff has been done if indicated
Or
– The young adult will be continuing with his/her current specialty care provider who is able to provide ongoing age-appropriate care
• The young adult is medically stable
• The young adult is stable from a psychosocial standpoint
• **All of the young adult and family's questions and concerns have been addressed**
Post-transfer checklist
• The young adult is receiving developmentally appropriate, high quality care from an adult-oriented provider per guidelines for his/her condition
• The young adult/family is satisfied with their care post-transfer
• Updates on the young adult's status have been conveyed back to the pediatric team

successful health care transition [14]. Using a 3-stage modified Delphi process, an international and interdisciplinary group of patients, parents, caregivers, clinicians, and researchers honed down a list of health transition outcomes to 10 items.

Topping the list were:

1. achieving optimal quality of life,
2. self-managing own condition, and
3. adherence to medications and/or other treatment.

Numerous institutions have built their own generalized transition programs with varying degrees of success. Gorter et al. developed the Youth KIT, an organizational tool using goal setting activities, and an online transition mentor [15]. The KIT: Keeping it Together for Youth tool aimed to promote organization, goal setting, and self-management in various life domains the authors targeted as key for successful transition. "TRACE" served the role of online transition mentor led by an occupational therapist with expertise in transition who was available four nights a week through a secure, online platform to discuss transition-related issues with youth and young adults introduced to the site. Interestingly, utility of the interventions was perceived to be greatest pretransfer, but rather ended up being highest post-transfer, likely concurrent with the realization of the differences between child- and adult-based healthcare services. Though users reported modest usefulness of the interventions, they acknowledged that the interventions were most helpful for goal setting. Nagra et al. developed a similar model in the context of a large National Health Service (NHS) teaching hospital [16]. As a generic program for youth with chronic health problems, "Ready Steady Go" is targeted at those patients age 11 and older to become empowered and take control of their lives through learning the necessary skills and knowledge to manage their own health conditions across the pediatric and adult spectrum. The process is comprised of sequential questionnaires (http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Hello-to-adult-services.aspx) to be completed progressively and independently by the pediatric patient, and can be modified as needed to include the assistance of a caregiver in patients with developmental disabilities [17]. This model purports to have been widely adopted across the UK where it is now established as an element of routine transition care.

Current urology transition care models in existence have taken on many forms. Earlier models have had pediatric urologists working with patients till the age of 18, or institutionally decreed adulthood, at which point the patient is then referred to and begins working with an adult urologist. Other institutions incorporate an adult urologist with the pediatric urologist into the care process in early adolescence, bridging the transition towards adulthood [18]. Woodhouse has named this new sector of care "adolescent urology," whereby adult specialists "work with pediatricians to create a transition process that enables children to move seamlessly from pediatric care to an adult environment in which patients remain under the same adult specialists" [10]. A similar concept can be seen in transitional urology clinics, where care extends beyond the traditional cutoff for adulthood, and either pediatric urologists with an interest in “congenitalism” or adult specialists well versed in the adult manifestations of pediatric urologic diseases will provide continuity of care into adulthood [19].

Limited research has been published to date examining which of these models works best, or if any of them work at all. The Royal Hospital for Sick Children in the United Kingdom established a hybrid transitional urology clinic called the Adolescent Transition Urology Clinic (ATUC) in 2009, incorporating both a pediatric and adult urologist, as well as a urology nurse, and if necessary a gynecologist [20]. Patients screened as requiring long-term urologic care were offered a 30-min appointment at the ATUC as they approached the age of 16. From October 2009 to March 2014, the group was able to conduct 9 ATUC clinics. To assess how the new clinic was functioning and whether improvements were needed, once the patients had transitioned to adult care, they were contacted and invited to complete two online transition satisfaction questionnaires. Of the 30 patients attending the clinic, 26 patients (87%) had transitioned at the time of the survey. 21 patients were able to be contacted to answer the study, of which 19 fully completed the survey (90% response rate). 47% of the patients who responded to the survey felt that 18 years old was the most appropriate age for transition. 74% felt that written information would have been useful to improve their satisfaction of and aid the process of transition. This study was only able to address the immediate response to transition, not the long-term success, and was limited by a small sample size.

Grimsby et al. sought to evaluate the barriers to retention in their transitional urology clinic [21]. Their clinic consisted of young adults (18–26 years old) with neurogenic bladders. Rates of referral to the clinic, successful enrollment in the clinic, and return to the clinic were monitored, along with reasons for missed appointments. At the time of their first visit, patients were asked to complete the Transition Readiness Assessment Questionnaire (TRAQ) as a gauge of readiness for transition to independent self-care. The mean age for TRAQ completion, and thus first visit to clinic, was 19.5 years old. Those patients with missed appointments most commonly cited lack of health insurance coverage (47%) as their barrier to care. Most patients responded that they were “learning to do this,” in reference to taking medications, using medical supplies, speaking with their healthcare providers, and helping with household duties. Alternatively, most patients said, “I do not know how, but I want to learn” in reference to insurance coverage, financial help, and use of community services, again echoing the need for improved resource access education to transitioning patients.

With the longest follow-up to date, Szymanski et al. retrospectively reviewed their patients who transitioned from their spina bifida clinic from 2006 to 2012 [22]. Patients were offered follow-up either in a transitional urology clinic, pediatric urology clinic, or adult urology clinic. Patients were advised to follow-up within 1 year after transition and were considered to have transitioned if they followed up within 2 years. Only 40.3% of patients successfully transitioned. Patients who had not had urologic follow-up were more likely to visit the emergency room for care. Those patients who had successfully transitioned tended towards having more frequent visits for health issues prior to transition. This study echoes the mediocre transition rates seen in larger special health care needs youth populations, reinforcing how further work needs to be done to identify and remove barriers to successful transition.

Seeking to unify spina bifida transitional care province-wide, Koyle et al. proposed a cost-effective model for integrated and comprehensive care of adolescent and young adults with spina bifida in Ontario [23]. Through the establishment of a Spina Bifida Treatment Network (SBTN), patients will have comprehensive, fluid access to pediatric and adult medical care, along with psychosocial and self-management support, community resources, and health information. The model hinges largely on a well-integrated, standardized electronic medical record system through which patients have a living document that is updated and modified as the individual's care evolves. In this model, the adult nurse practitioner (NP) specializing in the care of SB patients is the central care coordinator. The NP is linked institutionally with each transitioning SB patient as a care mediator to assess readiness for beginning the transition process, to coordinate annual care reviews, and to ensure the patient is referred to and established with their nearest SBTN adult urologist. Key to the success of the intervention is identification and engagement of interested pediatric and adult specialist providers with concurrent healthcare reform to align financial compensation with these collaborative relationships.

Opportunities for Collaboration

Optimal care for the child with chronic, complex urologic conditions requires the coordination of primary care and multidisciplinary input (Table 10.4) [10, 24, 25]. Clinician's goals center around preservation of function, management and treatment of infectious and neurocognitive complications, lifelong follow-up with potential need for surgical intervention and revision, transition from dependent to independent self-care, and management of adult sexual and reproductive functions [7]. Acknowledging the need for clinicians to longitudinally collaborate in the care of these patients, Koyle's model of the SBTN calls upon clinician specialists to build a network of care. His model places the NP at the center of the network, surrounded by adult urologists and primary care providers, as well as counselling services and peer-support through the Spina Bifida and Hydrocephalus Association of Ontario, aimed at providing strategies for self-management support and wellness management [23].

Alternatively, many institutions have approached the multidisciplinary needs of these complex patient populations through the development of multidisciplinary clinics. Often pediatric multidisciplinary clinics exist for conditions such as spina bifida, nephrolithiasis, disorders of sexual development, however an adult correlate does not. Institutions with adult mimics of the pediatric multidisciplinary clinic have had success, with urologic issues occurring in 88.5% of patients at some point in their follow-up, of which 81% required intervention [26, 27].

Table 10.4 Associated specialists required for support in an adolescent clinic by urologic diagnosis

Condition	Specialists required
Renal anomalies	Nephrologist Physician in hypertension Transplant team
Spina bifida	Nephrologist Orthopedist Neurologist Neurosurgeon Podiatrist Gynecologist/obstetrician Geneticist Plastic surgeon
Intestinal reservoirs	Gynecologist/obstetrician Biochemist Stone surgeon Stoma therapist
Exstrophy	Gynecologist/obstetrician Orthopedist Psychologist Oncologist
Posterior urethral valves	Nephrologist Andrologist
Disorders of sex development	Endocrinologist Biochemist Gynecologist Geneticist Sex therapist Plastic surgeon Fertility specialist
Prune belly syndrome	Nephrologist

This list is not exclusive. There is a universal need for specialist radiologists and nuclear medicine specialists. Psychologists are often required for any of these diagnoses

Addressing the Transition Process in the Context of Quality Improvement

As earlier alluded to, strong emphasis has been placed on approaching healthcare improvement from the perspective of the Triple Aim. First introduced by Berwick, Nolan, and Whittington in 2008, the “Triple Aim” seeks to broadly enhance health care by improving the individual experience of care, improving the health of populations, and reducing per capita costs of care for populations [28]. As Berwick et al. discuss, these three aims must not be addressed in exclusivity, but rather to successfully yield an improved system, they must be tackled together. This is of course challenging, as the individual patient and/or health care provider’s interests may seem distinct from the interests of the broader population, and vice versa. Additionally, improving the health of one individual or population may drive up costs, thus hindering the success of achieving reduced per capita costs. To successfully tackle these interrelationships, Berwick et al. suggest employing the following constraints to any quality improvement project: "1) recognition of a population as the unit of concern, 2) externally supplied policy constraints (such as a total budget limit or the requirement that all subgroups be treated equitably), and 3) existence of an 'integrator' able to focus and coordinate services to help the population on all three dimensions at once." The population of interest in this context is the group of patients for which the quality improvement project seeks to improve transitional care. Policy constraints are the financial and cultural and political contextual factors within the institution or region seeking improvement. The role of "integrator" is probably one of the most fundamentally important, yet challenging elements essential to the success of a QI initiative. Whether that role is embodied by an executive board member with strong leadership skills, a motivated physician group, or multidisciplinary clinic, the integrator must seek to accomplish and unite all facets of the triple aim through continuous patient and population communication, education, transparency, and shared decision making.

Fundamental to successful shared decision making is patient involvement. Though increasing emphasis has been placed on the importance of seeking out patient advice and input on improvement processes through focus groups and surveys, more worthwhile patient engagement in improvement efforts can yield greater success. Though patient-centered care was first referenced in the 1950s, it was not until the Institute of Medicine's 2001 report, *Crossing the Quality Chasm: A new Health System for the 21st Century*, that patient centeredness and patient experience were widely acknowledged as being fundamental aims critical to any improvement project [29]. Definitions of "patient centered care" are quite diverse, but most share the common goal of actively involving patients, healthcare workers, and the public in making individual and system-wide decisions that strengthen and improve the health care environment [30, 31]. Resistance to increasing patient involvement has been met, with practitioners citing increased workloads, decreased efficiency, and increased costs, though contradictory evidence has reported improved health outcomes, improved patient safety and quality, and decreased health care costs [32–37].

To optimize the benefits of patient centered care, patients must become involved on more than a "token" basis, such as a focus group, patient forum, or feedback survey. Patients have the benefit of lived experience, information which is precious and essential to the successful re-design of a care process and can result in a better care experience for a peer user. In their review on experience-based design (EBD), Bate and Robert frame the ideal state for the future of patient-centered improvement processes [38]. Just as an improvement team pulls from essential stakeholders at the origin of a project, EBD must also draw together relevant professionals and health care users to work together and co-design throughout the evolution of the change process. Patient and heath care user experiences bring the richness of not only the objective health care process journey, but also the subjective, sensory experience. They can communicate with professionals about the subjective interrelationships they experience as end-users, as well the usability, safety, and functionality.

Acknowledging the importance of patient and family experience, the Institute for Healthcare Improvement (IHI) developed a framework for achieving exceptional patient- and family-centered experiences for patients and families [30]. Though their model focuses on the inpatient experience, similar methodology can be applied to the outpatient ambulatory environment. Using a driver diagram to organize their model, the primary aim of their model is to yield "an exceptional patient and family experience." The primary drivers they identify to yield this outcome include:

1. leadership focused on patient and family centric care,
2. hearts and minds unified in a culture committed to patient-centered care,
3. respectful partnership,
4. reliable, quality care every hour of every day, and
5. evidence-based care.

Further developing the model, secondary drivers are then identified, yielding specific interventions and goals that contribute to establishing and supporting the success of the primary drivers. For example, in regard to the primary driver "reliable care," fundamental secondary drivers include a "physical environment [that] supports care and healing, patients are able to access care without long and unreasonable waits and delays, and patients say 'staff were available to give the care I needed.'"

To demonstrate progress towards the project's ultimate aim, "an exceptional patient and family experience," measures are then developed to track and evaluate each of the various secondary drivers. This data tracking culminates over time to paint a picture of a trend towards success or the need for additional improvement. As Steifel and Nolan outline in their guide to measuring the triple aim, high and lower level outcome measures as well as process measures associated with the various proposed interventions should be clearly delineated and tracked with data accordingly [39]. Specific to the aim of patient care experience, they recommend using the Institute of Medicine's six aims for improvement—safe, effective, timely, patient-centered, equitable, efficient—as a guideline for measuring successful delivery of care. In the United States, several data sources exist to evaluate the patient care experience. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys provide granular data on several levels and aspects of the patient care experience, such as communication with nurses and doctors, understanding of patient care plans, and overall ratings of hospitals, and is available for both adults and children in various forms [40]. Alternatively, The Joint Commission (TJC) can provide measures relative to effectiveness of care. Each institution should evaluate and tailor its available resources for tracking and measuring care data to meet its project's needs.

Ultimately, in those institutions where a quality improvement initiative is deemed a success, there may be a drive to spread the intervention to other departments, clinics, or even to other institutions. Before embarking on a diffusion journey, a project should be reviewed for internal sustainability and long-term success. Where possible, simplification and modification are recommended to optimize internal strength, durability, generalizability, and potential viability outside of the originating institution [41].

Improvers wishing to spread must also keep in mind that just because an intervention is successful in one environment, does not mean the same will be the case elsewhere. Just as diagnostics were performed to understand the root causes and drivers in the initial institution, the same must be conducted at all potential spread sites to understand suitability for the project's uptake, and the potential need for project modifications. The new environment(s) must also be assessed for receptiveness to quality improvement and for strength and supportiveness of leadership, as the success or failure of an intervention lies in the surrounding culture and support for change [41–44].

Conclusion

Transitional care represents a relatively novel opportunity for growth and innovation within urology. The general pediatric community already has several well-established guidelines and initiatives to structure transition programs, however, no clear consensus yet exists within pediatric urology. This lack of consensus likely reflects the complexity and uniqueness of each institution's provider and care resources along with the variability of patient care protocols. As the need for transitional programs for pediatric urologic patients is undeniable, moving forward institutions must work to establish and iteratively improve their transitional processes. Using quality improvement methodology and patient experience co-design, institutions may yield personalized programs that achieve all three tenants of the Triple Aim. They must also continuously analyze and refine their programs to ensure that the desired outcomes continue to be attained. As these programs evolve, collaboration and education amongst the urologic community will ideally generate ideas that can be spread and sustained broadly to create an optimal experience for our transitioning pediatric urology patients.

References

1. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics. 2002;110(6):1304–6.
2. Centers for Disease Control and Prevention; National Institute on Disability and Rehabilitation Research; US Department of Education. Disability and secondary conditions. Healthy People 2010. Washington, DC. 2000. https://www.cdc.gov/nchs/healthy_people/hp2010.htm. Accessed 5 Aug 2018.
3. Prevention D of H and HSC for DC and 2005-2006 National Survey of Children with Special Health Care Needs. 2007. https://www.cdc.gov/nchs/slaits/cshcn.htm. Accessed 5 Aug 2018.
4. No Title. Healthy People 2020. Washington, DC. 2014. https://www.healthypeople.gov/node/4887/data_details. Accessed 5 Aug 2018.
5. McManus MA, Pollack LR, Cooley WC, McAllister JW, Lotstein D, Strickland B, et al. Current status of transition preparation among youth with special needs in the United States. Pediatrics. 2013;131(6):1090–7.

6. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011;128(1):182–200.
7. Hsieh MH, Wood HM, Dicianno BE, Dosa NP, Gomez-Lobo V, Mattoo TK, et al. Research needs for effective transition in lifelong care of congenital genitourinary conditions: a workshop sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases. Urology. 2017;103:261–71.
8. Got Transition. Six Core Elements of Health Care Transition 2.0: Side-by-Side Version. 2014;1–2. https://www.gottransition.org/resourceGet.cfm?id=206. Accessed 5 Aug 2018.
9. World Health Organization. International classification of functioning, disability and health—children & youth version. Geneva: Switzerland; 2007.
10. Woodhouse C. Adolescent urology and transitional care. Eur Urol. 2015;68(5):745–6.
11. Moynihan M, Saewyc E, Whitehouse S, Paone M, Mcpherson G. Assessing readiness for transition from paediatric to adult health care: revision and psychometric evaluation of the Am I ON TRAC for Adult Care questionnaire. J Adv Nurs. 2015;71(6):1324–35.
12. Vaks Y, Bensen R, Steidtmann D, Wang TD, Platchek TS, Zulman DM, et al. Better health, less spending: redesigning the transition from pediatric to adult healthcare for youth with chronic illness. Healthc (Amst). 2016;4(1):57–68.
13. Prior M, McManus M, White P, Davidson L. Measuring the "Triple Aim" in transition care: a systematic review. Pediatrics. 2014;134(6):e1648–61.
14. Fair C, Cuttance J, Sharma N, Maslow G, Wiener L, Betz C, et al. International and interdisciplinary identification of health care transition outcomes. JAMA Pediatr. 2016;170(3):205–11.
15. Gorter JW, Stewart D, Cohen E, Hlyva O, Morrison A, Galuppi B, et al. Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: a mixed-methods longitudinal prospective cohort study. BMJ Open. 2015;5(5):e007553.
16. Nagra A, McGinnity PM, Davis N, Salmon AP. Implementing transition: ready steady go. Arch Dis Child Educ Pract Ed. 2015;100(6):313–20.
17. "Ready Steady Go" and "Hello to adult servies" developed by the Transition Steering Group led by Dr. Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation.
18. Tanaka ST, Kaufman MR, Brock JW. The aging pediatric urology patient: obstacles and opportunities in transition care. J Urol. 2012;187(4):1159–60.
19. Szymanski KM, Misseri R, Whittam B, Large T, Cain MP. Current opinions regarding care of the mature pediatric urology patient. J Pediatr Urol. 2015;11(5):251.e1–4.
20. Shalaby MS, Gibson A, Granitsiotis P, Conn G, Cascio S. Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. J Pediatr Urol. 2015;11(2):89.e1–5.
21. Grimsby GM, Burgess R, Culver S, Schlomer BJ, Jacobs MA. Barriers to transition in young adults with neurogenic bladder. J Pediatr Urol. 2016;12(4):258.e1–e.5.
22. Szymanski KM, Cain MP, Hardacker TJ, Misseri R. How successful is the transition to adult urology care in spina bifida? A single center 7-year experience. J Pediatr Urol. 2017;13(1):40.e1–6.
23. Koyle MA, Golda N, Hillis C, Oldershaw B, Demelo M, Uyeno J. A proposed solution to a urological tightrope walk: the challenge of transition of spina bifida patients from pediatric to adult care in Ontario. Can Urol Assoc J. 2016;10(9–10):E340–1.
24. Woodhouse CRJ, Neild GH, Yu RN, Bauer S. Adult care of children from pediatric urology. J Urol. 2012;187(4):1164–71.
25. Misseri R. Comparing transition of care from adolescence to adulthood for patients with congenital urological conditions in Canada and the U.S. Can Urol Assoc J. 2016;10(9/10):311–2.
26. Duplisea JJ, Romao RLP, MacLellan DL, Cox AR, Anderson PA. Urological follow-up in adult spina bifida patients: is there an ideal interval? Urology. 2016;97:269–72.
27. Anderson PAM. "If you build it…": Creating an adequate support system to transition the care of pediatric patients with spina bifida into adulthood. Can Urol Assoc J. 2016;10(9–10):313.

28. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. Health Aff. 2008;27(3):759–69.
29. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. 2001. http://nationalacademies.org/hmd/~/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf. Accessed 5 Aug 2018.
30. Balik B, Conway J, Zipperer L, Watson J. Achieving an exceptional patient and family experience of inpatient hospital care. IHI innovation series white paper. Cambridge, MA: Institute for Healthcare Improvement. 2011. http://www.ihi.org/resources/Pages/IHIWhitePapers/AchievingExceptionalPatientFamilyExperienceInpatientHospitalCareWhitePaper.aspx. Accessed 5 Aug 2018.
31. Carman K, Dardess P, Maurer MEA. Patient and family engagement. Canada Found Healthc Improv. 2013;2:223–31.
32. Epstein R, Street R. Patient-centered care for the 21st century: physicians' roles, health systems and patients' preferences. Philadelphia: American Board of Internal Medicine Foundation; 2008.
33. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. BMJ. 2007;335(7609):24–7.
34. Charmet P, Frampton S. Building the business case for patient-centered care. Healthc Financ Manage. 2008;62(3):80–5.
35. Keating NL, Green DC, Kao AC, Gazmararian JA, Wu VY, Cleary PD. How are patients' specific ambulatory care experiences related to trust, satisfaction, and considering changing physicians? J Gen Intern Med. 2002;17(1):29–39.
36. Haynes RB, Ackloo E, Sahota N, McDonald HP, Yao X. Interventions for enhancing medication adherence (Review). Cochrane Database Syst Rev. 2008;(2):2–4.
37. Meterko M, Wright S, Lin H, Lowy E, Cleary PD. Mortality among patients with acute myocardial infarction: the influences of patient-centered care and evidence-based medicine. Health Serv Res. 2010;45(5 PART 1):1188–204.
38. Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Qual Saf Heal Care. 2006;15(5):307–10.
39. Institute for Health Care Improvent. A guide to measuring the triple aim: population health, experience of care and per capita cost. 2012. http://forms.ihi.org/free-white-paper-a-guide-to-measuring-the-ihi-triple-aim. Accessed 5 August 2018.
40. Consumer Assessment of Healthcare Providers and Systems (CAHPS®). https://www.ahrq.gov/cahps/about-cahps/index.html. Accessed 18 Jun 2018.
41. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Source. 2009;82(4):581–629.
42. Massoud M, Nielsen G, Nolan K, Nolan T, Schall M, Sevin C. A framework for spread: from local improvements to system-wide change. IHI Innovation Series White paper. Cambridge, MA: Institute for Healthcare Improvement; 2006. www.IHI.org.
43. Barker PM, Reid A, Schall MW. A framework for scaling up health interventions: lessons from large-scale improvement initiatives in Africa. Implement Sci. 2016;11(1):1–11.
44. Coleman KJ, Magnan S, Neely C, Solberg L, Beck A, Trevis J, et al. The COMPASS initiative: description of a nationwide collaborative approach to the care of patients with depression and diabetes and/or cardiovascular disease. Gen Hosp Psychiatry. 2017;44:69–76.

Building the Multidisciplinary Transition Team

11

Andrew Baird

The transition of a patient from paediatric to adult healthcare has emerged as a defined discipline within urology and is regarded as paramount in fostering high quality and efficient lifelong care with focussed, appropriate and specialist follow-up. Treatment of the urological condition must be paralleled with a focus on preventing ill health/complications and the promotion of healthy living with access to appropriate support [1]. In healthcare across the board we are now encountering a growing population of young adult patients who have benefitted from paediatric care that may include major reconstructive surgery in a range of specialties and who require reliable and accessible care into young adulthood and beyond by a practitioner with an appropriate level of expertise.

A major challenge arises in adolescent patients because the ongoing care needs when entering young adulthood can be complex and far-reaching. The patient with a congenital condition is on a lifelong journey, and their experiences in healthcare will play a large part in shaping their long-term outcome [2]. Effective transitional care is paramount, and it has been clearly demonstrated in many life-long conditions that seamless transition to adult healthcare carries significant benefits in health outcomes [3, 4].

A. Baird (✉)
Department of Urology, Alder Hey Children's Hospital and Aintree University Hospital, Liverpool, UK
e-mail: andrew.baird@aintree.nhs.uk

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_11

Transition Planning

When considering the basis of a transition team, a number of core principles should be considered. These ideals are outlined below:

Defining Adolescence

Adolescence is a crucial period of time in a young persons' life during which a complex series of biological, physiological and social changes take place simultaneously. Relationships and interactions develop while behaviours change as the brain matures, and the end point of the process is a young adult with a strong sense of independence, a passion for justice and righteousness. It is important to be able to help and guide all patients—especially those who are more vulnerable through this period of, often, turbulent change.

Adolescence begins at puberty (which in some young people may be as young as 10 or 11 years) and is often felt to extend well beyond the age of 20—with the brain continuing to mature until the age of around 25 years of age. It is difficult to apply hard boundaries to these age ranges, more often the upper age is defined by the readiness of the young person to fully embrace adulthood and all that adult life has to offer.

The National Institute for Health and Care Excellence (NICE) in the United Kingdom published a comprehensive guidance document in 2016 in which support for young people in transitional care is recommended up to the age of 25 years [5].

Defining Transition

It is helpful to consider transition as a series of steps rather than a one-off transaction or event. Moving healthcare delivery from paediatric to adult services may involve a change of geographical location and sometimes a change of specialist medical practitioner, as well as often involving a shift of emphasis from a family-centred decision-making approach to a more person-centred approach encouraging independent thinking and choices. The change in facility or personnel is the transfer. The assumption of responsibility by the young adult and their involvement in their own healthcare is the fundamental principle of transition.

Therefore, *transition* can be defined as the preparation, planning and support given before, during and after the process of *transfer* of care delivery [6]—including the safe and confidential transfer of health information documentation.

The Multidisciplinary Transition Team

The key elements of transition planning include;

- Communication and documentation
- Forward planning

- Transferable medical records
- Clear onward care plan, involving the young person in decisions at all stages
- Inclusivity; consider which key medical and supporting persons may be required
- Remain person-centred rather than focussed on process

A transition team may consist of as few or as many members as is deemed necessary based on local service arrangements and the particular care needs of the service. The underlying diagnosis and treatment will play a key part in the design of the service and the members required to deliver a successful MDT.

A minimum requirement or core team should be determined, and this should be applied consistently to all young people requiring transition. An example of a core transition team might include:

- Lead clinician
- Named specialist nurse
- Transition coordinator
- Clerical Secretary or personal assistant (PA) to handle administrative tasks
- Community services coordinator

Lead Clinician

The lead clinician will have full knowledge and understanding of the background diagnosis, treatment received to date, problems and challenges ongoing, and the future care needs. A discussion between the lead clinician and the young person with their family/advocate will reach an agreed stage whereby the process of preparation for transition will begin with an agreed future target date for the transfer of care.

The lead clinician may be a paediatric specialist, a specialist in adolescent and/or transitional care, or an adult specialist with an interest in ongoing care of patients with lifelong congenital conditions.

The availability of a specialist with the relevant expertise in caring for such patients varies greatly across healthcare systems, specialties and the specific arrangements in place in any local, regional or national setting will depend heavily upon appropriate service design.

A specialist receiving young adult patients with transitional care needs due to congenital lifelong conditions must have a good understanding of the relevant pathophysiology of the relevant anatomy and embryology, be able to be responsive to patient-specific care needs, and have the correct skills and equipment available to troubleshoot emerging problems in a timely manner.

For example a young person struggling with a complex situation such as catheterisation of a Mitrofanoff (continent catheterisable) channel with pain in their augmented bladder and blood in their urine should expect to receive attention without delay from a urologist fully capable of endoscopic evaluation using appropriate instruments and able to manage unexpected findings such as a bladder calculus.

Named Specialist Nurse

In many clinical circumstances, the appropriate person to act as a first point of contact is a named Specialist Nurse. Depending on local service planning a named nurse may be a dedicated full time Transition nurse, or otherwise may be an appropriate specialist nurse with responsibility for transitional care alongside the other aspects of their role.

However the role is defined within a particular unit, the named nurse should have a comprehensive knowledge of the full range of the relevant congenital conditions and should be familiar with the details of each individual young person entering the period of transition to adult care.

The named nurse should be present at transition clinic appointments and be integral in care planning for each young person.

Transition Coordinator

In some larger paediatric hospitals, where transitional care occurs across multiple specialities, a transition coordinator plays a vitally important role in keeping care coordinated and aligned. They can facilitate transition planning and moving ahead at an appropriate pace, ensuring that appointments are made at convenient times for the young person and their family. The aim of this is (aside from excellent care) to minimise wasted Hospital resources through missed appointments and to maximise the effectiveness of the transition/transfer process. Document handling and storage, availability of case notes and care pathways at forthcoming appointments, may be enhanced through the effective use of a transition tracking database system managed by the transition coordinator and good administrative support.

Administrative Support

An efficiently managed transition/transfer system is greatly enhanced by the involvement of an administrative focal point such as clerical secretary or personal assistant (PA) who works closely with the lead clinician, specialist nurse and transition coordinator. A clear understanding of the care pathway being used and the ability to monitor progress of each young person during their individual transition journey is pivotal to success. The integration of a secretary/PA in the transition team to maintain clear and accurate administrative tasks is vital.

Community Services Coordinator

In many cases, where a child has successfully accessed a range of hospital or community services throughout paediatric care the same services may not be so easily or readily accessible after transition to adult health care. An example may be psychological support or mental health services. Many young people with complex health conditions experience anxiety and stress as a result of their health or in association with a chronic condition. In many areas, good access to child and adolescent mental health services exist and a period of stability is reached during adolescence. After transfer to adult services, access to good quality and regular mental health care can be challenging and consequently mental health is at risk of deterioration. A coordinator of services based in the community can be very helpful in bringing together all of the surrounding elements of care needed for an individual in a way that seeks to avoid the interruption of care and further helps to streamline the transition period [7]. Such community-based services may include physiotherapy and occupational therapy, psychology, obtaining pharmacy prescription items, access to family doctor appointments, continence services, supplies of medical equipment such as catheters and vocational help such as assistance in accessing college education.

Inclusion of Additional Resource

The wider multidisciplinary approach in urology (as an example) might include involving the following disciplines in care planning (while not necessarily being present at each transition clinic or meeting);

- Nephrologist
- Endocrinologist
- Orthopaedic Surgeon
- Neurosurgeon
- Gynaecologist
- Psychologist
- Pain specialist

This serves to demonstrate the breadth and depth required to form the whole multidisciplinary team. Clearly, not all specialties are needed for all cases but all need to be available when required. Different diagnoses and specialties will, clearly, require different input.

Conclusion

Both transition and transfer remain developing areas in healthcare for long-term conditions. Careful transition planning, the use of a core team and a wider multidisciplinary group are key in helping young people to navigate the complex landscape of healthcare systems in which it can be difficult to achieve seamless flow and continuity. We must strive to improve not only the transition process but also the overall care systems in which young people and adults with long term healthcare needs exist. Quality metrics are required in order to understand how and why some adolescents still fail during the transition/transfer process. To access adult healthcare appointments may not be the most important goal for all young people; becoming a fully independent adult with employment prospects, feeling valued, and in meaningful relationships is, for many, the desired endpoint of their journey into young adulthood [8]. Appropriate healthcare needs to play its role in supporting that for our patients.

Irrespective of the detail of the transition system in place, the safe, meaningful and effective onward delivery of care between two very different healthcare environments (paediatric and adult care) is paramount. From good quality care comes trust and a more enriched relationship between young adult patient a doctor. If we hold the welfare of our young patients at the centre of multidisciplinary transition planning, the process cannot go far wrong.

References

1. Michaud PA, Suris JC, Viner R. The adolescent with a chronic condition. Part 2: healthcare provision. Arch Dis Child. 2004;89:943–9.
2. Borer JB. Current approaches to the urologic care of children with spina bifida. Curr Urol Rep. 2008;9:151–7.
3. Kraynack NC, McBride JT. Improving care at cystic fibrosis centres through quality improvement. Semin Respir Crit Care Med. 2009;30:547–58.
4. Sawyer SM, MacNee S. Transition to adult health care for adolescents with spinal bifida: research issues. Dev Disabil Res Rev. 2010;16:60–5.
5. National Institute for Health and Care Excellence. Transition from children's to adult services for young people using health or social care services. NICE guideline [NG43]. 2016. https://www.nice.org.uk/guidance/ng43. Accessed 19 Oct 2018.
6. Sawyer SM, Blair S, Bowes G. Chronic illness in adolescent—transfer or transition to adult services? J Paediatr Child Health. 1997;33:88–90.
7. Okumura MJ, Saunders M, Rehm RS. The role of health advocacy in transitions from pediatric to adult care for children with special health care needs: bridging families, provider and community services. J Pediatr Nurs. 2015;30(5):714–23.
8. Okumura MJ. The transition journey: time to systematically address transition planning to adult health care. Pediatrics. 2018;142(4):e20182245.

Political Concerns in Transitioning Medical Care

12

Joshua D. Roth and Rosalia Misseri

Establishment of Transition Clinics

The introduction of successful transition of pediatric patients to an adult setting is reported to start as early as 11 years. For children with congenital urological conditions (CUC), some recommend that children begin attending a joint pediatric and adult clinic at around the age of 13 [1]. While this model likely allows for introductions between patient and healthcare provider and a better understanding of the patient's history, health status and personal goals, the logistics of having two senior clinicians present at each visit for an extended period may be impractical in many systems. Reasons behind this will include a lack of personnel, space, reimbursement and financial support by the host institution. Furthermore, additional services such as neurosurgery, nephrology, orthopedics, and endocrinology, among others, may be unable to participate in multidisciplinary encounters. Support services such as social work can play an important role in transition of care and ideally, should be involved. Funding for such clinics may be particularly problematic. There are several potential barriers in setting up these clinics, for example, location, staffing, how will health care professionals from different institutions participate, and how is reimbursement divided. While this may not be a concern globally, these are questions faced by any healthcare professional seeking to start a transition program in the United States.

J. D. Roth (✉) · R. Misseri
Department of Urology, Riley Hospital for Children, Indianapolis, IN, USA
e-mail: joshroth@iupui.edu; rmisseri@iupui.edu

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_12

Government Support

Successful transition of care for adolescents and the continuity of care for adults with congenital conditions is dependent on the availability of healthcare professionals to provide expert care. In addition to clinical expertise, the ability of these professionals to provide quality care hinges upon support at multiple levels, ranging from the unit and hospital in which he or she works. The influence of national specialty organizations, education and training committees, and the nation's health care system may significantly affect the success of a program. Additional support such as that afforded by charities and support groups are also important in the development of successful programs. Given the complexity of delivering such care, many countries, including the United States, continue to struggle with the development of programs to transition the care of patients with complex, long-term, congenital conditions. Additionally, care may be limited by restraints placed on health care professionals and institutional rules. For example, a pediatrician's license may limit his/her ability to care for people over the age of 18 or 21. Moreover, a pediatric hospital may not allow admission of patients over the age of 18 or 21. This age may even vary from institution to institution and country to country.

United States of America

The US population as of the 2010 census was 308.7 million. Almost one-quarter of Americans (74 million) were under the age of 18 at the time of the 2010 census [2]. In 2010, approximately 56.7 million people living in the United States had a disability. Approximately 8.4% of children under 15 had a disability, with half of these children having a severe disability and 0.5% of children under 15 requiring some assistance. The percentages of those with a disability, severe disability, and those requiring assistance increased with age [3].

As children with disabilities age, they are nearly twice as likely to be unemployed (41.4% employment rate) compared to their non-disabled counterparts (79.1% employment rate). Approximately 10.8% of adults between the ages 15 and 64 with severe disabilities were likely to experience persistent poverty over a 24-month period, which is twice the rate seen in adults with non-severe disabilities (4.9%) and almost three times as often as adults with no disabilities (3.8%). In 2008, the US federal government spent an estimated $357 billion on programs for working-aged people with disabilities, representing 12% of federal outlay. With advances in medical care, both the number and percentage of people with a severe disability continues to increase [3]. As an example, the economic burden of medical care for individuals with spina bifida is immense. In 2010, an estimated $1.79 billion were spent on emergency and inpatient services for people with spina bifida alone. This value does not include the cost of outpatient visits, surgery, medications, or the opportunity cost of missing work and/or school for the patient or caretaker [4].

In the United States, federal and state governments help provide health insurance and benefits to adults with disabilities through services like Medicare and Medicaid [3]. Medicare is a federally funded healthcare insurance typically for legal residents of the United States over the age of 65. Individuals over age 18 who have received Social Security disability benefits or have been diagnosed with end stage renal disease and been on dialysis for 3 months or have had a kidney transplant may also benefit from this insurance. Therefore, children with congenital conditions without renal failure will only be eligible for this form of insurance if Social Security deems physical and/or intellectual impairment are sufficiently severe that the individual cannot earn more than $1090/month from work and is not expected to earn that amount for at least 12 months [3].

Medicaid is a social health care program that provides free or low-cost health coverage for low-income people, families with children, pregnant women, the elderly and people with disabilities with resources insufficient to pay for health care. This program is funded jointly by state and federal governments. Currently, each state individually manages and determines who is eligible for the program and which services are covered [5]. Total Medicaid spending in 2016 was over $550 billion dollars [6]. The income limit to qualify for Medicaid differs by state. For example, in New York and California, the Medicaid income eligibility limit is $28,179 for a two-parent household and $16,642 in a one-parent household. In Indiana, the Medicaid income eligibility limit is $28,383 for a two-parent household and $16,763 for a one-parent household. In addition to Medicaid, Children's Health Insurance Program provides low-cost health coverage to children in families that earn too much money to qualify for Medicaid. Other public health insurance programs cover nearly half (44%) of children with special health care needs [7].

With the passage of the Patient Protection and Affordable Care Act (ACA) in 2010, often referred to as ObamaCare, children can stay on their parents insurance through age 26 and those with pre-existing conditions can obtain insurance coverage during open enrollment [8]. When data was last measured in 2010, prior to the full enactment of ObamaCare, the uninsured rates were no different in adults aged 15–64 with severe disabilities (21.0%), non-severe disabilities (21.3%) and no disability (21.9%). However, those with severe disabilities were less likely to have private insurance (40.2%) compared to those with non-severe disabilities (65.2%) and no disability (71.1%). Overall, almost half (48%) of adults with severe disabilities received government health coverage [3].

The future of the ACA remains an issue of intense debate in the United States. Shortly after passage, there were several challenges to the constitutionality of the ACA. In *National Federation of Independent Business v. Sebelius*, the Supreme Court ruled that the ACA's individual mandate was constitutional when viewed as a tax and that individual states had the right to opt out of the ACA's Medicaid expansion without losing preexisting Medicaid funding [9]. Several states have opted out of the elements of the ACA for which they had discretion. In *King v. Burwell*, the Supreme Court ruled that federal subsidies could be used in the 34 states that did not set up their own insurances exchanges, prompting *United States House of Representatives v. Price* in which the House sued the administration alleging that the money for premium subsidy payments to insurers had not been appropriated, which is required for federal spending [10]. The uncertainty regarding continued subsidy payments prompted some insurance companies to raise premiums.

In addition to judicial challenges to the ACA, there have been legislative repeal efforts. Since passage of the ACA, there have been unsuccessful repeal efforts in the 111th, 112th, 113th, 114th, and 115th Congress. In 2017, the American Health Care Act was introduced to partially repeal the ACA, which was passed in the House of Representatives [11]. The Senate attempted to pass multiple amendments to this bill, including the Better Care Reconciliation Act of 2017, the Obamacare Repeal Reconciliation Act of 2017, and the Health Care Freedom Act of 2017 [12–14]. So far, all specific bills were defeated in the Senate. There remains significant uncertainty about the future of the ACA under the current Trump administration.

Those with disabilities, especially severe disabilities, are significant consumers of the health care system. This usage will continue to grow as people with severe disabilities have improvements in survival. As children with disabilities mature into adolescents and adults with anomalies and disabilities, transition of care becomes important. Neither the American Pediatric Surgical Association (APSA) nor the Society of Pediatric Urology (SPU) has a statement regarding the transition of care of patients from pediatric to adult providers. Pediatric general surgeons surveyed revealed that nearly all (95%) treated patients up to 22 years of age, and many cared for older patients. Institutional limitations and lack of a qualified adult surgeons were cited as the most common barriers to transition [15]. In a similar survey amongst pediatric urologists, 2/3 reported caring for adult patients, while more than 80% felt that a pediatric or adult urologist with an interest in transitional care would provide optimal care. Nearly 70% of pediatric urologists surveyed reported that they would refer mature complex genitourinary patients to a urologist with an interest in adolescent/transitional urology, if one were available [16].

As urologists, we have used our own specialty as an example to represent the challenges faced, in this field. When thinking of this one should consider that there is no adult equivalent of bladder exstrophy, posterior urethral valves or hypospadias (to suggest some examples)—hence these are often less familiar to adult practitioners. As more patients with complex genitourinary disease and reconstruction grow, approach adulthood and survival to old age, the United States will develop a growing need to formalize an approach to transition care from pediatric to adult providers. Formalization of the process remains difficult for several reasons. There are many components necessary for transition beyond governmental support and insurance previously described. While it is unclear how many “adolescent urologists” or “congenital urologists” are necessary, Woodhouse estimates the need to be one “congenitalist” for four million people [17]. Currently, most “congenitalists” are part of the division of pediatric urology or adult urology at their respective institutions. To date there are no formal training programs for adolescent or congenital urology. Training in general urology may not adequately prepare a urologist to care for an individual with a chronic CUC. Currently, in the United States, there seems an increased willingness of those trained in pediatric urology, reconstructive urology and/or female pelvic medicine to care for these individuals. Additional training beyond a general urology residency in both adult reconstructive techniques and pediatric urology and knowledge of transition processes would be optimal. However, the American Board of Urology (ABU) mandates that an individual must dedicate

75% of his/her effort to pediatric urology in order to be eligible for a certificate of added qualification in the discipline. This may thwart residents interested in "congenitalism" from pursuing additional training in pediatric urology for fear they may not be recognized as having this additional expertise particularly if they are devoting more than 25% of their time to the care of adults, albeit with congenital conditions. Development of training programs for "congenitalists" requires the interest of practicing urologists as well as the support of specialty governing bodies such as the ABU and Royal College of Surgeons.

The specific needs of adults with CUC almost always outweigh those of a child who presents to a pediatric urology clinic with the same congenital disorder. This can be attributed to a "longer history", increasing needs or worsening of the disease process. For example, concerns associated with sexuality and fertility arise, and renal or bladder function may worsen. Colleagues within the division may not appreciate longer patient encounters and more tedious and complicated surgeries given the patients extensive surgical history. This may be viewed negatively by departmental colleagues, as peers can see more patients over the same period of time and in turn generate more income for the group.

The American Academy of Pediatrics, American Academy of Family Medicine, and American College of Physicians-American Society of Internal Medicine released a consensus statement describing a framework to ensure a smooth transition to healthcare [18]. Unfortunately, applications of these principles and adoption of transitional programs have been observed in multiple fields throughout the United States. Due to similar problems and obstacles observed in children with congenital urologic diseases, anorectal malformations, Hirschsprung disease, HIV, allergic disorders and immunodeficiencies, type 1 diabetes, hypercholesterolemia, inflammatory bowel disease, sickle cell disease, congenital heart disease, autism, rheumatic conditions, transplant recipients, and children with other chronic diseases requiring hospitalization, research into optimal transition plans have been described [19–31].

As part of its work, the National Alliance to Advance Adolescent Health, sponsor of Got Health, and the American Academy of Pediatrics have actively worked to support the delivery of transition services in both primary and specialty care settings. As reimbursement for such services remains difficult, they have developed a transition payment tip sheet that includes CPT codes and alternative payment methods to support the delivery of recommended transition services. These include pay for performance, capitation, bundled payments, shared savings arrangements, and administrative or infrastructure payments. Details are available at www. gottransition.org.

Canada

In sharp contrast to the American healthcare system, a group of socialized health insurance plans provide coverage to all Canadian citizens. Health insurance in Canada is publicly funded and administered locally with guidelines provided by the federal government. This is available to all citizens regardless of medical history or personal income. Private health insurance plans are also available to supplement primary health coverage. While private clinics do exist, they are not legally allowed to provide services covered by the Canada Health Act [32]. Private clinics may decrease wait times for certain services and are a subject of controversy, as some feel this leads to discrepancies in health care delivery based on income. In 2001 health care expenditures in Canada were $100 billion. In 2015, approximately 10.1% of Canada's gross domestic product is spent on health care (approximately 16.9% in US) [33].

The Canadian Pediatric Society has provided a mission statement on the transition of care from pediatric to adult practices. Health care goals include involvement of the adolescent in the management of the condition, adolescent and family understanding of the condition, understanding of personal potential, completion of adolescent developmental tasks, and attaining self-esteem and self-confidence [34].

They have outlined several strategies to help transition. At teenage visits, they recommend part of the visit occurring without parents to give the patient an opportunity how to discuss their problems, ask and answer questions, and advocate for themselves. Educational material dealing with youth issues and youth living with health conditions are provided to patients and the patients are recommended to attend peer-support meetings in person or online. Similar parental and sibling support groups also exist. The hospitals arrange family and teen education days to allow teens to meet each other, gather information, and discuss transitioning to the adult system. Finally, a formal acknowledgement of "graduation" in the form of a certificate from the pediatric staff given to the patient marks a rite of passage, while a letter to the patient and family about the new facility and staff can allow the patient and family know what to expect in the adult setting [34].

United Kingdom

Most healthcare in the United Kingdom (UK) is provided by the National Health Service (NHS). Within the UK, each country has some variability in healthcare policy and delivery, but the general system is similar. The NHS is a free service to all residents of the UK and is financed from mandatory national insurance taxation paid by employees directly from their salaries and supplemented by an obligatory contribution from employers. Self-employed persons pay the full contribution themselves. The onus is on the employer to deduct contributions from its employee's wages. Dependents, those with special needs and the unemployed are exempt from contributions. In England, the NHS accounts for most of the Department of Health's budget (£110 billion in 2013–2014) [35]. The total expenditure on healthcare as a proportion of GDP in 2015 was 9.8%, which was less than comparable economies such as Canada (10.1%), Belgium (10.4%), Denmark (10.6%), Netherlands (10.8%), France (11.0%), Germany (11.1%), Sweden (11.1%), Switzerland (11.5%), and the USA (16.4%) [33].

The Department of Health in the United Kingdom has clear guidelines recommending pathways to facilitate optimal transitional care across all specialties [36]. In addition, there are government initiatives to establish centers of expertise to develop clinical care, including better transition, to support clinical research and expand education and training programs for healthcare professionals [36]. Specific guidelines for the transition of patients with HIV are available from the Children's HIV Association [37]. Neither the British Association of Paediatric Surgeons (BAPS) nor the British Association of Paediatric Urologists (BAPU) have a statement on transitioning of surgical patients with complex congenital problems. Similarly, there is not a clear defined pathway of transition from child and adolescent mental health services to adult mental services, with half of trusts reporting children with attention deficit hyperactivity disorder were prematurely discharged from service due to a lack of suitable adult services. Additionally, there was a reported lack of written transition protocols, care pathways, commissioned services and inadequate information sharing between services [38].

There are several prominent multidisciplinary transition clinics in the UK. The adolescent urology department in University College Hospitals (UCHL) in London works closely with the Great Ormond Street Hospital's Department of Paediatric Urology where there is a transition clinic. Patients are brought to UCHL and seen by clinicians in the multidisciplinary adolescent unit, where there are joint clinics and joint operating sessions with adolescent gynecologists. There is a lifelong commitment to patients, and there is no further transitioning process. Similarly, the Adult Transition Urology Clinic (ATUC) in Glasgow, Scotland was established as a joint effort between Royal Hospital for Sick Children and Southern General Hospital. In this clinic, a pediatric urologist and adult urologist see patients concomitantly. Other specialists, e.g., adolescent gynecologists, will participate if needed. A survey of the 26 out of 30 patients who attended the clinic and completed transition over 4.5 years was conducted and completed by 19 patients. It revealed that 95% thought the clinic was useful and 89% would recommend it to others. Those involved in the clinic recommended 18 as the ideal transition age. They further recommend written information be provided to patients to help address patient needs and concerns as well as allowing the patient to decide when and if they should transfer their care to the adult setting, as one in five patients did not feel comfortable in the adult setting [39].

Australia and New Zealand

Adolescents make up more than 10% of most general practitioners practice in Victoria, Australia. These providers reported having an incomplete understanding of developmental aspects of adolescence and reported concerns about their knowledge of and competence in delivering adolescent health care. They perceived a range of barriers to effective health care provision, including issues of confidentiality, communication and cost and desire changes in the Medicare card and rebate systems to ensure improved access to affordable, confidential care for adolescents [40].

Since 1999, a Private Health Insurance Rebate has supplemented the public health plan. For this rebate, the government funds up to 30% of any private health insurance premium covering people eligible for Medicare. Including these rebates, Medicare makes up about 43% of the total Commonwealth health budget [41]. In 2016–2017, Medicare expenditure was $22.0 billion [42]. Expenses are expected to increase by 2.5% to 2020-2021 reflecting higher demand for health services. Medicare and Private Health Insurance Rebate expenses comprise 41.2% of total estimated health expenses for 2017–2018 [43].

In Australia, there are some good examples of successful transition programs. A “transition support programme” for young adults aged 15–25 with Type 1 diabetes was developed in Sydney to assist young people as they move from pediatric to adult health services. This allows them to remain under a system of care including a diabetes specialist, primary care physician and diabetes educator with the hopes of improving specialist clinic attendance after leaving pediatric services, improving glycemic control, and reducing hospital admissions for reasons related to Type 1 diabetes, like diabetic ketoacidosis [44].

The Australia and New Zealand Association of Paediatric Surgeons Inc. (ANZAPS) does not have a written policy on transitioning of pediatric patients with complex congenital conditions. However, hospitals are addressing the issue of transition at the hospital level. The Royal Children’s Hospital in Melbourne has developed an adolescent transition program that is equipped to introduce transition programs into every specialty at RCH. They have a separate transition department that identifies a transition lead in each department and tries to establish a transition service and clinic. In New Zealand, Starship Children’s Health in Auckland, New Zealand has developed web tools outlining the transition process. They have devoted clinics to transitioning of patients with diabetes and congenital heart conditions and are currently working on clinic for other specialties [45].

Cultural Issues

Cultural differences in religion, family structure, expected early adulthood experiences, relationship to health care providers, health literacy, and goals for independence exist across various countries and ethnicities [46, 47]. This becomes compounded when language differences exist between provider and patient. However, even when a language barrier can be bridged with an interpreter, cultural variations can still interfere in the relationship between a patient and medical provider [47].

One of the major differences between cultures is a young adult’s experience as they develop from late teens to early adulthood. This developmental time period has been termed “emerging adulthood.” In China, for example, much of the population is rural and poor, and only 20% obtain any post-secondary education. However, as China’s middle class continues to grow, it can also be expected that many life experiences associated with the transition from childhood to adulthood experienced in western societies will be experienced by a growing proportion of young Chinese [46].

In Latin America, like China, only those in wealthier families experience emerging adulthood. In more economically developed countries, emerging adulthood is experienced across a range of social classes. In one such country, Argentina, young adults resemble their counterparts in the United States in many ways but are found to have more enduring family ties and stronger family obligations [46].

Emerging adulthood is widespread across Europe. Many Europeans spend their young adult years studying, traveling, and socializing before settling into the commitments of adulthood. However, this varies somewhat across Europe, as southern Europeans are accustomed to living with their parents during young adulthood [46].

In western societies, numerous factors, such as healthcare systems, the availability of healthcare professionals, social services, support groups and family structure and support can influence the success of transition. Families are crucial in transition planning and implementation. Numerous family variables, such as living arrangements, extended family support, education, income, and marital/familial support impact health care transitions [48].

Familial support has been linked to traits such as emotional resilience and independence in adolescents and young adults with chronic illness [49]. When parental and child views differ with regards to a patient's increasing maturity or perceived readiness for more independence in their own healthcare, transition planning and implantation may be negatively affected [49–52].

Even after patients are old enough to assume legal responsibility for making their own medical decisions, parents and close family members will often provide emotional and financial support during transition and beyond. However, many patients with congenital abnormalities also have varying levels of cognitive impairment. Parents, or other close relatives, often continue as legal decision makers when the patient is unable to assume the responsibility. As such, reliance on emotional and financial support from parents may be more important for young people with disabilities compared to their non-disabled peers [53].

State agencies assume the role of guardian and act in lieu of the parents and/or close relatives in some children with disabilities. The rates of disability of children in foster care are high. Approximately 14% have a disability usually involving a cognitive or psychological condition [54]. In addition, many former foster children live in poverty, with many former foster youths homeless, poorly educated, or unemployed. Further, studies have shown that 30% of former foster youth had difficulties accessing healthcare due to inadequate finances or insurance, while 40% had worries about their health care. Fortunately those with more severe disabilities may receive ongoing support from various social service agencies, however, there remain serious deficiencies in how foster care programs manage the transition from child to legal adult with respect to health care services [55–57]. Some critics have recommended extending childhood Medicaid coverage to age 21 in an effort to assist young people leaving the foster care system [58].

Range of Services

The range of services differ largely between institutions based on institutional support, the training of the physicians providing care and the availability of subspecialty services. In the United States, there is no formalized training for those interested in treating adult patients with congenital disorders for most specialties. In addition, there is no agreed upon process for transition. As such, the services provided at each institution and by each service are highly variable.

The Canadian Pediatric Society recommends a multidisciplinary approach integrated into existing specialty clinic settings that provide a stepwise plan of increasing responsibility for self-care. Transition services may include individual counseling, psychoeducational groups, joint transition clinics, educational materials, and online tools [34].

In the United Kingdom, there are government initiatives to establish centers of expertise to develop clinical care, which includes transitional care. There are several prominent multidisciplinary clinics across the country. Similarly, hospitals in Australia are focusing on developing multidisciplinary clinics to treat common diseases.

Supporting Organizations

There are numerous international, national and local support groups for various diseases. Individuals and families affected by rare medical conditions often look to nonprofit support organizations and advocacy groups to understand how the condition may affect their lives, for medical information about the condition, treatment options, latest research, and other resources.

Advocacy groups often help people connect with each other online via Facebook, blogs, listservs, etc. and may provide opportunities to meet in person at local meetings, summer camps or yearly conferences. These supporting organizations provide medical information in easy-to-understand terms and often have a list of helpful resources, such as financial assistance resources, sources for special medical equipment, and advice on dealing with school or health insurance issues [59]. Many groups will work closely with centers of excellence and can be involved in the training of specialists. They can often help patients and families find specialists with experience diagnosing and treating rare medical conditions [60].

Advocacy groups often help advance medical research by maintaining rare disease registries to collect information about individuals with specific medical conditions or referring patients to appropriate registries [59, 61]. Often these groups will keep information about the progress of research and will help raise money to offer grants to medical researchers and pharmaceutical companies who are developing new treatments [59–61]. Perhaps most importantly, advocacy groups help educate the public and medical community about the condition and may take issues to local, state, and federal governments to help pass legislation that will improve the lives of those affected by rare and genetic conditions [59, 62].

Many advocacy groups focus on one rare condition or a group of closely related conditions. These groups may join together to create umbrella groups to tackle larger issues, such as advocating for legislation to help or protect all individuals with rare conditions. Examples include NORD (National Organization for Rare Disorders), Genetic Alliance, Global Genes, and EURORDIS (European Rare

Disease Organisation). Umbrella organizations have helped pass the Orphan Drug Act, GINA (Genetic and Information Nondiscrimination Act), and the European Union Regulation on Orphan Medicinal Products.

The National Alliance to Advance Adolescent Health, sponsor of Got Health, and the American Academy of Pediatrics has actively worked to support the delivery of transition services in both primary and specialty care settings. As reimbursement for such services remains difficult, they have developed a transition payment tip sheet that includes CPT codes and alternative payment to support the delivery of recommended transition services. These include pay-for performance, capitation, bundled payments, shared savings arrangements, and administrative or infrastructure payments. Details are available at www.gottransition.org [29].

In summary, optimizing transition services is necessary. Beyond the willingness of healthcare professionals to care for these patients, political support at all levels will be needed for continued success and further improvements in care.

References

1. Gleeson H, Turner G. Transition to adult services. Arch Dis Child Educ Pract Ed. 2012;97(3):86–92.
2. US Census Bureau. US Census [Internet]. 2010. www.census.gov.
3. Brault MW. Americans with disabilities: 2010: Household economic studies: US Department of Commerce. Economics and Statistics Administration; 2012.
4. Inouye BM, Wang H-H, Jiang R, Tejwani R, Wiener JS, Purves JT, et al. Estimating the economic impact of spina bifida in the United States. J Pediatr Rehabil Med. 2017;10:S61.
5. Centers for Medicaid and Medicare Services. Medicaid General Information. 2017. https://www.medicaid.gov/index.html. Accessed 8 June 2018.
6. Total Medicaid Spending. 2016. http://kff.org/medicaid/state-indicator/total-medicaid-spending/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D. Accessed 8 Jun 2018.
7. Medicaid and Children with Special Health Care Needs. 2017. http://kff.org/medicaid/issue-brief/medicaid-and-children-with-special-health-care-needs/. Accessed 8 Jun 2018.
8. Public Law. Law 111–148—Patient Protection and Affordable Care Act of 2010. Congressional Record; 2012.
9. States SCOTU. National Federation of Independent Business v. Sebelius 11-393. Nov 6, 2012.
10. Circuit USCOAFTDOC. United States House of Representatives v. Price 16-5202. 2017 July 17.
11. US Congress. HR 1628–American Health Care Act of 2017.
12. US Congress. S. Amdt. 270—Better Care Reconciliation Act of 2017. Accessed 25 Jul 2017.
13. US Congress. S. Amdt. 271—Obamacare Repeal Reconciliation Act of 2017. Accessed 25 Jul 2017.
14. US Congress. S. Amdt. 267—Health Care Freedom Act of 2017. Accessed 27 Jul 2017.
15. Durkin ET, Zurakowski D, Rangel SJ, Lillehei CW, Fishman LN. Passing the baton: the pediatric surgical perspective on transition. J Pediatr Surg. 2015;50(7):1196–200.
16. Szymanski KM, Misseri R, Whittam B, Large T, Cain MP. Current opinions regarding care of the mature pediatric urology patient. J Pediatr Urol. 2015;11(5):251.e1–4.
17. Woodhouse CRJ, Neild GH, Yu RN, Bauer S. Adult care of children from pediatric urology. J Urol. 2012;187(4):1164–71.
18. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics. 2002;110(6 Pt 2):1304–6.

19. Vijayan T, Benin AL, Wagner K, Romano S, Andiman WA. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. AIDS Care. 2009;21(10):1222–9.
20. Duke NN, Scal PB. Adult care transitioning for adolescents with special health care needs: a pivotal role for family centered care. Matern Child Health J. 2011;15(1):98–105.
21. Wiener LS, Kohrt B-A, Battles HB, Pao M. The HIV experience: youth identified barriers for transitioning from pediatric to adult care. J Pediatr Psychol. 2011;36(2):141–54.
22. LaRosa C, Glah C, Baluarte HJ, Meyers KEC. Solid-organ transplantation in childhood: transitioning to adult health care. Pediatrics. 2011;127(4):742–53.
23. Garvey KC, Markowitz JT, Laffel LMB. Transition to adult care for youth with type 1 diabetes. Curr Diab Rep. 2012;12(5):533–41.
24. Kaufmann Rauen K, Sawin KJ, Bartelt T, Waring WP, Orr M, Corey O'Connor R. Transitioning adolescents and young adults with a chronic health condition to adult healthcare - an exemplar program. Rehabil Nurs. 2013;38(2):63–72.
25. Chira P, Ronis T, Ardoin S, White P. Transitioning youth with rheumatic conditions: perspectives of pediatric rheumatology providers in the United States and Canada. J Rheumatol. 2014;41(4):768–79.
26. Cheak-Zamora NC, Farmer JE, Mayfield WA, Clark MJ, Marvin AR, Law JK, et al. Health care transition services for youth with autism spectrum disorders. Rehabil Psychol. 2014;59(3):340–8.
27. Kasinskas K, Colomb-Lippa D. Congenital heart disease: transitioning from pediatric to adult cardiology care. JAAPA. 2014;27(8):32–4.
28. Bemrich-Stolz CJ, Halanych JH, Howard TH, Hilliard LM, Lebensburger JD. Exploring adult care experiences and barriers to transition in adult patients with sickle cell disease. Int J Hematol Ther. 2015;1(1):1–6.
29. McManus M, Molteni R. Coding and reimbursement tip sheet for transition from pediatric to adult health care. PRACTICE. 2015.
30. Kelleher K, Deans KJ, Chisolm DJ. Federal policy supporting improvements in transitioning from pediatric to adult surgery services. Semin Pediatr Surg. 2015;24(2):61–4.
31. Gooding HC, Rodday AM, Wong JB, Gillman MW, Lloyd-Jones DM, Leslie LK, et al. Application of pediatric and adult guidelines for treatment of lipid levels among US adolescents transitioning to young adulthood. JAMA Pediatr. 2015;169(6):569–74.
32. Public Law. Canada Health Act. 1984. pp. 1–18.
33. Organization for Economic Co-operation and Development. Health Expenditure [Internet]. http://www.oecd.org/els/health-systems/health-expenditure.htm. Accessed 8 Jun 2018.
34. Kaufman M. Transition to adult care for youth with special health care needs. Review date: 2007-Nov (Reviewed 2012-Jan); 2007.
35. Department of Health. Department of Health corporate plan 2013–2014 [Internet]. https://www.gov.uk/government/publications/department-of-health-corporate-plan-2013-14/department-of-health-2013-14-corporate-plan#resources. Accessed 8 Jun 2018.
36. National Service Framework for Children, Young People and Maternity Services. Transition: getting it right for young people. London; 2006.
37. Foster C. CHIVA guidance on transition for adolescents living with HIV. 2010.
38. Hall CL, Newell K, Taylor J, Sayal K, Hollis C. Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: a national survey of mental health trusts in England. J Psychopharmacol (Oxford). 2015;29(1):39–42.
39. Shalaby MS, Gibson A, Granitsiotis P, Conn G, Cascio S. Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. J Pediatr Urol. 2015;11(2):89.e1–5.
40. Veit FC, Sanci LA, Young DY, Bowes G. Adolescent health care: perspectives of Victorian general practitioners. Med J Aust. 1995;163(1):16–8.
41. Britnell M. In search of the perfect Health system. London: Palgrave; 2015. p. 1.
42. Australian Government Department of Health. Annual Medicare Statistics [Internet]. www.health.gov.au/internet/main/publishing.nsf/content/annual-medicare-statistics. Accessed 8 Feb 2018.

43. Commonwealth of Australia. Statement 6: expenses and net capital investment [Internet]. 2018:1–53. http://www.budget.gov.au/2017-18/content/bp1/download/bp1_bs6.pdf. Accessed 8 Feb 2018.
44. Holmes-Walker DJ, Llewellyn AC, Farrell K. A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with type 1 diabetes aged 15-25 years. Diabet Med. 2007;24(7):764–9.
45. Upadhyay V. Transitioning of paediatric patients with complex congenital gentirourinary conditions: study of current status in New Zealand and recommendations for the future. 2011.
46. Arnett JJ, Eisenberg N. Introduction to the special section: emerging adulthood around the world. Child Dev Perspect. 2007;1(2):66–7.
47. Smith K, Freeman KA, Neville-Jan A, Mizokawa S, Adams E. Cultural considerations in the care of children with spina bifida. Pediatr Clin N Am. 2010;57(4):1027–40.
48. Institute of Medicine US Committee on Disability in America, Field MJ, Jette AM. The future of disability in America. Washington (DC): National Academies Press (US); 2007.
49. McDonagh JE. Growing up ready for emerging adulthood. An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities. 2006. https://councilfordisabledchildren.org.uk/sites/default/files/uploads/documents/import/growing-up-ready-for-emerging-adulthood.pdf. Accessed 8 Jun 2018.
50. Resnick MD, Bearman PS, Blum RW, Bauman KE, Harris KM, Jones J, et al. Protecting adolescents from harm. Findings from the National Longitudinal Study on Adolescent Health. J Am Med Assoc. 1997;278(10):823–32.
51. Werner EE. Vulnerable but invincible: high-risk children from birth to adulthood. Acta Paediatr Suppl. 1997;422:103–5.
52. Shaw KL, Southwood TR, McDonagh JE. Growing up and moving on in rheumatology: parents as proxies of adolescents with juvenile idiopathic arthritis. Arthritis Rheum. 2006;55(2):189–98.
53. Thorin E, Yovanoff P, Irvin L. Dilemmas faced by families during their young adults' transitions to adulthood: a brief report. Ment Retard. 1996;34(2):117–28.
54. Smith JM. Foster care children with disabilities. J Health Soc Policy. 2002;16(1–2):81–92.
55. English A, Morreale MC, Larsen J. Access to health care for youth leaving foster care: Medicaid and SCHIP. J Adolesc Health. 2003;32(6 Suppl):53–69.
56. English A, Stinnett AJ, Dunn-Georgiou E. Health care for adolescents and young adults leaving foster care: policy options for improving access. Center for Adolescent Health & the Law; 2006.
57. Reilly T. Transition from care: status and outcomes of youth who age out of foster care. Child Welfare. 2003;82(6):727–46.
58. CPPP Center for Public Policy Priorities. All grown up, nowhere to go: teens in Foster Care Transition. CPPP, Texas Foster Care Transitions Project. 2001. pp. 1–56.
59. Hall JG. The role of patient advocacy/parent support groups. S Afr Med J. 2013;103(12 Suppl 1):1020–2.
60. Chad DA, Bidichandani S, Bruijn L, Capra JD, Dickie B, Ferguson J, et al. Funding agencies and disease organizations: resources and recommendations to facilitate ALS clinical research. Amyotroph Lateral Scler Frontotemporal Degener. 2013;14(Suppl 1):62–6.
61. Groft SC. Rare diseases research: expanding collaborative translational research opportunities. Chest. 2013;144(1):16–23.
62. Dunkle M, Pines W, Saltonstall PL. Advocacy groups and their role in rare diseases research. Adv Exp Med Biol. 2010;686(Chapter 28):515–25.

Taking a Service Forward: The Adolescent and Adult Care of Major Congenital Anomalies—The Move from Adolescent to Lifelong Care

13

Göran Läckgren, Anders Stenbäck, Gillian Barker,
and Johan Heinius

Time is the teacher for mankind.
—Greek Proverb

Background

The transition of children, born with congenital anomalies, into adulthood has always been and is still today a challenging problem for the patient, the family and also the different systems of medical care. This is a problem that for many years has been neglected. Over the last decade there has, however, been more focus on "adolescent care." The survival of children with severe anomalies has improved significantly and this has further emphasized the need for continuous care and follow-up of these patients. Children born with major anomalies deserve and require life-long evaluation, follow-up care and treatment. For many years, in urology, Christopher Woodhouse shone the light on the different problems that patients may encounter in adult life ("An Adolescent Urologist is a Pediatric Urologist who knows everything but 20 years too late"). He and others have shown that it is possible to significantly improve the health and well-being using a planned follow-up system and has also shown the benefits of reconstructive surgery in post-pubertal life [1].

G. Läckgren (✉) · A. Stenbäck · G. Barker
Section of Pediatric Urology, Department of Pediatric Surgery, Uppsala University Children's Hospital, Uppsala, Sweden
e-mail: goran.lackgren@kbh.uu.se; anders.stenback@akademiska.se; gillian.barker@akademiska.se

J. Heinius
Department of Urology, Uppsala University Hospital, Uppsala, Sweden
e-mail: johan.heinius@akademiska.se

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1_13

In pediatric patients, the parents are a vital channel for information from the doctors and nurses. They also act as key decision makers—this changes dramatically in adolescence and adulthood as the young adult gains independence and responsibility and the role of the parent changes. Historically, the patient can be ill-prepared for the new care-system (Table 13.1). Therefore, these patients need to be cared for in a system where the adult practitioner has knowledge of the anomaly, the potential long-term consequences of the illness and the treatment [2].

The system for the transition of patients to adult departments may differ from country to country depending on the social welfare systems, but regardless of where in the world they live a poor transition appears to have a negative effect on the morbidity of the patient and the long-term socio-economic consequences for the patients the family and society [3].

Furthermore, the organization differs dependent on whether the pediatric department is a part of a department of pediatric care [4, 5] or integrated into an adult department. The latter case may facilitate a natural continuation of the follow-up of the patients in the same department and often by the same doctor at least in the early part of transition. A recent report based on a questionnaire to pediatric urologists in USA showed that the majority recommend that patients with previous complex genitourinary reconstructions should be followed by a urologist with a specific interest, training and experience in the area of transitional urology. However, the study also showed that many of these pediatric urologists will keep the patients long-term because of poor trust of the adult care system and the lack of trained Adolescent urologists [6]. This study focuses on urology but exemplifies the importance of good transition and adolescent/adult services with expertise in any specialty.

In a survey of pediatric urologists around the world many of the problems were described [7]. In many countries, there is no structure for transition but many individual efforts. Adult urologists are not generally interested in this complex group of patients and do not have the experience to care for them. It is the main problem for pediatric urologists, especially working in isolated Children's Hospitals. Designated centers are the only solution to assure high quality care. There is a need for a definition of structure, funding and administrative support.

Today, it is generally recommended that an adult specialist takes over care after the transition period. Early cooperation between Pediatric Urology and Adult

Table 13.1 What happens to these young patients when they leave the control system from pediatric care?

Anxiety from parents and patients—do not want to leave the safe and caring surroundings
"Anxiety" from pediatric specialists—do not want to "let go"
"One step closer to complications and death"
The patients are referred to "any" urology department
Limited knowledge of the congenital anomaly among the adult practitioner
Long term complications of pediatric reconstructive surgery are unknown
Less understanding of the "natural course" of the MMC bladder and renal function
Sexology and fertility problems are not discussed and parents are "overprotective" in this sense
The patients are "most often consults of many but patients of none?"

healthcare is necessary, and we believe that this should continue into lifelong care. Every large University Hospital, where both specialties exist, should be obliged to create a unit for Congenital Lifelong Urology.

Continuation of the patients within a pediatric setting may hinder some aspects of appropriate adult care [8]. The therapeutic goals may be different and include more emphasis, for example, on sexual function, fertility and further reconstructive surgery [9, 10].

The patients have, of course, a strong desire to be as "normal" as possible and they deserve special attention in many aspects. The transfer to adult care is particularly important in young people with medical complexity, including those with congenital, multisystem organ anomalies, and who often are surgically reconstructed. Some patients will have multiple different medical problems which are outside the skill set of a single practitioner. It is of utmost importance to have a close cooperation with other specialties and to organize multidisciplinary expert groups. As an example, in Table 13.2 we have outlined the specialties, that we consider necessary for the control and care of congenital abnormalities.

Congenital anomalies may present prenatally, at birth or in early childhood, but some will present in later life (adolescence or adulthood). There are a variety of reasons for this but it highlights the need for an understanding of the congenital urogenital anomalies and their embryology among adult practitioners. A clear example in urology is the potential change in bladder function in boys with urethral valves, who may experience underactivity of the bladder with increasing age [11]. It is different from the adult bladder outflow obstructions and the adult urologist must understand and handle the long-term problems in these patients. Over recent years a basic knowledge of pediatric urology and embryology has been included for certification as a urologist in Sweden and other countries too. This is a small step forward towards creating an interest in pediatric urology and towards understanding the anomalies treated in childhood. However, in specialties (such as urology) where there is a lack of an adult equivalent to the pediatric team—the lack of education is

Table 13.2 The following specialists should be required for adolescent and adult care of urogenital anomalies

Nephrologist
Neurologist/Rehab
Other subspecialized urologists (reconstructive urologist, Andrologist)
Sexologist
Gynecologist
Urotherapists
Gastro-enterologist
Colo-rectal surgeon
Plastic surgeon
Orthopedic surgeon
Psychologists and psychiatrist
Radiologist
Endocrinologist
Geneticist

still an obvious obstacle to optimal care for patients. The need for continued intervention, surgical reconstruction or reoperations are still common in adulthood [12, 13]. In recent years the ESPU (European Society for Pediatric Urology) and the EAU (European Association of Urology) have started to build a common working group in order to create recommendations for the follow-up and care of adults born with urogenital anomalies. We are moving from Adolescent Urology to "Congenital Lifelong Urology" (CLU).

Example of a Good Practice

In Sweden, as in most other countries, there is a lack of well-developed organizations for transition from childhood to adulthood in many medical fields. Health care organization plays an important role. If, for example, pediatric urology is organized under a department of urology that handles both pediatric and adult cases, the transition is often smoother because the same urologist can follow the patient throughout life. If on the other hand pediatric urology is organized under pediatric surgery in a children's hospital the transition means change of caregivers as well as change of hospital—this can be more difficult to manage.

The complexities of caring for patients with multiple medical concerns are often amplified as the patient moves into adult care. Adult care tends to be more widely separated so this can mean a transition from a team-based pediatric approach to many different providers—often with separate appointments and an apparent lack of coordination. From a surgical point of view there might also be a lack of interest from the adult counterparts if there is limited or no surgery involved in the follow-up.

However, there are some outstanding exceptions to this rule. For example, in congenital heart disease there is a working cooperation between pediatric cardiologists, pediatric cardiac surgeons and their adult counterparts [14].

Around 1000 children in Sweden are born each year with congenital heart disease (CHD). Almost 95% survive till adulthood. Since 2009 there is a nationwide web-based registry called SWEDCON. It includes grown-ups with congenital heart disease (GUCH), pediatric patients with heart disease, patients operated on by pediatric cardiac surgeons and it is now starting to register fetal cardiac anomalies. It is estimated that around 95% of all eligible patients are entered into the registry. In that way there is an almost complete coverage of all patients with congenital heart disease and a tremendous resource for research and follow-up of long term results in patients with CHD and after pediatric cardiac surgery. In addition, seven regional competence centers for GUCH have been formed and there is an ongoing work to educate adult cardiologists. The goal is that there should be at least one adult cardiologist in each larger hospital that is dedicated to GUCH and will have good knowledge of the underlying conditions. Swedish cardiologists are also striving to make GUCH a recognized sub-specialization in cardiology.

The GUCH centers are run by adult cardiologists since mid-1990s and is a team focused enterprise. The team includes pediatric cardiologists, physiologists, specialized nurses, physiotherapists, radiologists, psychologists, obstetricians, thoracic surgeons and geneticists. It is possible for the patients to contact their GUCH team directly without referral and this makes it very accessible. The transfer to adult care usually takes place as a process between 15 and 18 years of age. The goal is that every patient with CHD, even milder forms, should have at least one appointment with a GUCH specialist during this time.

Moreover, there is a nationwide videoconference network called GERTRUD arranged by the pediatric cardiologist for ongoing education.

Even with a rigorous program like the above it is estimated that almost 50% of the patients are lost to clinical follow-up.

Creation of a Section of Congenital Urology

The most important questions are still waiting for good answers. What do we do? What do we leave for the adult life? How can we create a good system for follow-up for our patients? How can we create interest among the adult practitioners in specialties where it is lacking?

These are questions that arise in any medical care system. In Sweden, as many countries, there have been different follow-up systems in different regions and different hospitals mainly depending on the individual interest from the adult caregivers. In our region most of the larger county hospitals have taken care of the casual long-term controls. Today, unfortunately, there is a lack of doctors and nurses undertaking adolescent medicine in many specialties. Therefore, one of the most important issues is to attract doctors and nurses who are genuinely interested in working with this challenging group of patients and who also understand the adult-oriented care [15]. For some there has been limited regular follow-up in adulthood, leaving adult patients to organize their own medical care via local hospitals or GPs. This statement by Margaretha Dahl (Consultant Pediatric Neurologist, Uppsala University Children's Hospital and past President of the "Society for the Research of Hydrocephalus and Spina Bifida" (SRHSB)) shows us the situation in Sweden today.

> As an adult you are expected to contact hospital care if you want help. Young adults with MMC (myelomeningocele) do not contact hospitals or care because they do not feel sick!! As most of them live "at home" their parents have a dilemma. They see that their children need help, but it is difficult to act and difficult to get in contact with care givers. Many of the rehabilitation centers in Sweden lack qualified doctors. As MMC is a rare anomaly, many GPs lack knowledge and experience of this group of patients

Lifelong follow-up by many specialists is necessary for individuals with MMC. The complex medical situation, often in combination with cognitive difficulties, makes it necessary to coordinate medical services for this increasingly large group of adults with multiple impairments [16].

In a Swedish study of adult patients with MMC [17] it was shown that 53% of the urologically operated adults had a consultation with a urologist every 3 years, but only 31% of those not operated had any contact. Very few had urotherapy support and none had support for their bowel regimen. This study shows that the majority of these patients with MMC are left without any specialist follow-up of the urinary tract or bowel in adult life.

It is clear that many of the patients seek help only as emergency cases and this is costly and risky—placing an avoidable burden on both the patient and the healthcare system. Those who are lost to follow-up and to specialty care may suffer from recurrent UTI, incontinence, renal insufficiency occasionally and other complications such as decubitus, poor bowel function, stones etc. A lack of individual planning from the adult providers leads to poor coordination of smooth and efficient long-term follow-up [18]. With a good transitional care, the number of hospital admissions and the number of unnecessary complications for these patients can be significantly reduced. Disease specific knowledge of the congenital anomalies and their potential complications are essential for setting up an individual follow-up plan. The indications for any further interventions should build on the experience of both pediatric and adult practitioners -they are the key to providing life-long care. By introducing a better standard of care in adult life many of these emergency hospital visits can be prevented, which is of course beneficial for both the patient, family and society [19].

> We estimate that a population of 4–5 million people would require one Adolescent Urologist. It will only be practical to have him/her in a large urology unit in a major University Hospital. Ideally there will be two such sub-specialists in the unit (Woodhouse and Wood [1]).

Each country and healthcare system will need to make its own estimation according to each disease area and the lessons learned to date. Every center should be obliged to carry out long-term studies, to establish national and international collaborations and to have research projects on the follow-up of different diagnostic groups. There should also be a strong emphasis on training and education of the long-term outcomes of these congenital anomalies for all practitioners in order to create interest among future specialists. As an example, the requirements for accreditations as an Adolescent or Congenital urologist are shown in Table 13.3.

Table 13.3 The requirements for “Adolescent or Congenital Urologists”

• General urology specialization and also training in pediatric urology
• Training and competence in reconstructive urology—ureter, bladder, urethra, and genitalia
• Abilities to organize a multidisciplinary team that meets on a regular basis to formulate patient treatment plans
• To have close cooperation with urotherapists
• To have competence in the management of adult consequences of congenital anomalies either personally or through associated specialists
• Must follow patients throughout adult life
• Must report outcome regularly in pediatric and adult urology meetings/literature
• Must initiate clinical research projects
• Must collaborate with other national and international centers

Taking a Service Forward

In our adolescent unit the first steps to this type of organization were done many years ago. We started with transition meetings together with the Rehabilitation Centre and our own specialty for children aged 15–18 years. The University Hospital has a geographically large region with approximately three million inhabitants. More "organized and professional" care and follow-up started with an "Adolescent" clinic in 2007. A key decision that made us go further was the creation of a half-time position as Consultant Adolescent Specialist—in this case, within the adult urology department. He (JH) had a background as consultant in general and reconstructive urology and was also trained in pediatric urology. All patients born with a severe urogenital anomaly and between the age of 15–18 years were transferred to the Urology Department. Initially all patients in our region with neurogenic bladder disorders (MMC, spinal trauma, neurogenic bladder in patients with anal atresia, etc), the epispadia- exstrophy complex, and urethral valves were the targets for our clinical follow-up [18, 20]. In time all adults born with other urogenital anomalies, e.g., hypospadias, renal abnormalities and bladder dysfunctional problems [21] etc. have been a large part of our work (Table 13.4). In our system it is essential that the pediatric urologist works together with the adult urologist and is continuously involved in the life-long follow-up of these patients.

This is an example from within our own specialty. This chapter shows it is achievable in others.

The urological disorders that require long-term follow-up on a yearly basis include MMC and other neurogenic bladders, bladder exstrophy and DSD. For many years the DSD patients have been followed via a multidisciplinary DSD-team where specialists from pediatric urology, gynecology, clinical genetics, pediatric endocrinology, psychology have been involved even in adult care [10, 22]. Of the patients that we today see in our clinic approximatively 50% need some minor or major reconstructive surgery. Furthermore, the team is today involved in most penile - urethral reconstructive surgery in adolescents and adults. In brief, our organization of a section of Congenital Urology is seen in Table 13.5. It is very important to allow more time with this group of patients not only in the transition period. The importance of having trained urotherapists or specialized nurses involved in the

Table 13.4 Urogenital malformations or multiple anomalies that may create urological problems and contacts for long-term

• Neurogenic bladder and bowel (MMC, spinal injuries and diseases)
• Exstrophy—epispadia complex
• Cloacal anomalies
• Urethral valves
• Hypospadias
• Disorder of sex development (DSD)
• Renal anomalies with affected renal function
• Vesicoureteral reflux
• Bladder dysfunction and incontinence; adult enuresis

Table 13.5 Congenital Urology in Uppsala

Transfer meetings starting in puberty
Patient and parents
Pediatric habilitation—neurology, pediatric and adult urology, adult rehabilitation, urotherapy
Referral to adult specialties
Congenital Urology in Uppsala
Outpatient clinic 2 days per month, 30–60 min per patient
• Adult and pediatric urologist
• Adult and pediatric urotherapist
• Every patient is contacted by phone once a year
• Patients with neurogenic bladder (MMC), bladder exstrophy or urethral valves are followed up yearly
• 150 patients per year
Surgery 2 days per month
• Adult and pediatric urologist
• 40–50 operations per year

clinics cannot be over-emphasized and will apply in any area of medicine. They are the key people in the organization and are involved in both organization and treatment. We are aiming at having one from the pediatric and one from the adult department. We have found this to be a simple way of increasing the competence on both sides and also maintaining the trust of the patients and parents. The team is also involved in teaching and information about adolescent urology.

Conclusions

It is from experience and the long-term outcomes that we can both learn and improve the care of our primary patients who are enrolled in our follow-up-system. A registry should be created [16] already from childhood as long-term complications with specific aspects of care is important—in our work these include—bladder function, sexual function and fertility. This should be elucidated in follow-up studies. For the Congenital urology-team, these are stimulating and rewarding tasks as each group of patients will certainly benefit from a standardized plan for their life-long care.

One important task is to be part of international networks and to create national networks where both pediatric and adult urology are involved. This will enhance the interest and understanding for our organization, patients and Congenital Urology.

Another important result of a careful follow-up may eventually change some of our treatment strategies as pediatric specialists when it comes to reconstructive surgery and the timing of procedures. There are still many obstacles in both transitional care and long-term follow-up. It is shown by many pediatric surgical specialty groups that even with an elaborate and well-functioning system, not more than 50% of the patients who need life-long follow-up are actually followed. In many centers the creation of Congenital Urology for lifelong care is mainly built on individual dedication and interest with little support from the specialty. However, over the last 10 years there has been much more interest and new centers have been organized in many countries. In Europe the ESPU has prioritized adolescent urology in meetings and also created working groups together with EAU and the reconstructive urologist. This may be a way to increase the interest and to educate the adult urologists.

Our future goal is to create an "Adolescent or Congenital Urologist" who can match the requirements shown in Table 13.3. All Urology departments in large University Hospitals should be obliged to create such positions and to build the clinics and surgical care that have been discussed in this book. We have shown that a good follow-up system can be created in hospitals where both pediatric urology and adult urology exist and at least in Sweden we are convinced that this model with both specialties working together is of importance and vital for the life-long follow-up.

References

1. Woodhouse CRJ. Adolescent urology and long-term outcome. Oxford: Wiley; 2015. p. 1–10.
2. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993;14(7):570–6.
3. Viner RM. Transition of care from paediatric to adult services: one part of improved health services for adolescents. Arch Dis Child. 2008;93:160–3.
4. Jesus LE, Dekermacher S, Frota J, Braganca JJ, Anderson KM. Adolescents and adults in pediatric urology clinics. J Pediatr Urol. 2014;10(3):408–11.
5. Timberlake MD, Corbett ST, Costabile RA, Herndon ACD. Identification of adolescent and adult patients receiving pediatric urology care and establishment of a dedicated transition clinic. J Pediatr Urol. 2015;11:62.e1–6.
6. Szymanski KM, Misseri R, Whittamm B, Large T, Cain MP. Current opinions regarding care of the mature urology patient. J Pediatr Urol. 2015;11:251.e1–4.
7. Tekgul S. Long-term outcome of common congenital problems surgically treated in childhood. Eur Urol Suppl. 2017;16(8):189–93.
8. van der Toorn M, Cobussen-Boekhorst H, Kwak K, D'Hauwers K, de Gier RP, Feitz WF, Kortmann BB. Needs of children with a chronic bladder in preparation for transfer to adult care. J Pediatr Urol. 2013;9(4):509–15.
9. Lambert SM. Transitional care in pediatric urology. Semin Pediatr Surg. 2015;24:73–8.
10. Creighton SM, Wood D. Complex gynaecological and urological problems in adolescents: challenges and transition. Postgrad Med J. 2013;89:34–8.
11. Holmdahl G, Sillén U. Boys with posterior urethral valves: outcome concerning renal function, bladder function and paternity at ages 31 to 44 years. J Urol. 2005;174:1031–4.
12. Chan R, Scovell R, Jeng Z, Rajanahally S, Boone T, Khavari R. The fate of transitional urology patients referred to a tertiary transitional care center. Urology. 2014;84(6):1544–8.
13. Woodhouse CRJ, Neild GH, Yu RN, Bauer S. Adult care of children from pediatric Urology. J Urol. 2012;187:1164–71.
14. Mandalenakis Z, Rosengren A, Skoglund K, Lappas G, Eriksson P, Dellborg M. Survivorship in children and young adults with congenital heart disease in Sweden. JAMA Intern Med. 2017;177(2):224–30.
15. Foster BJ, Bell L. Improving the transition to adult care for young people with chronic kidney disease. Curr Pediatr Rep. 2015;3:62–70.
16. Olsson I, Dahl M, Matsson S, Wendelius M, Åström E, Westbom L. Medical problems with myelomeningocele (MMC): an inventory of the Swedish MMC population born during 1986-1989. Acta Paediatr. 2007;96(3):446–9.

17. Vu Minh Arnell M, Seljee Svedberg K, Lindehall B, Jodal U, Abrahamsson K. Adults with myelomeningocele: an interview study about life situation and bladder and bowel management. J Pediatr Urol. 2013;9(3):267–71.
18. Stephany HA, Ching CB, Kaufman MR, Squiers A, Trusler L, Clayton DB, et al. Transition of urologic patients from pediatric to adult care: a preliminary assessment of readiness in spina bifida patients. Urology. 2015;85(4):959–63.
19. Wood D. Adolescent urology: developing lifelong care for congenital anomalies. Nat Rev Urol. 2014;11(5):289–96.
20. Jalkanen J, Mattila AK, Heikkilä J, Roine RP, Sintonen H, Taskinen S. The impact of posterior urethral valves on adult quality of life. J Pediatr Urol. 2013;9(5):579–84.
21. Kyrklund K, Taskinen S, Rintala R, Pakarinen MP. Lower urinary tract symptoms from childhood to adulthood. A population based study of 594 Finnish individuals 4-26 years old. J Urol. 2012;188:588–93.
22. Liao LM, Taconelli E, Wood D. Adolescent girls with disorders of sex development; needs analysis of transitional care. J Pediatr Urol. 2010;6:609–13.

Index

D. Wood et al. (eds.), *Transitioning Medical Care*,
https://doi.org/10.1007/978-3-030-05895-1