Pamela Gallagher
Deirdre Desmond
Malcolm MacLachlan *Editors*

Psychoprosthetics

Springer

Psychoprosthetics

Pamela Gallagher • Deirdre Desmond •
Malcolm MacLachlan
Editors

Psychoprosthetics

Springer

Pamela Gallagher, BA Mod, DipStat, PhD
Senior Lecturer in Psychology
Faculty of Science and Health
School of Nursing, Dublin City University
Dublin
Ireland
and
Dublin Psychoprosthetics Group
Ireland

Malcolm MacLachlan, BSc, MSc, MA, PhD,
DipBA, FPSI, FTCD, MRIA
Associate Professor
School of Psychology
Trinity College
University of Dublin
Ireland
and
Dublin Psychoprosthetics Group
Ireland

Deirdre Desmond, BA, DipStat, PhD
Lecturer
Department of Psychology
National University of Ireland
Maynooth
Co. Kildare
Ireland
and
Dublin Psychoprosthetics Group
Ireland

British Library Cataloguing in Publication Data
Psychoprosthetics
1. Prosthesis – Psychological aspects
I. Gallagher, Pamela II. Desmond, Deirdre III. MacLachlan,
Malcolm
617.9’019

Library of Congress Control Number: 2007933181

ISBN-13: 978-1-84628-979-8 e-ISBN-13: 978-1-84628-980-4

9 8 7 6 5 4 3 2 1

Springer Science+Business Media
springer.com

Preface

This book brings together, into one easily accessible volume, the most recent and exciting research and knowledge in this new field. Psychoprosthetics is the study of psychological aspects of prosthetic use and of rehabilitative processes, in those conditions that require the use of prosthetic devices. For people with limb loss—the primary focus of this volume—the fitting of a prosthesis can give rise to a variety of issues, from functional rehabilitation to quality of life, well-being, participation in society, and cosmetic satisfaction. As prosthetic technology continues to become more sophisticated and advanced, there is a responsibility on those who work with prosthetic users to be aware of the impact of prosthetics on the ways in which people understand and construct their realities and their attempts to cope with and relate to them.

There is a growing need to match what is technically available with what is subjectively desirable. Increasingly, professionals in this field acknowledge that an important aspect of their ongoing interactions with people with limb loss is their understanding and consideration of the prosthetic user's psychology. The human body is endowed with varied forms of psychosocial significance, and there is significant loss and gain that is associated with limb loss. Issues to consider include the ways in which people relate to a changed body and how people relate and adjust to the prosthetic technology that now is part of the bodily experience. However, despite the broad and increasing interest in psychosocial aspects of prosthetic use and rehabilitation, to date there has not been a complete volume on the topic. This book now addresses that need. Psychoprosthetics is now a regular feature of conference programs in the area of prosthetics, rehabilitation medicine, and health psychology, and there is regular acknowledgment in the leading journals that psychology is a key feature in the understanding of adjustment to and use of prosthetics.

It is our hope that this book will contribute to a better understanding of the complex human dynamics involved in prosthetic use. This volume therefore compiles, reviews, and analyzes the practice, research, and theory in the field of psychoprosthetics. We believe that the publication of an interdisciplinary review is very timely, as research in this rapidly developing area tends to be both scattered and compartmentalized across a number of disciplinary domains. This book seeks to maximize the readers' reach and utility by bringing much of it together in one volume.

The chapters in this volume are written by some of the leading contributors to the field, and will be of relevance to students, practitioners, and researchers from a wide range of disciplines, including prosthetics and orthotics, occupational therapy, physiotherapy, rehabilitation medicine, engineering, nursing, and psychology. In addition, as it is equally important that the psychosocial aspects of prosthetic use are taken into consideration at all stages, including prosthetic design and application, we hope that this book will also be a valuable resource for the many manufacturers of prosthetic devices.

Contributors are well-established clinicians, practitioners, researchers, and academics who work with people who use prosthetic devices. We encouraged contributors to structure their chapters around a common framework to facilitate the reading of chapters on a stand-alone basis, in addition to recognizing the interplay between many of the themes running through the book. Contributors were asked to provide an overview of their specified area, outlining relevant issues and supplementing where appropriate with experience from practice. Each chapter also includes a brief outline of the literature relating to the identified area, which draws on clinical/practice literature in addition to the research literature, identifies upcoming research and practice issues, and speculates on the development of the area. Finally, each contributor provides a summary of the key points of their chapter, key terms and definitions for a glossary, and recommended reading including key books, research articles, and Web sites.

Chapter 1 places the purpose of the book in context and summarizes the content of each of the subsequent chapters in the book. Chapters 2 to 9 review key psychosocial issues such as coping, body image, pain, cognition, meaning, assessment, and interventions, and the role of societal and cultural factors. Chapters 10 to 12 look at some of the advanced technologies and related psychosocial issues and interventions.

We would like to express our heartfelt thanks to the people who enabled this venture to proceed and progress. In particular, we would like to thank all at Springer for their vision, patience, and assistance, most especially Grant Weston and Hannah Wilson. We are also indebted to all the contributors who gave willingly of their time, experience, and expertise in contributing to the book; we greatly appreciate it.

Pamela Gallagher, Deirdre Desmond, and Malcolm MacLachlan
Dublin, Ireland, November 2007

Contents

List of Contributors

Jay Behel, PhD
Assistant Professor, Department of Behavioral Sciences, Rush University Medical Center, Chicago, IL, USA

Rickard Brånemark, MD, PhD
Department for Prosthetics and Orthotics and Department of Orthopaedics, Sahlgrenska University Hospital, Gothenburg, Sweden

Jonathan Cole, DM, FRCP
Honorary Senior Lecturer in Clinical Neurosciences at the University of Southampton, Professor at the University of Bournemouth, and Consultant in Clinical Neurophysiology in Poole and Salisbury Hospitals, UK

A. Barry Deathe, MD, FRCPC
Professor Emeritus, Department of Physical Medicine and Rehabilitation, University of Western Ontario, London, Ontario, Canada, and Medical Director, Southwestern Ontario Regional Amputee Programme, Parkwood Hospital, SJHC, London, ON, Canada

Deirdre Desmond, BA, DipStat, PhD
Lecturer, Department of Psychology, National University of Ireland, Maynooth, Co. Kildare, Ireland, and Dublin Psychoprosthetics Group, Ireland

Michael Devlin, MD, FRCPC
Assistant Professor, Division of Physiatry, Department of Medicine, University of Toronto, Toronto, Ontario, Canada, and Physiatrist, Amputee Rehabilitation Services, West Park Healthcare Centre, Toronto, ON, Canada

Dawn M. Ehde, PhD
Associate Professor, Department of Rehabilitation Medicine, School of Medicine, University of Washington, Seattle, WA, USA

Pamela Gallagher, BA Mod, DipStat, PhD
Senior Lecturer in Psychology, Faculty of Science and Health, School of Nursing, Dublin City University, Dublin, Ireland, and Dublin Psychoprosthetics Group, Ireland

Kerstin Hagberg, RPT, PhD
Department for Prosthetics and Orthotics and Department of Orthopaedics, Sahlgrenska University Hospital, Gothenburg, Sweden

Eva Häggström, CPO
Department for Prosthetics and Orthotics and Department of Orthopaedics, Sahlgrenska University Hospital, Gothenburg, Sweden

Jackie S. Hebert, MD, FRCPC
Assistant Professor, Division of Physical Medicine and Rehabilitation, University of Alberta, Edmonton, Alberta, Canada and Clinical Director, Adult Amputee Program, Glenrose Rehabilitation Hospital, Edmonton, Alberta, Canada

Susan Hofkamp, PhD
Department of Physical Medicine and Rehabilitation, School of Medicine, Johns Hopkins University, Baltimore, MD, USA

Stewe Jönsson, CPO
Department for Prosthetics and Orthotics and Department of Orthopaedics, Sahlgrenska University Hospital, Gothenburg, Sweden

Malcolm MacLachlan, BSc, MSc, MA, PhD, DipBA, FPSI, FTCD, MRIA
Associate Professor, School of Psychology, Trinity College, University of Dublin, Ireland, and Dublin Psychoprosthetics Group, Ireland

Seth D. Messinger, PhD
Department of Sociology and Anthropology, University of Maryland, Baltimore County, MD, USA

William C. Miller, PhD, OT
Associate Professor, School of Rehabilitation Sciences, University of British Columbia, Vancouver, British Columbia, Canada, and Scientist, GF Strong Rehabilitation Research Laboratory, Vancouver Coastal Health Research Institute, Vancouver, British Columbia, Canada

Craig D. Murray, PhD
School of Psychological Sciences, University of Manchester, UK

Sinéad Ní Mhurchadha, BA, MSc Health Psychology
Faculty of Science and Health, School of Nursing, Dublin City University, Dublin, Ireland, and Dublin Psychoprosthetics Group, Ireland

Brian O'Neill, DClinPsych
Clinical Psychologist, West of Scotland Mobility and Rehabilitation Centre, Southern General Hospital, Glasgow, Scotland, UK

Luljeta Pallaveshi, RN, LLA
Research Assistant, Aging, Rehabilitation and Geriatric Care Program, Lawson Health Research Institute, London, ON, Canada

Bruce Rybarczyk, PhD
Associate Professor, Department of Psychology, Virginia Commonwealth University, Richmond, VA, USA

Björn Rydevik, MD, PhD
Department for Prosthetics and Orthotics and Department of Orthopaedics, Sahlgrenska University Hospital, Gothenburg, Sweden

Elisabeth Schaffalitzky, BA
Faculty of Science and Health, School of Nursing, Dublin City University, Dublin, Ireland, and Dublin Psychoprosthetics Group, Ireland

Stephen T. Wegener, PhD
Associate Professor, Department of Physical Medicine and Rehabilitation, School of Medicine, Johns Hopkins University, Baltimore, MD, USA

Dalton L. Wolfe, PhD
Research Associate, Aging, Rehabilitation and Geriatric Care Program, Lawson Health Research Institute, London, ON, Canada, and Adjunct Professor, Bachelor of Health Sciences Program and Department of Physical Medicine and Rehabilitation, University of Western Ontario, London, ON, Canada

1

Psychoprosthetics: An Introduction

Pamela Gallagher, Deirdre Desmond, and Malcolm MacLachlan

Overview

Psychoprosthetics is the study of psychological aspects of prosthetic use and of rehabilitative processes in those conditions that require the use of prosthetic devices. Central to this definition is an emphasis on the individual experience of the person with limb loss and the inclusion of personal perspectives and preferences across the continuum of care. This demands an exploration of psychological, neurological, social, cultural, and environmental factors inherent in the experience of limb loss, in addition to physical factors. For the past 10 years our focus has been on the ways in which people cope with limb loss, positive adjustment, affective distress, issues around identity, body image, the construction of self, and quality of life. We have also emphasized the development of appropriate assessment tools with a view to establishing quality benchmarks and promoting high-quality care. We are interested in psychoprosthetics for a number of reasons, but most notably because a more comprehensive understanding of the psychological and social realities of limb loss and prosthetic use will contribute to a holistic rehabilitation and limb-fitting experience and the optimization of ongoing care for the person. An interdisciplinary approach—psychoprosthetics—presents exciting challenges, breaking through conventional disciplinary boundaries and calling for imaginative explorations of the interplay between people and the technologies that can enable their psychological, social, and physical functioning. It is often at the boundaries of established knowledge, at the interface of where different disciplines meet, that some of the most exciting and enlightening insights and discoveries occur.

Epidemiology of Limb Loss

People with an amputation, stemming from a multitude of causes, mainly through complications of diabetes mellitus, peripheral vascular disease, trauma, and malignancy, represent a sizable number of people worldwide who require some form of health intervention or service provision, including being supplied with and trained to use prostheses. According to Esquenazi (1), a calculation of the exact number of people who have had amputations worldwide is rendered difficult by the fact that many countries do not keep records. In the United States, the Amputee Coalition of America (2) reports that there are approximately 1.9 million people living with limb loss, and Dillingham et al. (3) estimated that 158,000 persons (or 52.4/100,000 persons) undergo amputations per annum. The Amputee Statistical Database for the United Kingdom (4) reports annually on new referrals to 44 prosthetic service centers throughout the U.K. The latest report indicates that there were 5000 new referrals in their most recent reporting period from April 1, 2005, to March 31, 2006. To give a sense of gender, age, type, and cause of limb loss, females accounted for just over 30% of these new referrals; 54% of all referrals were over 65 years of age, and 25% were over 75. Only 3% of new referrals were younger than 16 years of age. With regard to type, 91% were referrals following lower limb amputation, 5% were referrals following upper limb amputation, and 3% were referrals for congenital absence cases. Trauma accounted for 53% of upper limb referrals, neoplasia 14%, dysvascularity 12%, and infection 6%. For lower limb referrals, dysvascularity accounted for 67%, trauma 9%, infection 7%, and neoplasia 3%. According to Ephraim et al. (5), limb loss has been internationally acknowledged as a significant public health issue, yet the development of programs and policies aimed at promoting health and well-being among people with limb loss requires a more extensive research knowledge base.

Foregrounding Personal Experience

Limb loss is a human experience. Many aspects, including those related to the limb loss itself, such as type, level, cause, and presence of comorbidities, conspire to give rise to the individual experience of having and wearing a prosthetic limb. We are concerned with the whole person and his or her collection of psychological and social experiences. Psychology is a medium through which subjective lived experiences can be foregrounded. Furthermore, psychology is a medium through which multifactorial explanations for psychological phenomena are sought; psychological explanations for physiological, social, or cultural phenomena are found; and phenomena are described and understood, and their meaning for the person ascertained (6).

Psychologically based issues include not just advocating and developing interventions to bring about change for the person, but also recognizing the changes that often occur within the person, and, crucially, that there is an emotional component to such experiences. Darnall et al. (7), in a sample of community-dwelling individuals with limb loss, found that the prevalence of depressive symptoms was two to four times greater than rates for the general population. Their findings identified the significance of social support in psychological interventions and of sociodemographic variables (e.g., marital status, household poverty level, level of education) as significant predictors of depressive symptomatology. Taking into consideration psychosocial issues can also enhance functional outcome. Fitzpatrick (8) notes that loss of ability to relate psychologically, socially, sexually, and vocationally after amputation might have more impact on quality of life than the loss of the limb itself. As a final exemplar of placing the whole person center stage, Pasquina et al. (9) stipulate that prosthetic prescriptions should be individualized based on the functional capacity and goals of the person with limb loss.

Psychology, Disability, and Rehabilitation

We recognize that in the past, psychology has been linked with a pathogenic or deficit model of disability, and has often paid insufficient attention to a more socially orientated model, one that addresses aspects of the environment—psychological, social, and physical—that disable and oppress some people more than others. Our concern with understanding the psychology of people with limb loss and how they manage prosthetic technology is in no way an attempt to pathologize limb loss, to normalize impairment, or to suggest that a person conforms to a norm. It is also not our intention to subjugate the significance of the physical environment in a person's experience, but rather we wish to acknowledge that irrespective of the hypothetical presence of an ideal enabling environment, there is an individual who, following an amputation, is living with a new reality, and part of this reality is living with a prosthesis. We acknowledge the importance of the person's internal experiences, thoughts, and emotional well-being, in addition to their interactions with the environment, as others are increasingly doing (see, for example, Shakespeare and Watson (10)).

Contemporary disability paradigms emphasize the dynamic intersection of environmental factors and individual characteristics and the role this plays in shaping the disability experience (11). The International Classification of Functioning, Disability, and Health (ICF) attempts to integrate the medical and social models of disability, incorporating biological, individual, and societal perspectives in a biopsychosocial approach (12). So, for instance, two people with similar body structures and functions may differ in their experience of disability (e.g., ability to perform tasks or participate in society and life activities) because of different personal (e.g., age and gender) or environmental (e.g., enabling technology) factors. Dijkers et al. (13) argue that social outcomes should be more routinely included in disability and rehabilitation research. The importance of social outcomes to persons with disabilities is emphasized by a meta-analysis finding that subjective quality of life is related to social participation more strongly than to activities of daily living or impairment (14). There are also a number of international policy developments that emphasize the importance of participation and involvement in life situations. "Participation restriction," according to the World Health Organization (WHO) (11), refers to problems an individual may experience in involvement in life situations. According to Cardol et al. (15), a thorough assessment of perceived restriction(s) in participation is essential to understand the social impact of chronic illness on a person's life and to be able to offer tailored rehabilitation programs according to individual needs.

It is acknowledged that the environment is an important determinant of disability. As reflected in the ICF, policy, services and systems, social supports, attitudes, products and technology, in addition to the physical environment, contribute to the experience of disability and impede participation. The greater extent to which environmental barriers are removed or reduced, the greater likelihood that individuals with limb loss will be enabled to participate fully in their life activities. Indeed, Ephraim et al. (16) found that perceived environmental barriers among individuals with limb loss were highly prevalent as assessed by the Craig Hospital Inventory of Environmental Factors-Short Form (CHIEF-SF) (17), which addresses five domains: policies, physical/structural, work/school, attitudes/support, and services/assistance. In particular, individuals with limb loss reported the greatest perceived barriers in the physical/structural environment. Furthermore, when compared with a sample of nondisabled individuals, a greater proportion of individuals with limb loss reported persistent perceived barriers in all environments except the work/school domain.

Positive Psychology and Prosthetic Enablement

Within psychoprosthetics, we espouse the principles of positive psychology and strongly support the notion that limb loss is not inevitably distressing or tragic. For instance, it may be a welcome relief from chronic pain endured over many years. However, even when it does occur in tragic circumstances, such as a lifesaving procedure following a motor vehicle accident, positive psychology promotes the building, reinforcing, and extending of person's strengths and capacities to optimize (as opposed to normalize) their functioning in all aspects of their life and thereby promote wellness (18). Naturally, readjusting to life postamputation is likely to be challenging for most people. The evolving physical and psychosocial consequences may, at least temporarily, challenge the individual's ability to maintain emotional well-being, a positive sense of identity, and previous relationships, resulting in poor psychosocial adjustment. Hence, much of the postamputation research understandably concerns itself with its most distressing aspects. However, an exclusive emphasis on the negative consequences of amputation belies the possibility for positive meaning and growth in the amputation experience and the ability to continue to optimally participate in life activities as desired and to get on with one's life. There is considerable scope for research on factors that enhance or promote positive adjustment to amputation and for the development of appropriate brief interventions to improve quality of life after amputation. As prosthetics and other assistive devices often play key roles in enabling the life of the individual with an amputation, personally appropriate prosthetic provision has tremendous potential to contribute to positive adjustment (19).

According to Murray (20), when we deny the psychological reality of others, our capacity for empathy is forfeited. Similarly, what we know influences what we say and do in practice. Consequently, understanding some of the psychosocial issues intrinsic to prosthetics and rehabilitation provides the potential not only of greater empathy, but also—and perhaps more importantly—of greater utility, from the perspective of the users of prosthetic devices. As we will see in later chapters, psychoprosthetics contributes to an understanding of how people cope and adjust to limb loss, issues of body image, pain, cognition, assessment, interventions, culture, and embodiment. We now briefly review some of the issues highlighted in these chapters.

Chapter Previews

Chapter 2, written by Deirdre Desmond and Pamela Gallagher, addresses the role of coping processes in adjustment to amputation. The stress-coping paradigm offers a framework for understanding how individuals manage their amputation and its consequences and may be useful in explaining adjustment differences among individuals with amputations. Although limb amputation can lead to significant psychosocial dysfunction among some individuals, many others adjust and function well despite numerous physical and psychosocial threats and challenges. Desmond and Gallagher introduce key concepts in the stress-coping model before summarizing critical issues in coping assessment and reviewing the nascent body of amputation coping research. Distinguishing between research addressing coping with amputation in general and research specifically addressing coping with postamputation pain, phantom limb pain in particular, they conclude by offering suggestions for future development and exploration in the area.

The impact of limb loss/absence on physical appearance renders an understanding and awareness of body image an integral component of the rehabilitation process. Bruce Rybarcyzk and Jay Behel in Chapter 3 draw on evidence from their own clinical practice and the research literature to explore the relationship between body image and each of the amputation-specific factors (e.g., type, level, cause, presence of pain), prosthetic factors, upper extremity amputation, psychological adaptation, developmental issues, and social perceptions. We are reminded that body image is not simply about our body's static appearance, but also about the sense of our bodies in action, that is, the kinetic aspect of body image. In restoring function, prosthetic rehabilitation may result in a different gait or a slower pace. Rybarcyzk and Behel argue for the importance of reconciling preamputation kinetic representations of the self with new ways of functioning, so as to achieve the optimal adjustment process. Furthermore, they state that postamputation, there are two body images that individuals need to adapt to: (1) their body image with a prosthesis, and (2) their body image without a prosthesis. Each of these in turn can be a social or private experience.

There are also the actual or perceived social stigmas relating to disability and assistive technology. Indeed, the perceived responses of those in the social sphere of the person experiencing the limb loss play an important role in the person's resultant sense of self and their body image. Rybarcyzk and Behel state that the preamputation body image is continuously challenged with ongoing new information about the self to which it must adapt. Although it is acknowledged that most people who experience limb loss ultimately develop a healthy body image, drawing on their collective clinical experience, they introduce the reader to three categories of individuals—instant accepters, distorters, and deniers—each of whom, they argue, display particular adjustment challenges. They conclude their chapter with the recommendation that given the potential increase in the number of amputations in the coming years, more longitudinal research with standardized measures and representative samples is warranted. They argue that there is much to be learned from the fact that the majority of people eventually integrate the loss of a limb into their self-concept. Exploring this further would facilitate a strengths-based approach.

Chapter 4, written by Dawn Ehde and Stephen Wegener, addresses the common experience of pain that follows amputation. The chapter starts with definitions of acute and chronic pain, phantom limb pain, nonpainful phantom limb sensations, and residual limb pain, and introduces the notion of pain as a multidimensional experience incorporating not only location and intensity but also frequency, duration, affect, and interference with activities and participation. The prevalence of the different types of pain postamputation, including pain in other anatomical regions such as the back and nonamputated limb, is detailed, as is the impact of pain on functioning and quality of life. Here, although the potentially pervasive and distressing nature of pain is elucidated, it is equally acknowledged that the experience of pain is not universally associated with distress or disability. The chapter continues by identifying the importance of a biopsychosocial perspective for understanding the pain experience after amputation and discussing the biopsychosocial correlates of pain after amputation. These include biological correlates (e.g., preamputation pain, acute pain severity, time since amputation, etiology of pain, level of amputation, and prosthetic use), psychological correlates (e.g., cognitive factors such as perceived control and catastrophizing, coping strategies, and acceptance of pain) and the social-environmental correlates (e.g., social support, and solicitous responses by others). Standardized instruments for the clinical assessment for pain are outlined, and this is followed by a review of pain interventions, with emphasis on psychosocial interventions (e.g., self-hypnosis training, relaxation, cognitive-behavioral therapy, and self-management approaches). Ehde and Wegener conclude their chapter with a series of questions to help guide future developments in an area that warrants significant ongoing attention.

The important, albeit relatively undocumented, role of cognitive ability in prosthesis use is addressed in Chapter 5, written by clinical psychologist Brian O'Neill from the West of Scotland Mobility and Rehabilitation Centre. Mobility rehabilitation after lower limb amputation is physically and cognitively demanding, as the person needs to acquire new skills such as transferring, standing, and walking without the proprioceptive feedback of the lost limb, and donning and removing the prosthesis. Donning a transtibial prosthesis and standing from a wheelchair is clearly delineated as a complex sequence of behaviors consisting of 12 steps, and it becomes evident that the presence of cognitive deficits compromises ideal rehabilitation outcomes. This is compounded by the fact that the most common etiology of lower limb amputation in high-income countries is peripheral arterial disease. The pathology of the condition is common to the continuum of vascular disorders affecting cerebrovascular function and leading to impairments in cognition. O'Neill demonstrates an important relationship among cognition, cognitive impairment, and prosthetic rehabilitation outcome, and illustrates how this could be utilized to a greater extent to maximize beneficial outcomes following amputation in an older adult population. Overall, he asserts that the case for assessing cognition postamputation is strong and allows for realistic goal setting and support.

The issue of assessment is integral, as exploring the psychosocial issues in a standardized and systematic way facilitates the selection of appropriate interventions. Indeed, Heinemann ([21]) stipulates that routine measurement of outcome facilitates clinicians in documenting the results of their interventions, provides a valuable medium through which to develop standardized clinical practices, guides clinical decisions regarding care, and benchmarks outcome standards. The importance of appropriate measurement emerges in many of the chapters; for example, Rybarcyzk and Behel in Chapter 3 address the need for standardized assessment of body image, Ehde and Wegener in Chapter 4 address the need for standardized measurement of pain, and O'Neill in Chapter 5 discusses the importance of appropriate assessment of cognition.

This theme is developed further in Chapter 6 by Dalton Wolfe and colleagues, who describe and critique outcome assessment tools used in the measurement of psychosocial adaptation to lower limb amputation. This comprehensive review of the evidence for reliability, validity, and responsiveness of measurement instruments in four psychological adjustment domains (cognitive affective responses, behavioral responses, specific adjustment problems, and health-related quality of life) highlights the continuous and evolving nature of the process of psychometric validation, outlines key developments to date, and points to the substantial scope for further research in this domain. Wolfe and colleagues provide a clear and considered evaluation of available instruments and highlight issues to consider when selecting measurement instruments and furthering their development.

Outside of the focus adopted in Chapter 6, and therefore not included in it, are assessment tools that look at coping. However, issues to consider in coping assessment are described in Chapter 2, together with a brief overview of the coping instruments most commonly used in amputation coping research. Furthermore, Wolfe et al. do not include in their chapter tools specific to people with an upper limb prosthesis. As documented elsewhere, there is significantly less published research concerned with people with upper limb loss as compared with research concerned with people with lower limb loss. This reflects the smaller proportion of people with upper limb prostheses compared to people with lower limb prostheses attending limb-fitting services. However, this translates into the limited availability of outcome measures specifically for upper limb loss and prosthetic use. Such measures include the Trinity Amputation and Prosthesis Experience Scales (TAPES)-Upper (22), the Orthotics and Prosthetics Users' Survey (OPUS) (23), the Disabilities of the Arm, Shoulder and Hand (DASH) (24), and the Prosthetic Upper-Extremity Functional Index (PUFI) for use with children (25). As a result of the differences in visibility, the functional roles of the upper and lower limbs, their role in social and expressive communication, and the different extent to which a sense of self may be embodied in them (22,26), what are seen as meaningful outcomes are likely to differ for people with lower limb and upper limb prosthetics. Hence, it cannot be assumed that outcome measures used with one group will automatically be applicable to another.

In Chapter 7, Stephen Wegener, a clinical psychologist based at John Hopkins University, addresses, with colleagues, the rehabilitation team and how it can employ interventions to address psychosocial issues arising in people with limb loss. They put forward a number of guiding principles to facilitate greater attentiveness to the psychosocial aspects of limb loss and to improve outcomes of care. These include adopting a biopsychosocial approach that attaches importance to the biological, psychological, and social dimensions of limb loss; patient-centered care and the goal of increasing self-efficacy and activation, acknowledging that psychopathology after limb loss is the exception, not the norm; and recognizing and building on the individual's strengths. They subdivide the clinical issues for psychological interventions into four broad categories: (1) affective disturbances including depression, anxiety, and posttraumatic stress disorder; (2) intrapersonal issues such as body image; (3) interpersonal issues such a social stigma and intimacy/sexuality; and (4) substance use. They argue that attention to psychosocial health is a responsibility shared by all members of the rehabilitation team beginning with the individual and family and including clinicians who are not formally identified as mental health professionals.

To this end, Wegener et al. propose a model for team involvement in psychological care, the PLISSIT model (permission, limited information, specific suggestions, and intensive therapy), which identifies different types of interventions based on the needs of the patients and the skills and training of the clinicians. The "permission" level of care is concerned with introducing and integrating psychological care in the clinical setting. The clinician providing permission grants an opportunity for psychosocial issues to be discussed. "Limited information" is concerned with self-management and patient education (e.g., peer support, peer mentoring, and self-management approaches), whereas "specific suggestions" refers to useful psychological and behavioral strategies to address a particular issue (e.g., relaxation training; effective coping strategies that decrease avoidance coping and catastrophizing and increase active coping; assertiveness training; problem solving; and behavioral activation of pleasant activities, encouraging positive emotions via activities and social connections). The final stage relates to "intensive therapy" for more severe symptoms that have not been alleviated with other interventions, and incorporates motivational interviewing, psychotherapy, cognitive behavioral therapy, medication, and effective consultation. This is a useful model to explore the different types of potentially useful interventions depending on the person's readiness to engage and their needs. It highlights that psychosocial issues are not solely the remit of the psychologist, counselor, or social worker.

Seth Messinger, an anthropologist working at the University of Maryland–Baltimore County, contributes Chapter 8, which helps us to stand back from the everyday action of prosthetic fitting and rehabilitation and to reflect on the broader sociocultural processes at play. His chapter explores the idea of individuals inhabiting three bodies: an individual body, through which one has personal physical experience; a social body, through which one experiences social and cultural attitudes toward different sorts of bodies (for example, disabled bodies); and a body politic, through which one experiences the regulatory forces of society (such as regarding appropriate and inappropriate sexual behavior) but also its political economy (who is entitled to what health care, for what reason, for how long, and who should pay for it?). Of course, the body politic is a metaphor and within this context Messinger explores how prosthetics are interpreted as cultural symbols: what they imply for their users—outcast or war hero; objects of pity or of wonder?

Messinger's account of his work at Walter Reed Army Medical Center is of particular interest because the veterans with amputations there are considered a very special group—and a group for whom it is important (not just personally but also politically) that their amputation not be associated with loss. Here the aim is to return soldiers to their preinjury level of ability, and perhaps even to combat readiness. Textured through Messinger's account of this work is a sense, again symbolically, that an individual's loss of potency must not be read as a metaphor for a nation's loss of potency; yet the broader social and political context of debate regarding American-led coalition forces in Afghanistan and Iraq makes this an unspeakable reality. It is argued that the resources provided at Walter Reed are so good, with the highest specification prosthetic devices being available, that the "body politic" cannot (must not) be seen as failing—the stigma associated in the United States with being a loser is perhaps therefore being channeled through the "social body" (cultural lens) as being due to individual characteristics, rather than institutional or political ones. How veterans navigate and negotiate their way through the rehabilitation process at Walter Reed, as simultaneously clinical patients and research participants, engaged in a rehabilitation social matrix of professional and personal relationships, and as American citizens whose access to health and enablement is structured by political opportunities and realities, is the focus of Messinger's ongoing research. While the Walter Reed example brings personal, social, and political factors into sharp focus, these factors do of course pattern prosthetic provision in all other contexts too.

The relationship between prosthetic use and a sense of embodiment is explored by Craig Murray in Chapter 9. He notes that while prosthetic devices have an obvious role in restoring function, their significance as objects that are incorporated into personal and bodily identification, and which have a personal meaning, has been much less researched. Murray defines embodiment as the way in which individuals experience their own body, and thus it considers how bodily attachments affect this experience. Murray explores the phenomenology of this concept through extracts from interviews with prosthetic users. He also points out that while a prosthesis may be intended to replace a natural function (for instance, ambulation), there is nothing natural about the process of learning to use it; and yet with perseverance its naturalness may be associated with the extent of the user's sense of its embodiment.

The meaning of a prosthetic device is rooted in the broader social-cultural context in which the user lives and Murray develops this argument into a consideration of how different cultural readings of prosthetic use have different implications for the user. He also tells us of a cringe-making instance of cultural bias where a black women with an amputation was told, "We only do feet in pink"! While such crass examples are, of course, easily recognized, Murray's emphasis is in fact on the more subtle social and cultural readings of amputation, including the stigma associated with disability. This chapter, ranging from proximate personal readings of a prosthesis to more distant cultural readings—and recognizing that these influence each other—sharpens our attention to the importance of personal experiences and understandings of prosthetic use.

There are other interpretations of "embodiment" than the one given by Murray. For instance, MacLachlan (26) has suggested that embodiment may also include identification with objects that have a personal meaning, but which are not necessarily attached to the body, or indeed part of bodily experience, as such. This might include a book, a ring, a house, or any object with strong personal meaning. Thus a prosthetic limb, lying in a corner, may continue to embody a person's sense of identity and sense of ability or disability, even when it is not attached. In essence, prosthetic limbs are objects onto which people may project their values, fears, and wishes, just as they do onto their own body when they seek to be slim, or blonde, or tanned.

There is some interesting overlap in the chapters of Murray and Messinger, the former from the perspective of a psychologist and the latter an anthropological viewpoint. However, both are intent on promoting the individual's integration of the prosthesis into one's sense of self and the manner in which social and cultural influences impinge on this experience. This argument is developed further by Kerstin Hagberg et al. in Chapter 10, where it is noted that some individuals with an osseointegrated prosthesis feel that it is more like a natural part of the body than a socket prosthesis. Indeed, some of the discussion emerging in the chapters of Messinger and Murray regarding prosthetic embodiment could provide a tentative explanation for this. An osseointegrated prosthesis, that is, an artificial limb attached to the bone as an extension of the residual skeleton, may feel more like a natural part of the body. This may be because it is easier to use, with less physical and mental effort required to complete a task, and greater tactile feedback via the phenomenon of osseoperception. Such factors may therefore enable greater assimilation and integration of the prosthesis into the individual's sense of self.

Osseointegrated prostheses are a relatively innovative development in the field of prosthetics for individuals with an amputation not arising through serious peripheral vascular disorder. While the concept has been in existence for half a century, it is only in the past decade that it has emerged as a realistic alternative to socket prostheses. This movement has been pioneered in Sahlgrenska University Hospital, Gothenburg, Sweden. Consistent with best practice, the team pioneering this innovation has subjected it to ongoing evaluation over a 2-year follow-up period to clearly elucidate its advantages and have identified the importance of the potential psychosocial impact. To date, initial findings are positive, and this chapter, in particular, focuses on the improvements in quality of life and osseoperception, and the identification of tactile thresholds transmitted through the implant. Indeed, Hagberg et al. stipulate that osseoperception is integral for improved prosthetic function and the reduction in feelings of being disabled. They indicate that there is much scope to develop this perception of vibrations further to include artificial sensation, for example, thermal sensors in prosthetic fingers that would vibrate at different frequencies depending on the temperature. It is an exemplar of the person/technology interface and how advances in prosthetic technology have impacts on the person, above and beyond physical capabilities, into the psychosocial sphere of influence. It is also an exemplar of exploring the psychosocial outcomes of innovative procedures in the field of prosthetics.

In Chapter 11, Jonathan Cole details the confluence of theoretical and empirical observations leading to the application of emerging virtual and augmented reality technologies to phantom limb experience. Beginning with consideration of the role of visual and sensorimotor interactions and neuroplasticity in phantom limb pain, Cole explores the possible relations between loss of agency toward the missing limb and subsequent pain experience. Using Ramachandran's simple, but ingenious, mirror box experiments as a starting point, Cole describes how a variety of research groups have restored a sense of agency to the amputated limb utilizing visual feedback in virtual or augmented reality environments. In some instances the restoration of agency is accompanied by distinct sensations including pain reduction. Although Cole cautions that this research is at a very early stage, he argues that the findings suggest reconsideration of theories for sensorimotor integration and pain may be required.

The social role of the prosthesis, and the psychosocial meanings attached to it, impact on the use of the prosthetic limb. For example, the social role of the prosthesis can potentially play an even greater role than the functional and cosmetic roles of the prosthesis in its use, with users choosing to wear their prosthesis when they are not functional or cosmetic, or even comfortable, in certain social situations. The ability of the prosthesis to conceal limb loss and to navigate a disabling environment, which decreases stigma (whether perceived or actual), enables social integration and participation in life activities, and reduces the impact of barriers in the environment. Due to the ongoing development and advancement in prosthetic technology, there is an increased choice in the type, specification, and expense of the available prosthetic technology. It is important to understand how the experience of using a prosthesis affects the perception of self within an individual and social context, and also how the prosthesis is viewed in relation to alternative prosthetic options. This issue enables a greater match between the technology and the needs of the person (see Scherer ([27])). Sinéad Ní Mhurchadha et al. in Chapter 12 introduce the reader, via an illustrative case study, to a simple interview methodology, the repertory grid, which can be used to address the above issues for any individual. The repertory grid proves a sort of "psychological x-ray," illuminating both an individual's explicit and implicit values regarding, in this case, prosthetic use and choice. As with all forms of assessment, the repertory grid provides a snapshot of a person's experience, at a given point in time, and should be used in conjunction with other forms of assessment (for instance, standard clinical interviews, physical assessment, and psychometric measures), so that results can be triangulated, and thus give a multiperspective impression of the challenges and aspirations of the prosthetic user.

Conclusion

Overall, the chapters in this volume offer an informative and engaging account of the psychosocial issues encountered by those who use prosthetic devices, and those who work with people who use prosthetic devices, particularly prosthetic limbs. The contributors identify many exciting avenues for future work in psychoprosthetics: high-technology interventions; measuring, predicting, and facilitating the individual's responses to rehabilitation; and understanding broader sociocultural constructions of prosthetics and disability. We hope that the foundations of an interdisciplinary approach to psychoprosthetics, as outlined in this book, will make an important contribution to an evidence base that guides more effective rehabilitative practice. We are also aware that psychoprosthetics, being at a critical junction of mind–body technology interfaces, may also provide insights into profound and enduring philosophical debates and challenges.

Further Reading

www.tcd.ie/psychoprosthetics Dublin Psychoprosthetics Group: www.tcd.ie/psychoprosthetics

References

1. Esquenazi A. Amputation rehabilitation and prosthetic restoration. From surgery to community reintegration. Disabil Rehabil 2004;26(14–15): 831–836.
2. National Limb Loss Information Center Fact Sheet. Amputation Statistics by Cause. Limb loss in the United States. http://www.amputee-coalition.org/fact_sheets/amp_stats_cause.html.
3. Dillingham TR, Pezzin LE, MacKenzie EJ. Limb amputation and limb deficiency: epidemiology and recent trends in the United States. South Med J 2002;95(8):875–883.
4. National Amputee Statistical Database (NASDAB). The Amputee Statistical Database for the United Kingdom 2005/06. Edinburgh: Information Services Division, NHS Scotland, 2007.
5. Ephraim PL, Dillingham TR, Sector M, Pezzin LE, Mackenzie EJ. Epidemiology of limb loss and congenital limb deficiency: a review of the literature. Arch Phys Med Rehabil 2003;84(5):747–761.
6. Möller A, Nyman E. Why, what and how?—Questions for psychological research in medicine. Disabil Rehabil 2005;27(11):649–654.
7. Darnall BD, Ephraim P, Wegener ST, et al. Depressive symptoms and mental health service utilization among persons with limb loss: results of a national survey. Arch Phys Med Rehabil 2005;86(4):650–658.
8. Fitzpatrick M. The psychologic assessment and psychosocial recovery of the patient with an amputation. Clin Orthop Rel Res 1999;361;98–107.
9. Pasquina PF, Bryant PR, Huang ME, Roberts TL, Nelson VS, Flood KM. Advances in amputee care. Arch Phys Med Rehabil 2006;87(3 suppl 1): S34–43.
10. Shakespeare T, Watson N. The social model of disability: an outdated ideology? Res Soc Sci Disabil 2001;2:9–28.
11. World Health Organization. International Classification of Functioning, Disability and Health. Geneva: WHO, 2001.
12. Peterson DB. International Classification of Functioning, Disability and Health: an introduction for rehabilitation psychologists. Rehabil Psychol 2005;50(2):105–112.
13. Dijkers MPJM, Whiteneck G, El-Jaroudi R. Measures of social outcomes in disability research. Arch Phys Med Rehabil 2000;81(S2):S63–S80.
14. Dijkers M. Quality of life after spinal cord injury: a meta analysis of the effects of disablement components. Spinal Cord 1997;35:829–840.

15. Cardol M, de Jong BA, van den Bos GAM, Beelen A, de Groot IJM, de Haan RJ. Beyond disability: perceived participation in people with a chronic disabling condition. Clin Rehabil 2002;16:27–35.
16. Ephraim PL, MacKenzie EJ, Wegener ST, Dillingham TR, Pezzin LE. Environmental barriers experienced by amputees: The Craig Hospital Inventory of Enviromental Factors—Short Form. Arch Phys Med Rehabil 2006;87:328–333.
17. Craig Hospital Research Department. Craig Hospital Inventory of Environmental Factors (CHIEF) manual, version 3.0. Englewood, CO: Craig Hospital, 2001.
18. Naidoo P. Potential contributions to disability theorizing and research from positive psychology. Disabil Rehabil 2006;28(9):595–602.
19. Gallagher P, Desmond D. Exploring psychoprosthetics. InMotion 2006;16(6):18–20.
20. Murray P. Being in school? Exclusion and the denial of psychological reality. In: Goodley D, Lawthorm R, eds. Disability and Psychology: Critical Introductions and Reflections. Basingstoke Hampshire, UK: Palgrave Macmillan, 2006: 34–41.
21. Heinemann AW. Putting outcome measurement in context: a rehabilitation psychology perspective. Rehabil Psychol 2005;50(1):6–14.
22. Desmond DM, MacLachlan M. Factor structure of the Trinity Amputation and Prosthesis Experience Scales (TAPES) with individuals with acquired upper limb amputations. Am J Phys Med Rehabil 2005;84(7):506–513.
23. Heinemann AW, Bode RK, O'Reilly C. Development and measurement properties of the Orthotics and Prosthetics Users' Survey (OPUS): a comprehensive set of clinical outcome instruments. Prosthet Orthot Int 2003;27:191–206.
24. Beaton DE, Katz JN, Fossel AH, Wright JG, Tarasuk V, Bombardier C. Measuring the whole or the parts? Validity, reliability and responsiveness of the Disabilities of the Arm, Shoulder and Hand Outcome Measure in different regions of the upper extremity. J Hand Ther 2001;2(14):128–146.
25. Wright FV, Hubbard S, Jutai J, Naumann S. The Prosthetic Upper-Extremity Functional Index: development and reliability testing of a new function status questionnaire for children who use upper extremity prostheses. J Hand Ther 2001;14:91–104.
26. MacLachlan M. Embodiment: Clinical, Critical and Cultural Perspectives. Milton Keynes, UK: Open University Press, 2004.
27. Scherer MJ. The change in emphasis from people to person: introduction to the special issue on assistive technology. Disabil Rehabil 2002;24(1–3):1–4.

2

Coping and Psychosocial Adjustment to Amputation

Deirdre Desmond and Pamela Gallagher

Overview

Limb amputation confronts the individual with numerous physical and psychosocial threats and challenges including alterations in body image and self-concept, changes in employment status/occupation and lifestyle, impairments in physical functioning, disruptions to valued activities, prosthesis use, and pain (1,2). For many people the amputation of a limb may thus be considered a major stressful life event, characterized by evolving and recurrent stressors, which may pose significant challenges to physical, psychological, and social adjustment. Although limb amputation can lead to significant psychosocial dysfunction among some individuals, many others adjust and function well (3–5). Models describing influential factors in such variation implicate a complex interplay among risk factors, including disease/disability parameters, functional limitation, and psychosocial stressors; resistance or resource factors, including stress processing factors; intrapersonal factors; and social-ecological factors, such as social support and family environment (6,7).

Among these various factors contributing to variation in psychosocial adjustment to disability (6,8), a critical mediating role has been attributed to stress processing factors and the coping strategies individuals adopt to manage experiences associated with illness or injury (9–12). The stress-coping paradigm offers a framework for understanding how individuals manage their amputation and its consequences and may be useful in explaining adjustment differences among individuals with amputations. Using the stress-coping framework as a base, a number of researchers have investigated how individuals manage their amputation and its consequences (9,13–16). This chapter reviews this relatively limited but growing body of literature. The chapter begins with a brief, general introduction to concepts important in the stress-coping model. We then summarize critical issues in coping assessment, before reviewing amputation coping research.

Stress and Cognition

The basic premise of the stress-coping model is that people who are confronted with a potential stressor (in this case various aspects and consequences of amputation) evaluate the stressor, and this appraisal determines their emotional and behavioral reactions or coping responses (17). Thus, the stress process begins with awareness of change or the threat of change in the status of current goals and concerns. “Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing his or her resources and endangering his or her well being” (18, p. 19). Cognitive variables, that is, an individual’s beliefs and appraisals regarding a stressor, are critical mediators of person–environment relations. Beliefs and expectations about the controllability and consequences of a stressor may have a direct influence on mood, while appraisals may influence adjustment indirectly through their impact on coping efforts.

Coping and Coping Strategies

Although there is no universally accepted definition of coping, it has broadly been defined as “cognitive and behavioral efforts to manage specific external or internal demands (and conflicts between them) that are appraised as taxing the resources of a person” (19, p. 112). The dimensionality of coping responses has stimulated substantial theoretical and empirical enquiry (12,20). A classic bipartite classification proposed by Lazarus and Folkman (18) discriminates between problem-focused and emotion-focused coping. The former is action centered in that the person–environment relationship is altered by instrumental actions. The latter is mainly composed of cognitive coping strategies that do not directly change the situation but rather allow new meaning to be assigned, thereby changing the emotions associated with the stressful event (18,21,22). Emotion-focused coping includes engaging in distracting activities, using alcohol or drugs, or seeking emotional support, whereas making a plan of action and taking assertive action to solve the problem are forms of problem-focused coping (23). Within this framework coping is conceptualized as a fluid and dynamic process such that different coping strategies are employed in response to varying situational demands. The relationship between the person and environment evolves as a result of a dynamic interplay between coping strategies, changes in the environment, and changes in the individual (18).

In an extension of the classic Lazarus and Folkman (18) framework, Folkman (24, 25) suggests that when a problem cannot be resolved satisfactorily, meaning-based coping, a form of coping that specifically helps to develop and maintain a sense of psychological well-being in spite of difficult circumstances, may ensue. Positive psychosocial adjustment outcomes may result from four meaning-based coping mechanisms: cognitive reframing, goal-directed problem-focused coping, using spiritual or religious beliefs to seek comfort, and the infusion of meaning into ordinary events of daily life (24).

As an alternative to the dichotomy between problem-focused and emotion-focused coping, coping researchers in the area of chronic pain have categorized coping responses in terms of active and passive dimensions (26). Active coping strategies include requiring the person to take responsibility for pain management and to initiate attempts to control the pain or to function in spite of it. In contrast, passive strategies involve giving responsibility for pain management to an external force or allowing other areas of life to be adversely affected by pain (26). These coping dimensions have been associated with measures of behavioral and emotional adjustment to pain, functional disability, and pain ratings among individuals experiencing a variety of chronic pain syndromes (10,27–30).

Although these broad categorical descriptors are used extensively in the coping literature and provide a useful way of talking about many kinds of coping in general terms, Folkman and Moskowitz (23) caution that such categorization may also obscure important differences within categories. They contrast *distancing* (a form of coping in which the person recognizes a problem but intentionally attempts to put it out of mind) with *escape-avoidance* (an escapist flight that can include behaviors such as increasing alcohol consumption) noting that both strategies are avoidant forms of coping, typically grouped under the emotion-focused coping category. Distancing, however, is often adaptive in situations where individual control is limited, whereas escape-avoidance is usually a maladaptive approach to coping with the same situation. Clearly, this type of distinction is important to retain (23).

Conceptualizing Psychosocial Adjustment to Amputation

The terms *adjustment* and *adaptation* are often used interchangeably in the literature, and although they overlap, conceptually distinguishing features have also been highlighted (31). Livneh and Antonak (31) view adjustment as the final phase in the evolving process of adaptation and suggest it is characterized by (1) reaching and maintaining psychosocial equilibrium; (2) achieving a state of reintegration; (3) positively striving to reach life goals; (4) demonstrating positive self-esteem, self-concept, and self-regard; and (5) experiencing positive attitudes toward oneself, others, and the disability (32). Accordingly, adaptation is a dynamic process through which the individual gradually approaches an optimal state of person environment congruence (31).

The amputation literature evidences substantial diversity with respect to the conceptualization and operationalization of psychosocial adjustment (16). Indeed, frameworks for conceptualizing adjustment are not usually made explicit; rather, they are typically communicated through the particular outcome measures selected for use in studies addressing adjustment to amputation. Much of the research focuses on absence of psychological disorder as an indicator of favorable adjustment. Furthermore, difficulty in adjustment has typically been characterized in terms of negative affective reactions, most commonly in terms of depressive symptomatology (33,34). In recent years however, the dominance of pathology-based approaches has been tempered by emerging emphasis on resilience and adaptive psychological processes occurring following amputation (16,35). General appraisals of life satisfaction or appraisals of well-being across specific life domains, for example social participation, have also been used as indicators of positive adjustment (13). Here we consider the associations between coping and outcomes of adjustment in terms of psychological distress but also with reference to recent studies of psychological well-being and stress-related growth as indicators of successful coping with amputation. We are cognizant, however, that regardless of whether psychosocial maladjustment or psychosocial well-being is at issue, constructs such as depression or self-esteem, when considered in isolation, yield only a partial picture of adjustment.

Coping Assessment

In the coping literature at large, much of the research involves the use of self-report measures or inventories of coping. Numerous coping instruments have been developed to assess a variety of coping dimensions (36–40). However, consensus is lacking regarding the type and number of categories that should be assessed and whether to measure behavior, cognitions, or both. Most coping measures include scales to measure the two basic dimensions of problem- and emotion-focused coping, many also incorporate meaning-focused coping (37). Other coping dimensions routinely assessed include social coping and avoidance (36,41). Carver et al. (37) distinguish between seeking social support for instrumental reasons, considered a problem-solving strategy, and seeking social support for emotional reasons, regarded as emotional-focused coping. Similarly, avoidance may be considered either problem or emotion focused depending on the type of avoidant coping implemented.

A major weakness of many coping measures centers on their unstable factor structures and lack of cross-validation (20,42), that is, their appropriateness for use across different groups of people has not been established. In many instances, construct validity (see Table 6.1 in Chapter 6 for a description of the criteria used to evaluate assessment tools) has not been established, and much of the research is predicated on samples of young, healthy, well-educated people, thus limiting the generalizability of instruments and findings. Furthermore, although the dominant conceptualization, Lazarus and Folkman’s approach, sees coping as a dynamic process, a situation-specific reaction to stress, much of the research undertaken is based on a between-individual perspective using instruments to measure stable coping styles (43). This cross-sectional between-individual perspective does not capture within-individual change or response to a situational context. With these considerable limitations in mind, the results of studies using different measurement instruments must be interpreted and synthesized with caution.

Literature on coping with amputation can be broadly characterized in terms of two broad methodological categories: (1) qualitative investigations of the process of coping with amputation (15,16), and (2) studies using standardized assessment instruments to investigate the associations between coping and adjustment outcomes (9,13,14,44). A further distinction can be made between research specifically addressing coping with postamputation pain, in particular phantom limb pain (45,46), and research directed to coping with other facets of the amputation experience (9, 13,47). Where standardized scales and assessments have been used in the amputation coping literature (9,13,14,47), the Coping Strategy Indicator (36) is most widely used. In the literature specifically addressing coping with postamputation pain, the Coping Strategies Questionnaire (48), in particular the catastrophizing subscale, is the most widely used pain coping assessment (44–46,49). Pain-contingent rest is most commonly assessed (44,46) using the Resting Scale of the Chronic Pain Coping Inventory (39). We briefly describe the most commonly used instruments, before reviewing the research employing these instruments in investigations of amputation-related coping.

The Coping Strategy Indicator (CSI) (36) is a 33-item self-report questionnaire measuring the use of three coping strategies—problem solving, seeking social support, and avoidance—in response to a specific stressor. Cronbach's alpha coefficients (see Table 6.1 for evaluation criteria of assessment instruments) indicate adequate internal consistency for each of the subscales ranging from 0.86 to 0.98 for problem solving, 0.89 to 0.98 for seeking social support, and from 0.77 to 0.96 for avoidance (36,50–52). The instrument's trifactorial structure has been supported in a variety of samples (51–53), including a sample of people with amputations (54).

The Coping Strategies Questionnaire (CSQ) (48) comprises 44 items that yield scores on six cognitive measures (diverting attention, reinterpreting pain sensations, coping self-statements, ignoring pain sensations, praying or hoping, and catastrophizing) and one behavioral coping measure (increased behavioral activities). The final two items on the questionnaire assess individuals' personal evaluation of their ability to control and reduce their pain using coping strategies. For each subscale higher scores indicate greater use of that strategy. Assessment of internal consistency for each of the subscales indicates adequate reliability (Cronbach's alpha range, 0.70–0.85) (48). The catastrophizing subscale (CSQ-CAT) is the most widely used CSQ subscale in postamputation pain coping research. Keefe et al. (55) describe catastrophizing as a maladaptive coping strategy that intensifies the experience of pain and depression. The CSQ-CAT measures the frequency with which individuals respond to pain with catastrophizing thoughts such as, "It is terrible and I feel it is never going to get any better," and "I worry all the time about whether it will end."

The resting scale of the Chronic Pain Coping Inventory (CPCI) (39) is a seven-item assessment of the extent of individuals' use of pain-contingent rest as a means of coping with pain. Pain-contingent rest is considered a maladaptive coping strategy that contributes to greater pain interference and disability over time (39). Higher scores on the inventory indicate greater use of the strategy. The resting scale has demonstrated good internal consistency (Cronbach's alpha >0.70) (39,56).

Coping and Amputation: Qualitative Investigations

In recent years, a number of researchers have adopted qualitative methodologies to explore in depth the process of coping with amputation (15, 16,57,58). For example, using grounded theory, Oaksford and colleagues (16) investigated coping strategies among 12 individuals with an amputation of a lower limb. Analysis of participant's narratives revealed five coping categories whose use fluctuated across time: psychological escape, support seeking, humor, cognitive appraisal and practical coping. Moreover, most participants reported positive aspects of their amputation experience, which were characterized in terms of positive reframing and psychological growth. Participants were able to perceive some benefit from their amputation and felt psychologically strengthened by their experience (16). The ability of some to find positive meaning in amputation has also been documented elsewhere (15,35,57).

Sjödahl and colleagues (15), using a phenomenological approach, which gives primacy to the unique experience of the individual, conducted semistructured interviews on coping with 11 individuals with transfemoral amputations. Two overarching themes emerged; the first related to coping with experiences of the amputation, and the second to coping with a new norm. Coping with the initial amputation experience was predominantly characterized by avoidance and denial, whereas downward comparison, positive comparison, and repression dominated narratives of coping in the postacute period.

Looking specifically at the psychological adjustment individuals make in their recovery from a land-mine injury, Ferguson et al. (58) examined psychosocial aspects, coping strategies, and resilience characteristics of limb loss survivors across differing cultural, societal, and economic backgrounds to determine factors that contribute to recovery. Sixty-eight people with limb loss, 10 family members, and seven service providers were interviewed across the U.S. and six land-mine–affected countries: Bosnia, El Salvador, Eritrea, Ethiopia, Jordan, and Mozambique. The emerging themes highlighted that the survivors' acceptance of limb loss and their state of psychological recovery were greatly influenced by the individual's resilience characteristics, social support, medical care, economic situation, and societal attitudes toward people with disabilities. For example, they reported that people in their sample who recovered psychologically had "developed new coping strategies and ways of thinking that allowed them to address their new role in society, in their family, and in their work." Determination, perseverance, positive thinking, making what happened into something good, engaging in downward social comparisons (e.g., perceiving that there are worse situations than their own), and defining oneself as more than just having an amputation were important strategies in facilitating recovery. They conclude that recovery requires addressing the individual's physical, psychological, financial, and social needs within the context of family, community, and the sociocultural environment in which they live (58).

Association Between Coping and Psychosocial Adjustment to Amputation

Few studies have used standardized assessment instruments to examine the relationship between the use of coping strategies and adjustment to amputation. Studies to date have been predominantly concerned with people with a lower limb amputation (9,13,47,59). Indeed, we are aware of just one study explicitly investigating the association between coping and psychosocial adaptation to upper limb amputation (14). However, extant research consistent with the wider coping literature suggests that active task-oriented strategies such as problem solving and perceiving control over the disability are conducive to positive psychosocial adjustment (14). In contrast, emotion-focused and passive strategies such as cognitive disengagement, avoidance, and catastrophizing have been associated with poor psychosocial outcomes (9,13,14). For example, using a modified version of the COPE inventory (37) together with Tobin's Coping Strategies Inventory (60), Livneh et al. (9) found that greater active problem solving was negatively associated with depression and internalized anger and positively associated with adjustment and acceptance of disability. In contrast, emotion focused coping and cognitive disengagement were positively associated with depression, externalized hostility, and lack of acceptance of disability. Investigating psychosocial adjustment (general adjustment, social adjustment, adjustment to limitation) and symptoms of intrusion, anxiety, and depression in a sample of 796 individuals with lower limb amputations, Desmond and MacLachlan (13) also found that coping styles (on the CSI (36)) were important predictors of psychosocial adaptation. Avoidance was strongly associated with psychological distress and poor adjustment. In contrast, problem solving was negatively associated with depressive and anxious symptomatology, whereas seeking social support was negatively associated with symptoms of depression and positively associated with social adaptation.

In contrast with the two preceding studies, Gallagher and MacLachlan (47) specifically focused their investigation on the coping strategies implemented in adjusting to an artificial limb. Their study of 44 individuals with diverse amputation sites and etiologies revealed differential usage of coping strategies (as measured by the CSI) dependent on amputation etiology. Specifically, they found that those with traumatic amputations reported avoidance as their predominant coping strategy significantly more often than those whose amputations resulted from disease (47). This is in accord, they suggest, with the finding that individuals who have not had adequate warning or preparation tend to react with denial (61).

Focusing on well-being following amputation, Dunn (59) developed a measure of "finding positive meaning" unique to the research question addressed. Specifically, participants responded to the following item: "Some people say that every dark cloud has a silver lining. Has anything positive or good happened to you as a result of your amputation?" (59, p. 249). Finding positive meaning in one's amputation and perceiving greater control over one's impairment were associated with lower levels of depressive symptomatology and higher levels of self-esteem. Similarly, Gallagher and MacLachlan (57) asked 104 subjects if they considered anything good had emerged from their amputation and reported that finding positive meaning was significantly associated with more favorable physical capabilities and health ratings, lower levels of athletic activity restriction, and higher levels of adjustment to limitation.

Coping with Chronic Post-amputation Pain

The literature on coping with chronic pain indicates that the coping strategies that individuals adopt to manage their pain are associated with variable degrees of pain, physical disability, and variation in psychosocial outcomes (62). Many individuals with an amputation experience significant pain at more than one anatomical site (63–66) (see Chapter 4 for a more detailed discussion). For some, such pain experiences are associated with significant impairments in physical and psychosocial functioning, limitations in prosthesis use, and reduced quality of life (3,67–69). Generally speaking, within the spectrum of pain disorders experienced postamputation, phantom limb pain, that is, pain experienced in the part of the limb that is absent, is the most extensively researched. A number of researchers (44–46,70) have investigated associations between strategies specifically employed to cope with phantom limb pain and psychosocial adjustment. Given the predictive utility of catastrophizing in response to pain, documented in a variety of chronic pain conditions, catastrophizing has been a focus in studies of coping with phantom limb pain (44–46,49). Catastrophizing has been differentially conceptualized as a cognitive process characterized by expectation of negative outcomes and lack of control (71) and as a maladaptive coping strategy reflecting helplessness and pessimism in relation to the ability to deal with the pain experience (55). Although there is debate regarding whether catastrophizing represents a coping strategy per se or whether it is a cognitive process characterized by expectation of negative outcomes and lack of control (71), it has been found to predict both self-reported and objective measures of disability in a variety of chronic pain conditions (72).

In the largest study of phantom limb pain, coping and disability to date ($n = 315$), Whyte and Carroll (45) found that catastrophizing was a significant predictor of self-reported disability (measured using the Sickness Impact Profile [SIP]-total score (73)), and that catastrophizing (CSQ-CAT) accounted for 12.5% of the variance in the SIP psychosocial scale (73). In two earlier studies, Hill et al. (49,74) also used the CSQ to measure pain coping. Conceptualizing adjustment in terms of the SIP (73) and the McGill Pain Questionnaire (75) scores, Hill et al. noted that reinterpretation of pain symptoms (a cognitive coping strategy) and catastrophizing correlated positively with psychosocial dysfunction, whereas greater pain report was principally explained by catastrophizing, increasing behavioral activity, lower perceived ability to decrease pain, and less use of hoping and praying strategies (49). Conceptualizing poor adjustment in terms of psychological distress (measured using the General Health Questionnaire) and pain report (McGill Pain Questionnaire) in a study of 60 male outpatients, predominantly with lower limb amputations, Hill (74) found that the CSQ subscales accounted for 27% of the variance in pain report and 43% of the variance in psychological distress. Catastrophizing emerged as the most important predictor in both analyses. While Hill et al.'s findings are consistent with much of the wider pain literature suggesting that catastrophizing is associated with poor concurrent adjustment (55, 76,77), findings with respect to the association between catastrophizing, post-amputation pain and adjustment have been inconsistent.

Jensen et al. (46) focused on the associations between pain contingent rest and catastrophizing, both considered maladaptive coping strategies, and adjustment (conceptualized in terms of symptoms of depression, pain intensity, and interference) in a sample of 61 people with recent amputations. Results indicated that catastrophizing (measured using the CSQ-CAT) and pain contingent rest (CSCI resting scale) were associated with greater phantom pain intensity and greater pain interference at 1 month postamputation. However, use of pain-contingent rest at 1 month postamputation did not predict subsequent changes in pain or pain interference, suggesting that the use of pain-contingent rest at one time point may not have long-lasting negative impact on phantom limb pain. In contrast, and contrary to expectation, greater catastrophizing at 1 month postamputation was associated with subsequent decreases in pain interference assessed 5 months later.

In a follow-up study, Hanley and colleagues (44) highlighted catastrophizing as a significant predictor of changes in pain interference and depressive symptomatology. Consistent with earlier findings (46), greater catastrophizing (CSQ-CAT) 1 month after amputation was associated with improvement in pain interference and depressive symptoms at the 12- and 24-month follow-ups (44). Jensen and colleagues (46) speculate that the positive associations they document may result from indirect benefits of catastrophizing, such as successfully garnering support from others, or that they may be an artifact of the extent of pain interference and depression experienced by those in their samples who catastrophized extensively after amputation. Those who experienced higher levels of pain and depressive symptomatology in the early postamputation stages may have demonstrated more dramatic improvements in these variables in the months that followed. It is also possible that specific features of the measurement of catastrophizing (i.e., the CSQ-CAT) contributed to these results. Recently, Hirsh et al. (78) have demonstrated high intercorrelations between measures of negative mood and pain catastrophizing as measured by the CSQ-CAT, suggesting that the CSQ-CAT is confounded by negative mood (78,79). Hill et al. (49,74) did not control for depressive symptomatology in their analyses (see Chapter 4 for additional commentary on pain and coping).

Future Directions

First, as is evident from the literature reviewed here, empirical research pertaining to associations between coping and psychosocial adjustment to amputation, as a unique condition, is relatively scarce. Second, methodological issues limit the conclusions drawn and generalizability of these investigations. Many studies have used reasonably small sample sizes (9,47), and much available research is premised exclusively on coping with phantom limb pain (44–46,49). Although phantom limb pain is a very common sequela of amputation, most individuals with amputations experience infrequent, episodic phantom pain, which is not perceived to be significantly disabling or bothersome (64,67). Nevertheless, only a small amount of research attention has been directed to coping with other facets of the amputation experience. Third, assessments have largely been conducted using generic measures of coping formulated through factor analysis with general population samples. There is little or no evidence detailing their psychometric properties with individuals with amputations. Indeed, a major weakness of many coping measures is their unstable factor structures and lack of cross-validation (20,42). Fourth, it is important to conduct research that embraces and supports the notion of coping as a process that is subject to change based on situational factors. Although as pointed out by Lazarus (80), the use of questionnaires allows the study of larger samples and the quantification of the coping process, and although the limited but recent qualitative studies allow for detailed and in-depth information on individual coping processes to emerge, longitudinal, prospective, and observational studies are required. Fifth, it is not possible to determine the extent to which negative psychological responses are associated with the amputation itself, coexisting chronic conditions that preceded the amputation, postamputation pain experience, concurrent life stresses, or preamputation psychopathology. At the very least, it is important to specify the event with which the person is coping. Sixth, researching coping is complex. There are many variables involved in how people cope and the outcomes of coping. Indeed, effective coping involves a fit between person and the environment (18) and therefore what is perceived to be optimal coping depends on knowing the goals of the individual.

Yet despite these limitations and challenges, knowing the strategies that people adopt in dealing with the physical, personal, and environmental challenges that limb loss can bring about can supplement the existing body of knowledge that is available to the practitioner. It also acts as a facilitator in the clinical encounter to discuss strategies and endeavors that may be beneficial or threatening to the person. Finally, extending our knowledge base in this area is important in "helping some people some of the time, cultivating existing strengths, hastening the recovery from loss, and preserving or enhancing valued interpersonal relationships" (81).

Summary of Key Points

- The stress-coping paradigm offers a framework for understanding how individuals manage their amputation and its consequences and may be useful in explaining adjustment differences among individuals with an amputation.
- Coping has been categorized as problem focused and emotion focused, as meaning based, or in terms of active and passive dimensions.
- Within the amputation literature, there is variability in how psychosocial adjustment is defined and operationalized. Indeed, it is often not made explicit but communicated in terms of the outcome measures selected. While favorable adjustment is often conceptualized as the absence of psychological disorder and difficulty in adjustment typified by depressive symptomatology, more recently a strengths-based approach is being emphasized with an emerging focus on resilience and adaptive psychological processes.
- Much of the coping literature uses self-report measures of coping. In the amputation literature, the most widely used coping measures are the Coping Strategies Indicator, the Coping Strategies Questionnaire, and the resting scale of the Chronic Pain Coping Inventory.
- There is limited research that has specifically explored coping strategies in people with an amputation. The studies that have been undertaken can be characterized in terms of qualitative investigations, studies using standardized assessment instruments, and research specifically addressing coping with postamputation pain. Although the studies are few, the findings are consistent with the wider coping literature; that is, problem-focused strategies were conducive to positive psychosocial adjustment, whereas emotion-focused strategies such as cognitive disengagement and catastrophizing were associated with poor psychosocial outcomes.
- Although there are many limitations and challenges in this area, knowing the coping strategies that people adopt in dealing with the physical, personal, and environmental challenges that limb loss can bring about can supplement the existing body of knowledge that is available to the practitioner.

Glossary

Catastrophizing: A cognitive process characterized by expectation of negative outcomes and lack of control (71).

Cognitive variables: Individual's beliefs and appraisals regarding a stressor.

Coping: Cognitive and behavioral efforts to manage specific external or internal demands (and conflicts between them) that are appraised as taxing the resources of a person (19).

Emotion-focused coping: Cognitive coping strategies that do not directly change the situation but allow new meaning to be assigned, thereby changing the emotions associated with the stressful event.

Problem-focused coping: Action-centered coping in that the person–environment relationship is altered by instrumental actions.

Stress: A particular relationship between the person and the environment that is appraised by the person as taxing his or her resources and endangering his or her well being (18, p. 19).

Further Reading

de Ridder D, Schreurs K. Developing interventions for chronically ill patients: is coping a helpful concept? Clin Psychol Rev 2001; 21(2):205–240.

Folkman S, Greer S. Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. Psycho-oncology 2000;9(1):11–19.

Folkman S, Moskowitz JT. COPING: Pitfalls and Promise. Annu Rev Psychol 2004;55(1):745–774.

References

1. Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: a review. Disabil Rehabil 2004;26:837–850.
2. Rybarczyk B, Szymanski L, Nicholas JJ. Limb amputation. In: Frank RG, Elliot TR, eds. Handbook of Rehabilitation Psychology. Washington, DC: American Psychological Association, 2000:29–47.
3. Desmond DM, MacLachlan M. Affective distress and amputation-related pain among older men with long-term, traumatic limb amputations. J Pain Symptom Manage 2006;31:362–368.
4. Rybarczyk B, Nyenhuis DL, Nicholas JJ, Cash SM, Kaiser J. Body image, perceived social stigma, and the prediction of psychosocial adjustment to leg amputation. Rehabil Psychol 1995;40:95–110.
5. Pezzin L, Dillingham T, MacKenzie E. Rehabilitation and the long-term outcomes of persons with trauma-related amputations. Arch Phys Med Rehabil 2000;81:292–300.
6. Livneh H. Psychosocial adaptation to chronic illness and disability: a conceptual framework. Rehabil Counsel Bull 2001;44:151–160.
7. Taylor SE. Adjustment to threatening events: a theory of cognitive adaptation. Am Psychol 1983;38:1161–1173.
8. Schultz IZ, Crook J, Meloche GR, et al. Psychosocial factors predictive of occupational low back disability: towards development of a return-to-work model. Pain 2004;107:77–85.
9. Livneh H, Antonak RF, Gerhardt J. Psychosocial adaptation to amputation: the role of sociodemographic variables, disability related factors and coping strategies. Int J Rehabil Res 1999;22:21–31.
10. Endler NS, Corace KM, Summerfeldt LJ, Johnson JM, Rothbart P. Coping with chronic pain. Pers Individ Dif 2003;34:323–346.
11. Livneh H, Antonak RF, Gerhardt J. Multidimensional investigation of the structure of coping among people with amputations. Psychosomatics 2000;41:235–244.
12. Mikulinecer M, Florian V. Coping and adaptation to trauma and loss. In: Zeidner M, Endler NS, eds. Handbook of Coping: Theory, Research and Applications. New York: Wiley, 1996:554–572.
13. Desmond DM, MacLachlan M. Coping strategies as predictors of psychosocial adaptation in a sample of elderly veterans with acquired lower limb amputations. Soc Sci Med 2006;62:208–216.
14. Desmond DM. Coping, affective distress and psychosocial adjustment among people with traumatic upper limb amputations. J Psychosom Res 2007;62:15–21.
15. Sjödahl C, Gard G, Jarnlo G-B. Coping after transfemoral amputation due to trauma or tumour—a phenomenological approach. Disabil Rehabil 2004;26:851–861.
16. Oaksford K, Frude N, Cuddihy R. Positive coping and stress-related psychological growth following lower limb amputation. Rehabil Psychol 2005;50:266–277.
17. Maes S, Leventhal H, de Ridder DT. Coping with chronic diseases. In: Zeidner M, Endler NS, eds. Handbook of Coping: Theory, Research, Applications. New York: Wiley, 1996:221–251.
18. Lazarus RS, Folkman S. Stress, Appraisal and Coping. New York: Springer, 1984.
19. Lazarus RS. Emotion and Adaptation. London: Oxford University Press, 1991.
20. Schwarzer R, Schwarzer C. A critical survey of coping instruments. In: Zeidner M, Endler NS, eds. Handbook of Coping: Theory, Research, Applications. Oxford, England: Wiley, 1996.
21. Folkman S, Lazarus L. If it changes it must be a process: a study of emotion and coping during three stages of a college examination. J Pers Soc Psychol 1985;48:150–170.
22. Folkman S, Lazarus RS. An analysis of coping in an adequately functioning middle-aged community sample. J Health Soc Behav 1980;21:219–239.
23. Folkman S, Moskowitz JT. COPING: pitfalls and promise. Annu Rev Psychol 2004;55:745–774.
24. Folkman S. Positive psychological states and coping with severe stress. Soc Sci Med 1997;45:1207–1221.
25. Folkman S, Greer S. Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. Psychooncology 2000;9:11–19.
26. Brown GK, Nicassio PM. Development of a questionnaire for the assessment of active and passive coping strategies in chronic pain patients. Pain 1987;31:53–64.
27. Mercado AC, Carroll LJ, Cassidy JD, Cote P. Passive coping is a risk factor for disabling neck or low back pain. Pain 2005;117:51–57.
28. Haythornthwaite JA, Menefee LA, Heinberg LJ, Clark MR. Pain coping strategies predict perceived control over pain. Pain 1998;77:33–39.
29. Grossi G, Soares JJF, Angesleva J, Perski A. Psychosocial correlates of long-term sick-leave among patients with musculoskeletal pain. Pain 1999;80:607–620.
30. Keefe FJ, Rumble ME, Scipio CD, Giordano LA, Perri LM. Psychological aspects of persistent pain: current state of the science. J Pain 2004;5:195–211.

31. Livneh H, Antonak RF. Psychosocial Adaptation to Chronic Illness and Disability. Gaithersburg, MD: Aspen, 1997.
32. Johnson J, Morse J. Regaining control: the process of adjustment after myocardial infarction. Heart Lung 1990;19:126–135.
33. Rybarczyk B, Nyenhuis DL, Nicholas JJ, Schulz R, Alioto RJ, Blair C. Social discomfort and depression in a sample of adults with leg amputations. Arch Phys Med Rehabil 1992;73:1169–1173.
34. Williamson GM, Schulz R, Bridges MW, Behan AM. Social and psychological factors in adjustment to limb amputation. J Soc Behav Pers 1994;9: 249–268.
35. Gallagher P, MacLachlan M. Adjustment to an artificial limb: a qualitative perspective. J Health Psychol 2001;6:85–100.
36. Amirkhan JH. A factor analytically derived measure of coping: the Coping Strategy Indicator. J Pers Soc Psychol 1990;59:1066–1074.
37. Carver CS, Scheier MF, Kumari Weintraub J. Assessing coping strategies: a theoretically based approach. J Pers Soc Psychol 1989;56:267–283.
38. Carver C, Scheier M, Weintraub J. Assessing coping strategies: a theoretically based approach. J Pers Soc Psychol 1989;56.
39. Jensen MP, Turner JA, Romano JM, Strom SE. The chronic pain coping inventory: development and preliminary validation. Pain 1995;60:203–216.
40. Willebrand M, Kildal M, Ekselius L, Gerdin B, Andersson G. Development of the coping with burns questionnaire. Pers Individ Diff 2001;30:1059–1072.
41. Moos RH. Coping responses inventory: a measure of approach and avoidance coping skills. In: Zalaquett CP, Wood RJ, eds. Evaluating Stress: a Book of Resources. Lanham, MD: Scarecrow Education, 1997:51–65.
42. Parker JDA, Endler NS, Bagby RM. If it changes, it might be unstable: examining the factor structure of the Ways of Coping Questionnaire. Psychol Assess 1993;5:361–368.
43. Parker JDA, Endler NS. Coping with coping assessment: a critical review. Eur J Pers 1992;6:321–344.
44. Hanley M, Jensen M, Ehde D, Hoffman AJ, Patterson DR, Robinson LR. Psychosocial predictors of long-term adjustment to lower-limb amputation and phantom limb pain. Disabil Rehabil 2004;26:882–893.
45. Whyte AS, Carroll LJ. The relationship between catastrophizing and disability in amputees experiencing phantom pain. Disabil Rehabil 2004;26: 649–654.
46. Jensen MP, Ehde DM, Hoffman AJ, Patterson DR, Czerniecki JM, Robinson LR. Cognitions, coping and social environment predict adjustment to phantom limb pain. Pain 2002;95:133–142.
47. Gallagher P, MacLachlan M. Psychological adjustment and coping in adults with prosthetic limbs. Behav Med 1999;25:117–124.
48. Rosenstiel AK, Keefe FJ. The use of coping strategies in chronic low back pain patients: Relationship to patient characteristics and current adjustment. Pain 1983;17:33–44.
49. Hill A, Niven CA, Knussen C. The role of coping in adjustment to phantom limb pain. Pain 1995;62: 79–86.
50. Utsey SO, Ponterotto JG, Reynolds AL, Cancelli AA. Racism and discrimination, coping, life satisfaction, and self-esteem among African Americans. J Couns Dev 2000;78:72–80.
51. Bijttebier P, Vertommen H. Psychometric properties of the Coping Strategy Indicator in a Flemish sample. Pers Individ Dif 1997;23: 157–160.
52. Clark KK, Bormann CA, Cropanzano RA, James K. Validation evidence for three measures of coping. J Pers Assess 1995;65:434–455.
53. Ptacek JT, Smith RE, Espe K, Raffety B. Limited correspondence between daily coping reports and retrospective coping recall. Psychol Assess 1994;6:41–4.
54. Desmond DM, Shevlin M, MacLachlan M. Dimensional analysis of the Coping Strategy Indicator in a sample of elderly veterans with acquired limb amputations. Pers Individ Diff, 2006;40: 249–259.
55. Keefe F, Brown G, Wallston K, Caldwell D. Coping with rheumatoid arthritis pain: catastrophizing as a maladaptive strategy. Pain 1989;37: 51–56.
56. Osborne TL, Jensen MP, Ehde DM, Hanley MA, Kraft G. Psychosocial factors associated with pain intensity, pain-related interference, and psychological functioning in persons with multiple sclerosis and pain. Pain 2007;127:52–62.
57. Gallagher P, MacLachlan M. Positive meaning in amputation and thoughts about the amputated limb. Prosthet Orthot Int 2000;24:196–204.
58. Ferguson AD, Richie BS, Gomez MJ. Psychological factors after traumatic amputation in landmine survivors: The bridge between physical healing and full recovery. Disabil Rehabil 2004;26:931–938.
59. Dunn D. Well-being following amputation: salutary effects of positive meaning, optimism and control. Rehabil Psychol 1996;41:245–302.

60. Tobin DL, Holroyd KA, Reynolds RV, Wigal JK. The hierarchical factor structure of the Coping Strategies Inventory. Cogn Ther Res 1989;13:343–361.
61. Bradway JK, Malone JM, Racy J, Leal JM, Poole J. Psychological adaptation to amputation: an overview. Orthot Prosthet 1984;38:46–50.
62. Katz J, Ritvo P, Irvine MJ, Jackson M. Coping with chronic pain. In: Zeidner M, Endler NS, eds. Handbook of Coping: Theory, Research, Applications. New York: Wiley, 1996:252–278.
63. Ehde DM, Smith DG, Czerniecki JM, Campbell KM, Malchow DM, Robinson LR. Back pain as a secondary disability in persons with lower limb amputations. Arch Phys Med Rehabil 2001;82: 731–734.
64. Ehde DM, Czerniecki JM, Smith DG, et al. Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. Arch Phys Med Rehabil 2000;81: 1039–1044.
65. Smith DG, Ehde DM, Legro MW, Reiber GE, del Aguila M, Boone DA. Phantom limb, residual limb, and back pain after lower extremity amputations. Clin Orthop Rel Res 1999:29–38.
66. Marshall H, Jensen M, Ehde DM, Campbell K. Pain site and impairment in individuals with amputation pain. Arch Phys Med Rehabil 2002;83: 1116–1119.
67. Gallagher P, Allen D, MacLachlan M. Phantom limb pain and residual limb pain following lower limb amputation: a descriptive analysis. Disabil Rehabil 2001;23:522–530.
68. Ide M, Obayashi T, Toyonaga T. Association of pain with employment status and satisfaction among amputees in Japan. Arch Phys Med Rehabil 2002;83:1394–1398.
69. Houghton AD, Nicholls G, Houghton AL, Saadah E. Phantom pain: natural history and association with rehabilitation. Ann R Coll Surg Engl 1994;76:22–5.
70. Machin P, Williams A. Stiff upper lip: coping strategies of World War II veterans with phantom limb pain. Clin J Pain 1998;14:290–294.
71. Chaves JF, Brown JM. Spontaneous cognitive strategies for the control of clinical pain and stress. J Behav Med 1987;10:263–276.
72. Sullivan MJL, Thorn B, Haythornthwaite JA, et al. Theoretical perspectives on the relation between catastrophizing and pain. Clin J Pain 2001;17: 52–64.
73. Bergner M, Bobbitt R, Carter W, Gilson B. The Sickness Impact Profile: development and final revision of a health status measure. Med Care 1981;19:787–805.
74. Hill A. The use of pain coping strategies by patients with phantom limb pain. Pain 1993;55:347–353.
75. Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. Pain 1975;1: 277–299.
76. Martin MY, Bradley LA, Alexander RW, et al. Coping strategies predict disability in patients with primary fibromyalgia. Pain 1996;68:45–53.
77. Keefe FJ, Caldwell DS, Martinez S, Nunley J, Beckham J, Williams DA. Analyzing pain in rheumatoid arthritis patients. Pain coping strategies in patients who have had knee replacement surgery. Pain 1991;46:153–160.
78. Hirsh AT, George SZ, Riley JL III, Robinson ME. An evaluation of the measurement of pain catastrophizing by the coping strategies questionnaire. Eur J Pain 2007;11:75–81.
79. Sullivan MJL, D’Eon JL. Relation between catastrophizing and depression in chronic pain patients. J Abnorm Psychol 1990;99:260–263.
80. Lazarus RS. Toward better research on stress and coping. Am Psychol 2000;55:665–673.
81. Somerfield M, McCrae R. Stress and coping research: methodological challenges, theoretical advances, and clinical applications. Am Psychol 2000;55:620–625.

3

Limb Loss and Body Image

Bruce Rybarczyk and Jay Behel

Overview

Body image has been generally defined as a component of the self-concept, formed by both sensory and social experiences (1). Among health professionals working with individuals with amputations, body image changes are cited as a critical issue in adjustment to limb loss and prosthesis acceptance. Sometimes body image plays a central role in the adjustment process, and other times it is secondary to more global adjustments in self-concept (e.g., from nondisabled to disabled, independent to semi-dependent, employed to unemployed, etc.). These more fundamental changes in self-concept may take precedence over changes in body image, and body image changes may not be fully integrated until these other issues are addressed. In other cases, a focus on the tangible changes in appearance may serve as a diversion away from less tangible and more anxiety-provoking concerns about one's changed role or purpose in life.

Although many people manage this intricate transformation of self-concept with only mild, transient distress, some individuals with amputations develop lasting negative attitudes about themselves as a result of their altered body and consequent disability. In a less extreme form, others report that they feel positive when wearing a prosthesis but prefer not to see themselves without the prosthesis or look at their prosthesis when not wearing it. Some people with amputations may express embarrassment, shame, or even revulsion about their altered bodies (2). We have viewed this as a form of self-stigmatization, in the sense that an individual is internalizing the social stigma that often is applied to individuals who are viewed as abnormal in some significant way.

Body image does appear to have an important relationship to overall psychological adjustment to an amputation. Studies have shown that various measures of postamputation body image concerns were significantly predictive of depression (2,3), lower ratings of adjustment by the professional who provides the individual with prosthetic services (2), lower overall quality of life (2), and lower life satisfaction (4). Williamson (5) found that greater self-consciousness in public situations, which can be viewed as an index of body image concern, was significantly correlated with activity restriction among older adults with amputations. Similarly, Wetterhahn et al. (6) found a strong correlation between a (relatively) high level of physical activity and positive body image. Although further research certainly is needed to delineate the precise interrelations between activity and body image, a reciprocal model in which a well-integrated prosthesis facilitates an active lifestyle which in turn reinforces an adaptive, positive body image, is certainly rationally appealing and warrants further study.

The impact of limb loss and consequent prosthesis prescription on body image appears to depend on a wide range of factors. In the sections that follow, drawing from research findings, our previous writings (7), and our own clinical experience in rehabilitation medicine, we review the impact and relationship of six groups of factors on body image: amputation-specific factors, prosthesis factors, upper extremity amputation, psychological process of adaptation, developmental issues, and social perceptions.

Amputation-Specific Factors

For most people who experience limb loss, the factors that most immediately impact self-concept and body image are those that are specific to the facts of the amputation itself. The most basic factor to consider is the level of the amputation. A common misconception is that below-knee amputation has subjectively less impact on body image than an above-knee amputation or hip disarticulation. However, although concrete alterations in appearance are the trigger for associated changes in body image, these changes occur in the context of psychological, developmental, and sociocultural factors. As we have noted previously, paraphrasing a maxim used in medicine about illness, "what amputation an individual has is less important that what individual an amputation has" (8). All of the contextual factors play a crucial role in shaping an individual's response, diminishing the impact of limb loss for some and magnifying it for others. Furthermore, clinical examples of incongruous responses are not difficult to find. A transmetatarsal amputation may be psychically magnified to disfiguring proportions, while others may experience the loss of an entire limb as a relatively unimportant cosmetic change relative to the life-threatening medical conditions that necessitated the amputation.

Individuals' internal representations of their appearance tend to attach different cognitive-affective values to different parts of the body. For some women, for example, the body image threat of an amputation is heightened by the fact that wearing skirts that expose the leg or wearing fashionable high-heeled shoes has been an important part of their identity. Similarly, physical appearance in bathing suits and shorts can be an important aspect of body image for some individuals and relatively insignificant for others. The loss of a hand or arm, because of its highly symbolic and multifunctional nature, is known to be more traumatic than the loss of a leg (see discussion below). This finding underscores how disabilities that threaten body image may present a more challenging psychological adjustment than conditions that are equally disabling but have fewer body image and public acceptance implications.

Although the body's appearance while static is a core component of body image, one's sense of one's body in motion, performing activities both routine and extraordinary, also is an essential aspect of body image. This kinetic aspect of body image, while frequently overlooked, is central to the rehabilitation process. Although restoring individuals to their previous level of functioning is the primary goal of rehabilitation and complete recovery is viewed as ideal, the pragmatics of the rehabilitation process often require that individuals with amputations be instructed in the use of an alternative gait and a slower pace. While excellent as a means of returning functional mobility, these function-over-form approaches may result in gross changes in kinetic presentation. Therefore, the reconciliation of old kinetic representations of the self to new ways of functioning may be a critical aspect of the adjustment process.

The cause of a disability can also have a substantial impact on the individual's response to and ultimate ability to cope with the disability and attendant changes in body image. Identical amputations (e.g., above-knee amputation) can be experienced, interpreted, and managed in drastically different ways depending on the proximal cause of the disability. Limb loss due to trauma appears to be more difficult to adapt to in general (9), and has been found to precipitate more body image and prosthesis concerns (10). This may be related to the trauma associated with the precipitating event or the cognitive attributions that are made after the fact. Regarding the former, one study found that recent amputations caused by trauma had high levels of posttraumatic stress disorder (PTSD), while those with nontraumatic amputations had no such elevations (11). But attributions may also play a role if the pervasive view is that it was random, unnecessary, and unfair. These attributions can be perpetuated by a drawn-out process of litigation, which reinforces the individual's creating a personal narrative with a theme of tragedy, victimization, and overwhelming loss.

Similar issues are present when limb loss is perceived to be incurred as a result of medical mismanagement. Body image changes associated with these types of loss may be characterized by an idealization of the former appearance and may be closely associated with unresolved feelings of anger and resentment. On the other hand, amputations that are brought about by perceived personal neglect are often associated with feelings of self-blame. This response pattern may become entrenched, making progress beyond the initial feelings of loss difficult.

Conversely, limb loss incurred during the course of medically necessary, lifesaving interventions frequently is associated with altogether different response patterns. This type of disability may be viewed as the price of being saved from a life-threatening condition or an opportunity to resume a life interrupted by a protracted, painful illness. Such adaptive responses are not uncommon and are typically associated with positive adjustments in the self-concept and body image. However, it is important to be sensitive to the fact that individuals may express feelings of gratitude, relief, or renewal because they perceive such feelings as the socially sanctioned response. Consequently, it is important to evaluate and monitor patients for masked signs of distress.

Congenital limb absence, on the other hand, provides an altogether different set of issues. The limb absence is present during the formation of a self-concept and therefore allows for a full integration into one's body image. While difficulty accepting the absence of the limb and even the attendant disability is relatively uncommon, acceptance of the prosthesis and integration of the prosthesis into static and kinetic self-concepts may trigger unexpected body image crises. It may be particularly difficult for these individuals to preserve positive representations of their bodies while accepting and utilizing the prosthesis on a daily basis. This difficulty is almost certainly magnified when a prosthesis is offered in adulthood rather than childhood or adolescence.

Pain and other sensory changes associated with limb loss or prosthesis utilization also can significantly impact body image by serving as potent and, in some cases, constant reminders of the disability and the attendant changes in physical presentation. Moreover, as a sensory experience typically associated with illness and disability, pain may act as an agent for perpetual denigration of body image, long after functional changes have been adaptively integrated into one's self-concept.

In an examination of the relationship between emotional adjustment and phantom limb pain (PLP), Pucher et al. (12) demonstrated a potentially important link between PLP and body image. Not surprisingly, their primary finding was that participants rated as adaptive copers reported significantly lower levels of PLP. Somewhat unexpectedly, however, it was also discovered that well-adjusted, pain-free participants evinced a positive but realistic body image. In other words, they accurately perceived their altered appearance and were relatively comfortable with it. On the other hand, participants with high levels of PLP were more likely to perceive/portray their bodies as intact, that is, in their preamputation condition. The authors posit that by providing sensations in the amputated limb, PLP either reinforces or creates a distorted sense of the body's current condition. Additional research certainly is needed to clarify the nature and prevalence of this interaction, but this nexus of PLP and body image disturbance offers an interesting opportunity to examine the interrelation and combined impact of these two important postamputation complications.

Prosthesis Factors

A unique aspect of body image postamputation is the fact that prosthetic technology allows for a natural-looking and high-functioning limb that can be worn for a full day in many cases. This means that the individual has two distinct aspects of body images to adapt to: with a prosthesis and without a prosthesis. The former includes more social elements and the latter is often a very private experience. The impact of a prosthesis on body image is quite variable depending on the type of prosthesis and the nature of limb loss. For some, a prosthesis may be embraced unequivocally as a lifeline for functioning, with cosmetic issues being secondary, whereas others may experience considerable primary concern about the appearance of a prosthesis (how realistic it looks, how noticeable it is, etc.). Finally, for individuals with congenital limb absence, the introduction of a prosthesis may be experienced as an attack on an established, healthy body image that is seen as either implicit, negative feedback about or an unwelcome alteration in appearance.

Adaptive equipment including prostheses can trigger powerful negative associations in the minds of some individuals. Many of these negative associations revolve around the fears of the social stigma attached to disability in Western cultures. Other associations involve fears of growing old and feeble. Prostheses, as well as wheelchairs, walkers, canes, and braces can be laden with symbolism. Murray (13) conducted a qualitative examination of the experiences of 35 prosthesis users with a goal of parsing out the social and symbolic meaning of prosthesis use. His analysis focused on the functional and interpersonal value of prostheses. A subgroup of participants reported that they rarely, if ever, allowed others to see them without their prosthesis, while a few indicated that they use their prosthesis to completely hide the very fact of their limb loss, "passing" as individuals with intact limbs. This issue has created some degree of controversy in the amputation community in the sense that some individuals with amputations view this as an indication of lack of acceptance of one's own altered body and an internalization of the social stigma associated with being different. As such, some activist-minded individuals have advocated the use of prostheses that are visible and express their technological aesthetics rather than attempting to camouflage these aspects of the prosthesis (i.e., the "wear it loud and proud" approach).

Having an optimal prosthesis is critical to most individuals. For example, Murray and Fox (14) found that prosthesis satisfaction is highly positively correlated with lack of body image disturbance. They also noted that this relationship holds for both aesthetic and functional prosthesis satisfaction. This finding seems to suggest that the long-term impact of an amputation on body image may be moderated by acceptance of one's prosthesis as an adequate static and kinetic substitute. However, it has been suggested by some authors that individuals with an amputation who express dissatisfaction with their prostheses may be doing so as a defense mechanism, as a form of denial or displacement of their inability to cope with the amputation (15).

Upper Limb Amputation

Most articles and research on adjustment to amputation address *lower* limb amputation, reflecting that upward of 90% of all amputations in the United States and the United Kingdom are lower limb. However, there is a small body of work on individuals with arm and hand amputations. This work suggests that arm and hand amputations appear to entail qualitatively different experiences than lower limb amputations for several reasons. First, arm and hand function is central to many activities of daily living, including personal hygiene and food preparation, and carrying out some of these tasks can become quite challenging. Second, the arms and hands play a crucial role in nonverbal dimensions of social communication and interaction through actions like gesturing and physical contact. Even the wearing of a wedding ring is a critical symbolic function of the hand for many individuals. Third, since a missing arm or prosthetic hand is much more difficult to conceal than a leg or foot prosthesis, the amputation is much more noticeable to others, increasing the likelihood that the person with an upper extremity amputation might feel scrutinized and self-conscious (16). Visible disabilities may present a more challenging psychological adjustment than conditions that are perhaps equally disabling but are better masked. Fourth, the prosthetic devices available for hands, while advancing greatly in recent years, are not nearly as functional as those for lower limb amputations (17). Finally, most upper limb amputations occur from trauma (e.g., work-related injuries, war) and occur at younger ages than lower limb amputations (17). As noted previously, these issues serve to complicate the adjustment process for many individuals.

The use of prosthetic devices in upper limb amputation also presents many challenges. Some of the barriers to consistent use of prosthetic devices include how heavy it is and its limited function (18). Dudkiewicz et al. (18) studied prosthetic usage in 45 patients with upper limb amputation and found that more than 70% reported difficulty with their prosthetic device. Some reasons given included the weight of the device, excessive sweating, displeasure with its appearance or its functionality, and the experience of phantom limb pain. Interestingly, significantly more people consistently used a cosmetic prosthesis (55%) compared with a functional prosthetic device (40%). This finding speaks to both the concerns related to body image in those living with an upper limb amputation and the limitations of functionality in most upper limb prostheses.

Psychological Process of Adaptation

The process of physical rehabilitation following an amputation is paralleled by a psychological process during which the individual transitions from the "sick" role to recovery. The individuals' sense of self, particularly their sense of their physical self, is at the heart of this process. In fact, psychological rehabilitation may be conceptualized as a feedback loop in which the preamputation body image is continuously presented with challenging new information about the self to which it must adapt. This new information may include both increasing awareness and understanding of the actual limb loss as well as ever-changing feedback regarding static and kinetic appearance.

Ideally, this is a fluid process in which the old body image is constantly undergoing revision, and through an appropriate balance of assimilation and accommodation, a sense of integrity is preserved even as body image is transformed to accurately reflect ongoing changes. However, this equilibrium rarely is achieved without some degree of distress, and naturally, different responses are associated with different recoveries. We have observed several different dysfunctional patterns in our clinical work. To begin with, there is a subset of individuals who can be characterized as instant accepters—those who respond by attempting to accommodate to their disability instantaneously. In other words, these are individuals who respond to their amputation by attempting to effect an instant transformation in their self-concept. They try to adopt the role of integrated disabled person prematurely. Individuals in this group are likely to readily accept their prosthesis without taking the time to genuinely understand either its physical parameters or symbolic meaning. This response style runs the risk of either overwhelming the self with an unmanageable amount of distressing changes at some point in the future or allowing the person to only superficially process information about their disability, thereby postponing genuine adjustment to the new physical and psychic reality.

Another subset of individuals, distorters, attempt to preserve their preamputation sense of self by forcing information about their disability into their old schemata. For example, an older person with multiple chronic diseases who loses a leg may overassimilate by focusing on predisability limitations ("I wasn't very active anyway") and minimizing the extent to which they have changed. These individuals often have a distorted sense of reality and are poorly prepared to meet the challenges of their disability and may ignore the pragmatics of prosthesis management as too painful indicators that they have been changed by their limb loss.

Finally, some individuals, deniers, react by distancing themselves from their disability by either explicitly viewing it as separate from themselves or suppressing it outright. Cognitively, the response pattern is characterized by either a failure to process and classify disability-relevant information or an attempt to process information about the disability as self-irrelevant. Emotionally, it may manifest as frank denial of the disability and its impact with attendant prosthesis rejection, extreme avoidance of information about the amputation and prosthesis, and emotional crisis when reality becomes unavoidable. Denial has been widely observed to be an adaptive response in the short-term, but problematic in the long-range when plans, expectations, and goals are not adjusted accordingly.

In spite of the potential adjustment problems outlined above, most people who experience limb loss ultimately integrate these changes and develop a healthy self-concept and body image. Beatrice Wright (19) has provided some enlightening research on how individuals make such a positive adjustment, by focusing on the changes that take place in an individual's value system. These value shifts include moving away from basing one's worth on either physical qualities or comparative value (e.g., viewing oneself as a worthy person because of superior physical fitness or attractiveness). Positive adjustments occur when the individual shifts to basing his or her self-worth on nonphysical qualities and a sense of intrinsic value (e.g., "I'm as important as any other person because of my uniqueness"). A version of this intrinsic value perspective, for instance, is operating in the process by which an individual comes to see his or her prosthesis in a positive light because of what it enables him or her to do rather than in a negative light because of its inferiority to the natural limb.

Developmental Factors

The impact of limb loss and prosthetic prescription on body image are closely tied to the developmental timing of the loss. Several studies of children suggest that younger children cope relatively well with the loss of a limb and tend to accept prostheses readily (20). Adapting to limb loss becomes more difficult as children become older (21). These problems notwithstanding, some evidence suggests that prospects for adaptive long-term adjustment and integration of body image changes during these formative years may be better than when similar changes occur during early and middle adult years

Body image is a prime concern among adolescents, and physical changes during these sensitive developmental years can have a profound impact on social functioning. For example, increased high school dropout rates have been reported due to concern over cosmetic appearances among teenagers with upper limb amputations. Varni and Setoguchi (22,23) have identified several factors that predict how the adolescent with an amputation perceives his or her physical appearance, including social support from parents, teachers, and classmates, peer acceptance, thriving in academics or sports, few daily hassles, and low levels of marital conflict between parents. Much like adults, those who have a positive perception of their physical appearance tend to have higher self-esteem and fewer symptoms of depression.

At the other end of the life span, some research and anecdotal reports indicate older adults (age 65+), compared to younger adults, are less prone to adjustment problems and body image concerns following an acquired disability. We have hypothesized that older adults do not have as strong a reaction as younger adults because they view disability and changes in mobility and body image as an undesirable but relatively "on-time" event (i.e., common for their age; 2). They also frequently compare themselves favorably to more infirm and less physically intact older adults, which is a method of coping among older adults that has been broadly described as social downgrading (24). Events that are perceived as normative are far less likely to elicit a negative reaction. In addition, various developmental theorists, such as Erikson, have posited that many older adults reach a level of psychological maturity that allows them to view such changes in appearance with greater perspective and less ego involvement. Indeed, research done by Rybarczyk and colleagues (25) found a significant relationship between older age and fewer body image concerns following an amputation.

Social Perceptions and Body Image

As previously noted by a number of authors (1,26), body image is intertwined with social experience. Since postamputation body image is partly predicated on the perceived responses of others during the initial period, those responses are crucial to the formation of a new body image and self-concept. If individuals with amputations experience others as viewing them as inferior, freakish, or as someone to stay away from to avoid dealing with uncomfortable social issues, these experiences can be internalized in some fashion. Interestingly, because of advances in prosthetic technology and the use of strategies to conceal an amputation (e.g., clothing choice and not participating in certain activities), many individuals with amputations are able to "pass" as being nondisabled in social circles beyond their family and close friendships. In these cases, perceptions of others' potential reactions to an individual's amputation are often inferred from indirect comments and media depictions (13).

Indeed, some of the inferred negative perceptions can be accurate given the numerous studies documenting that the able-bodied public holds a wide range of prejudicial attitudes toward persons with disabilities (27). One of the most common negative social experiences described by individuals with amputations is that others view them as being globally inferior (i.e., not just in the domain of mobility in the case of amputation). Social psychologists refer to this "power of single characteristics to evoke inferences about a person" (19, p. 32) as the "spread effect." Similarly, the public frequently makes the mistake of assuming that individuals who undergo an amputation see it as a tragic event. The cumulative effect of these negative and biased attitudes can be a sense of alienation, which becomes a vicious cycle if an individual responds with further social withdrawal. Previous studies have suggested that diminished social support has a detrimental effect on psychological adjustment to amputation (3,28).

Being aware of the negative biases commonly held by the public and learning not to personalize these biases is often promoted as a healthy approach for individuals with disabilities (29). Chaiklin and Warfield (30) conducted one of the earliest adjustment studies with 24 patients with amputations and found that those who denied the existence of any kind of a social stigma were less likely to make good progress in a rehabilitation program (no psychological measures of adjustment were included). The authors suggested that awareness is a first step toward "managing" or "neutralizing" stigma.

In spite of the intuitive notion that it is adaptive to be aware of discrimination and stigma, our research found that individuals who reported being more stigmatized by others were more likely to be depressed (25). Higher levels of perceived social stigma also were linked to lower body image, as would be expected, and poorer overall adjustment, as rated by the individual's prosthetist. In effect, it seems more adaptive to be less attuned to the negative biases that others might hold, regardless of whether these biases were taken personally or not. An alternative explanation of this finding would be that these respondents accurately perceived a greater degree of bias from others because individuals with disabilities who have depression may actually elicit much stronger negative stereotypes and reactions from nondisabled persons (31). If this is the case, then it would be important for psychologists and other professionals to help these individuals differentiate between the negative responses they are getting in relation to their mood from those they are getting as a result of their amputation.

Future Directions

Although our knowledge of prostheses, amputation, and body image have advanced greatly in recent years, several avenues of inquiry warrant further exploration. First, future research projects should make a clearer distinction between individuals' experience of limb loss and their experience with and relationship to prostheses. Similarly, specific and potentially separate investigations of limb loss and limb absence are clearly indicated. There also is a need for preliminary work clarifying the role of depression, pain, and other medical and psychological factors in the body image–prosthesis relationship. Large, nomothetic, and prosthesis-specific investigations of vocational, social, and sexual functioning would also be valuable.

At a deeper level, we also need more sophisticated conceptual schema for understanding and classifying responses to prostheses and attendant changes in body image. Such a framework should be developed in conjunction with improved methods and measures for assessing the underlying constructs, including measures of both perceived stigma and body image following an amputation. Fortunately, the Amputation Body Image Scale (32) was developed and further revised and validated in recent research (33).

Moreover, a conceptual framework should be able to take into account emerging factors such as aging populations and changing prosthetic technology. Such a framework will become increasingly valuable as successive cohorts age into their peak amputation years and limb loss reaches epidemic proportions. In the U.S. alone, the incidence of diabetes and consequent peripheral vascular disease-related amputations are expected to double or even triple by the year 2025, due to the growing aging population and the obesity epidemic (34). Overall, given the size of this disability group and the prevalence of adjustment problems, more research attention is warranted using longitudinal methodologies, standardized measures, and larger, more representative samples.

Positive psychology and its emerging constructs also need to continue to be studied in context of psychological adjustment and adaptation of body image following an amputation (2,35). This would include the relationship of a positive body image to such variables as finding positive meaning in the amputation (36), hope, forgiveness, humor (e.g., jokes about one's prosthesis falling off in public), and downward comparison (i.e., comparing oneself to someone who sustained a more significant amputation or injury). There is much to be learned from the fact that the significant majority of individuals who undergo an amputation eventually integrate the change into their self-concept and body image and return to their preamputation "set point" levels of emotional health and satisfaction with their bodies.

Summary of Key Points

- Body image is thought to be a major component of the self-concept, and limb amputations pose a substantial threat to both body image and self-concept. A poor body image following amputation is correlated with a range of negative outcomes, including increased depression and decreased life satisfaction, quality of life, activity levels, and overall psychological adjustment.
- Individual variables tend to outweigh objective factors related to an amputation, such that level of the amputation does not appear to be related to overall adjustment or body image difficulties. However, traumatic amputations and phantom limb pain do appear to have a consistent negative impact on body image.
- The prosthesis is a central part of an individual's postamputation body image adjustment, allowing many individuals with leg amputations to "pass" in public as being nondisabled. Prostheses are often viewed as an extension of the body, and if there is a lack of satisfaction with either the functional or aesthetic aspects of the prosthesis, there are likely to be adjustment difficulties as well.
- Upper extremity amputations are much less common but tend to be more challenging in terms of psychological and body image adjustment, partly due to the fact that they are usually caused by trauma. In addition, arms and hands are crucial to both self-care and work activities as well as nonverbal communications. Upper limb prostheses are less effective than lower limb prostheses on both functional and aesthetic dimensions.
- Younger children integrate limb loss into their self-concept and body image but adolescents may have a more difficult time due the importance of body image during that period of development. Older adults may also have some developmental advantages when it comes to postamputation body image.
- Social perceptions regarding reaction to one's body have a significant effect on body image. Accordingly, following an amputation, perceived social stigma is predictive of poorer body image and wider adjustment problems.
- Further research, using more sophisticated methodology and measurement methods, is needed to further examine postamputation changes in body image and their impact on adjustment. In light of the healthy adjustment most individuals make in their body image, an increased focus on positive psychology is warranted.

Further Reading

http://www.landminesurvivors.org/what_limbloss.php

http://www.survivinglimbloss.org

Murray CD. The social meanings of prosthesis use. J Health Psychol 2005;10(3):425–441.

References

1. Orr DA, Reznikoff M, Smith GM. Body image, self-esteem, and depression in burn-injured adolescents and young adults. J Burn Care Rehabil 1989;10:454–461.
2. Rybarczyk B, Nicholas JJ, Nyenhuis D. Coping with a leg amputation: integrating research and clinical practice. Rehabil Psychol 1997;42: 241–256.
3. Rybarczyk BD, Nyenhuis DL, Nicholas JJ, Schulz R, Alioto RJ, Blair C. Social discomfort and depression in a sample of adults with leg amputations. Arch Phys Med Rehabil 1992;73:1169–1173.
4. Breakey JW. Body image: the lower-limb amputee. J Prosthet Orthot 1997;9:58–66.
5. Williamson GM. Restriction of normal activities among older adult amputees: the role of public self-consciousness. J Clin Geropsychol 1995;1: 229–242.
6. Wetterhahn KA, Hanson C, Levy CE. Effect of participation in physical activity on body image of amputees. Am J Phys Med Rehabil 2002;81: 194–201.
7. Rybarczyk BD, Behel JM. Rehabilitation medicine and body image. In: Cash TF, Pruzinsky T, eds. Body Image. New York: Guilford, 2002:395–402.

8. Rybarczyk B, Edwards R, Behel J. Diversity in adjustment to a leg amputation: case illustrations of common themes. Disabil Rehabil 2004;26:944–953.
9. Darnall BD, Ephraim P, Wegener ST, et al. Depressive symptoms and mental health service utilization among persons with limb loss: results of a national survey. Arch Phys Med Rehabil 2005;86:650–658.
10. Fisher K, Hanspal R. Body image and patients with amputations: does the prosthesis maintain the balance? Int J Rehabil Res 1998;21(4):355–363.
11. Cavanagh SR, Shin LM, Karamouz N, Rauch SL. Psychiatric and emotional sequelae of surgical amputation. Psychosomatics 2006;47:459–464.
12. Pucher I, Kickinger W, Frischenschlager O. Coping with amputation and phantom limb pain. J Psychosom Res 1999;46:379–383.
13. Murray CD. The social meanings of prosthesis use. J Health Psychol 2005;10:425–441.
14. Murray CD, Fox J. Body image and prosthesis satisfaction in the lower limb amputee. Disabil Rehabil 2002;24:925–931.
15. Delehanty R, Traschell L. Effects of short-term group treatment on rehabilitation outcome of adults with amputations. Int J Rehabil Health 1995;1: 61–73.
16. Cheung E, Alvaro R, Colotla VA. Psychological distress in workers with traumatic upper or lower limb amputations following industrial injuries. Rehabil Psychol 2003;48:109–112.
17. Esquenazi A. Amputation rehabilitation and prosthetic restoration. From surgery to community reintegration. Disabil Rehabil 2004;26:831–836.
18. Dudkiewicz I, Gabrielov R, Seiv-Ner I, Zelig G, Heim M. Evaluation of prosthetic usage in upper limb amputees. Disabil Rehabil 2004:26:60–63.
19. Wright BA. Physical disability: A psychological approach. New York: Harper and Row; 1983
20. Atala KD, Carter BD. Pediatric limb amputation: Aspects of coping and psychotherapeutic intervention. Child Psychiatr Hum D 1992;23: 117–130.
21. Tebbi CK, Mallon JC. Long-term psychosocial outcome among cancer amputees in adolescence and early adulthood. J Psychosoc Oncol 1987;5: 69–82.
22. Varni JW, Setoguchi Y. Correlates of perceived physical appearance in children with congenital/acquired limb deficiencies. J Dev Behav Pediatr 1991;12:171–176.
23. Varni JW, Setoguchi Y. Perceived physical appearance and adjustment of adolescents with congenital/acquired limb deficiencies. J Clin Child Psychol 1996;25:201–208.
24. Heckhausen J, Brim OG. Perceived problems of self and others: self-protection by social downgrading throughout adulthood. Psychol Aging 1997;12: 610–619.
25. Rybarczyk B, Nyenhuis DL, Nicholas JJ, Cash S, Kaiser J. Body image, perceived social stigma, and the prediction of psychosocial adjustment to leg amputation. Rehabil Psychol 1995;40: 95–110.
26. Goffman E. Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, NJ: Prentice-Hall, 1963.
27. Yuker HE. Variables that influence attitudes toward persons with disabilities: conclusions from the data. J Soc Behav Pers 1994;9:3–22.
28. Williamson GM, Schulz R, Bridges MW, Behan AM. Social and psychological factors in adjustment to limb amputation. J Soc Behav Pers 1994;9: 249–268.
29. Winchell E. Coping with Limb Loss. Garden City Park, NY: Avery, 1995.
30. Chaiklin H, Warfield M. Stigma management and amputee rehabilitation. Rehabil Lit 1973;34: 162–167.
31. Elliott T, Frank R. Social and interpersonal responses to depression and disability. Rehabil Psychol 1990;35:135–147.
32. Breakey JW. Body image: the lower-limb amputee. J Prosthet Orthot 1997;9:58–66.
33. Gallagher P, Horgan O, Franchignoni F, MacLachlan M. Psychometric and Rasch Analysis of the Amputee Body-Image Scale. Am J Phys Med Rehabit 2007;86:205–215.
34. Rowley, WR, Bezold, C. Diabetes Forecasts to 2025 and Beyond: The Looming Crisis Demands Change. Alexandria, VA: Institute for Alternative Futures, 2005. http://www.altfutures.com.
35. Rybarczyk B, Szymanski L, Nicholas JJ. Psychological adjustment to a limb amputation. In: Frank R, Elliott T, eds. Handbook of Rehabilitation Psychology. Washington, DC: American Psychological Association, 2002:29–47.
36. Dunn DS. Positive meaning and illusion following disability: reality negotiation, normative interpretation, and value change. J Soc Behav Pers 1994;9:123–138.

4

Management of Chronic Pain After Limb Loss

Dawn M. Ehde and Stephen T. Wegener

Overview

After limb loss, many individuals not only must adapt to the loss of their limb and the use of a prosthesis but also must contend with pain. Chronic pain too often disrupts physical functioning, sleep, mood, relationships, and participation in life activities. This chapter summarizes our current knowledge of the nature, scope, assessment, and treatment of pain in individuals with limb loss. First, the chapter briefly describes several relevant conceptual issues, followed by a summary of the research literature concerning specific types of pain after acquired amputation. The biopsychosocial risk factors for chronic pain are then described. After reviewing the clinical assessment of pain, our current knowledge regarding the treatment of pain is reviewed, followed by a discussion of some of the unanswered questions regarding pain after limb loss.

Conceptual Issues

Definitions

The International Association for the Study of Pain defines *pain* as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (1). Accordingly, pain is not only a sensory experience but also a psychological experience by virtue of its definition. Acute pain may be defined as pain elicited by the activation of nociceptive transducers at the site of local tissue damage due to injury, surgical procedures, or disease. Acute pain is sudden in onset and experienced for a limited time immediately following damage, and typically remits as the underlying pathology resolves (2). In contrast, chronic pain can be defined as recurrent or persistent pain that is present for 6 months or longer (1). Chronic pain may begin as acute pain with an obvious cause, such as an amputation surgery in the case of phantom limb pain, or it may have a more insidious and unknown onset. For some, chronic pain may persist beyond the expected healing time and may not arise from any detectable damage in the periphery.

After limb loss, chronic pain is most commonly classified based on the site of the pain. *Phantom limb pain* (PLP), one of the most commonly described types of pain following amputation, is defined as painful sensations perceived in the missing portion of the amputated limb. It is important to distinguish PLP from *nonpainful phantom limb sensations* (NPLSs), defined as sensations in the missing (phantom) limb that are not painful, as NPLSs are also common after limb loss. *Residual limb pain* (RLP) refers to pain in the portion of the amputated limb that is still physically present (i.e., the residual limb). As will be described in this chapter, persons with limb loss are at risk for chronic pain in a number of other sites, including the back, the contralateral limb, the hips, and the neck or shoulders (3–5). Pain after limb loss may also be classified according to whether it is due to nerve injury or damage (neuropathic pain) or some other cause such as inflammation or musculoskeletal pain (nonneuropathic pain). This distinction may be useful because some pain treatments are viewed as more appropriate for neuropathic pain and others for nonneuropathic pain. However, the extent to which this classification is ultimately associated with important treatments or outcomes has not been adequately examined in any patient population, including those with limb loss.

Pain as a Multidimensional Construct

Pain is a multidimensional experience beyond simply the location and severity of the pain. In clinical practice, pain is often conceptualized and assessed as a unidimensional construct, with patients typically being asked to rate their pain on a numerical rating scale (NRS) (e.g., 0 to 10 or 0 to 100, ranging from no pain to the worst possible pain). Such a rating scale assesses pain intensity, or the subjective rating of how much it hurts, can sometimes be thought of as the volume of pain. However, pain specialists now recognize the importance of other dimensions of pain as well, including duration, frequency of pain episodes, pain affect, and pain-related disability. Frequency and duration of pain episodes are especially relevant for understanding phantom limb pain due to its commonly episodic nature. Assessment of these dimensions is described in more detail later in this chapter.

Etiology

The common report of a perceived phantom limb (whether painful or not) for the majority of individuals with limb loss suggests the existence of innate neural networks in the brain able to generate all the qualities of experience felt to originate in the body. Melzack (6) proposed that humans have a neural network, the “neuromatrix,” widely extending throughout selective areas of the entire brain, including the somatic, visual, and limbic system. The output pattern from the hypothesized neuromatrix may account for the sensory, affective, and cognitive dimensions of pain experience and behavior (7). According to Melzack’s theory, input from the periphery is not necessary for the perception of sensation, as demonstrated by phantom limb perceptions.

Central and peripheral mechanisms are thought to contribute to the development of phantom limb pain (8), although their specific actions are not completely understood. Although central abnormalities may be more important for the maintenance of chronic PLP, the initiating event in the development of PLP is likely peripheral. One hypothesis is that the massive barrage of noxious afferent stimuli during injury or amputation surgery initiates central processes that subsequently generate pain. An alternative explanation is that the sudden loss of peripheral input may trigger central changes that result in deafferentation pain. Possible central processes involved in deafferentation pain include spinal sensitization and cortical reorganization. Spinal cord sensitization refers to the *N*-methyl-D-aspartate (NMDA) receptor-mediated sensitization of dorsal horn neurons in the spinal cord after amputation, possibly as a result of the loss of high threshold input to the dorsal horn neurons (9). This sensitization may result in spontaneous neuronal activity and increased sensitivity to afferent input (8). Cortical reorganization occurs when the topographic representation of the lost limb after amputation is taken over by sensory input from other areas of the body, a process that illustrates the plasticity of the nervous system (10). The functional role of cortical reorganization is unknown; one study found that greater cortical reorganization was associated with higher intensity phantom limb pain, suggesting that cortical reorganization may play a causal role (11). Peripheral mechanisms implicated in amputation-related pain include neural activity originating from afferent fibers in a neuroma, and spontaneous activity in injured dorsal root ganglion neurons (12).

Other possible etiologies of pain and discomfort exist for persons with limb loss, including neuromas, bone spurs, heterotopic bone, chronic wounds, and poorly fitting prostheses. Pain may also arise from stress and wear on anatomical structures due to limb loss and its subsequent biomechanical changes, including potential changes in gait pattern. Both joints and muscles may experience overuse wear and tear, resulting in pain over time. Similarly, pain in the back, neck, or shoulders may arise from an unnatural gait or changes in posture, although these biomechanical assumptions have not been empirically tested. For a more detailed discussion of these etiologies, the reader is referred to a recent review (13).

Scope and Nature of Pain in Limb Loss

Nonpainful Phantom Limb Sensations

Most individuals with limb loss experience NPLSs at some point (3,14,15). The NPLSs may include sensations such as touch, pressure, temperature, itch, posture, and location in space (16). Sensations may also involve feelings of movement in the phantom limb, such as the sensation that the distal part of the phantom limb is moving progressively closer to the residual limb, referred to as "telescoping" (6). Although by definition, these sensations are not perceived as painful, there has been no research, to our knowledge, regarding what impact, if any, NPLSs may have on individuals who experience them.

Phantom Limb Pain

At least 60% (17) but possibly as many as 85% (3,18,19) of individuals with amputation report PLP. Painful phantom sensations are commonly described as shooting, burning, stabbing, boring, squeezing, and throbbing (17). They have also been described as squeezing and knifelike (14). Phantom pain occurs most frequently in the hand or foot and is often most intense in these areas (20).

The onset of PLP typically occurs during the first week after surgery (14). Some studies have reported that PLP diminishes or disappears during the first 2 years postamputation (14,21), whereas others have reported that PLP persists for years or even decades after the surgery (19,22). Phantom limb pain is most often described in the literature as intermittent and episodic in nature (3,15), with episodes of PLP lasting anywhere from a few seconds to weeks, but most commonly reported in terms of minutes or hours. Using a prospective daily diary method, one study found that 84% of a sample of adults with limb loss (n = 89) reported PLP on each of the 7 study days, and 16% reported PLP on 3 to 5 days of the study period (23). A large majority, 71%, reported more than one episode of PLP per day, and of these, 75% reported experiencing four to five episodes per day. Regarding duration, 80% experienced PLP for 6 to 10 hours each day, with only 11% reporting an average of 12 or more hours of PLP each day. Average pain intensity in this same study was found to vary across the 7-day study period from 3 to 8 on a 0 to 10 NRS (mean = 4.5, standard deviation [SD] = 4.6). Two large cross-sectional studies found average pain intensity levels between 5 and 6 on the same scale (3) (22). Although there is variability across studies, average pain intensity at this level (5 to 6 on a 0 to 10 NRS) is generally classified as moderate in severity (24).

Conclusions regarding the prevalence and characteristics of PLP are influenced by the way PLP is defined and measured. For instance, studies that ask participants to report "any PLP" may include data from persons for whom PLP is occasionally present but not particularly problematic. Therefore, it is important to determine the extent to which pain is bothersome and disabling. Recent research suggests that PLP is present but not highly disabling for the majority, but may be very troublesome for a significant subset of persons with limb loss. For example, 23% of a community-dwelling sample with lower limb amputation (n = 255) reported that phantom pain was significantly disabling and moderately to severely limited their functioning (3). Another study reported that 22.4% of persons with limb loss secondary to trauma reported severe PLP in the previous month, with severe defined as being "extremely" or "very" bothered by pain (5). A recent large national study in the United States of 1538 persons stratified for etiology of limb loss observed that 39% reported PLP in the severe (7 to 10 on 0 to 10 scale) range (19).

Most of the research on the scope and nature of PLP has been conducted on samples composed mostly or completely of individuals with lower limb amputations. Upper limb amputation is less common than lower limb, and prevalence data for upper PLP are harder to find. Two recent community surveys have found rates of PLP of 41% ($n = 99$) (25) and 51% ($n = 72$) (15) in samples of persons with upper limb loss. The latter study also found that 48% of those with pain experienced it on a daily basis, and the presence of phantom sensations was associated with a greater relative risk (RR) of PLP (RR = 11.3). In a clinic sample (n = 76) of people with upper limb loss (26), 69% reported PLP. More research is needed on all aspects of PLP in persons with upper limb loss.

Residual Limb Pain

Acute residual limb pain (RLP) is a natural consequence of amputation that for many, but unfortunately not all, remits with healing of the surgical site. Prevalence rates for chronic RLP vary considerably in the literature from 13% to 71% of persons with limb loss (9,19). Nikolajsen and Jensen (17) contend in their review of the literature that RLP persists beyond the expected healing time for only 5% to 10% of those with limb loss. In contrast, chronic RLP has been reported as high as 74% in persons with lower limb (3) and 55% in persons with upper limb (26) loss. These results are supported by Ephraim and colleagues (19), who observed in a sample with an average of 4 years since amputation that 45% reported "sometimes" and 22% reported "always" experiencing RLP. Furthermore, 30% of those who experienced RLP described it as severe (7 to 10 on 0 to 10 scale). Methodological variations in terms of study populations (clinic versus community), study design, definitions of RLP, and measurement selection contribute to the variability across studies. Although longitudinal epidemiological studies that clearly define RLP are needed, recent data suggest that RLP may be a significant pain problem for this population.

Similar to PLP, RLP tends to be intermittent and episodic in nature. For example, Gallagher and colleagues (27) found that of the 48% of their sample ($n = 104$) who reported RLP, 13% experienced an episode of RLP once or twice in the week preceding the survey, 63% experienced an episode more than twice, and 13% experienced constant RLP. In another study of people with upper limb loss, three fourths of those with RLP described it as intermittent, and one fourth described it as continuous (26).Like PLP, several studies suggest that RLP is typically in the range of mild to moderate intensity, although a significant subset of individuals (15% to 35% across different studies) report RLP in the severe range (7 to 10 on a 0 to 10 scale) (3, 5, 19).

Pain in Other Anatomic Regions

Chronic pain problems may arise in anatomical regions beyond the amputated limb. Chronic back pain appears to be common in persons with lower limb amputations; the few studies that have examined its point prevalence suggest it is present in approximately half of all persons with lower limb loss (4, 28, 29), more than two times higher than the prevalence of chronic back pain in the general population (estimated point prevalence of 15% to 25%) (30). Further documentation of the problem of back pain for persons with limb loss was observed by Ephraim et al. (19), who found that 45% reported experiencing back pain "sometimes" and 18% "always." Of those who experienced back pain, 24% described it as extremely bothersome. Individuals with upper limb amputations may also experience chronic back and neck pain, due in some cases to biomechanical factors such as hiking one's shoulders and positional scoliosis, although the prevalence of pain in these regions has not been well documented.

Chronic pain problems in regions other than the back and amputated limb are sometimes seen in clinical practice as well as reported in the literature. In a large national sample in the U.S., pain in the contralateral limb was reported as being present "sometimes" by 38.6% and "always" by another 10.5% (19). Of those who had pain, 18.7% described it as severe. These results are similar to the 16.9% of individuals with traumatic lower limb loss who reported severe pain in the contralateral limb (5). Although the scope and nature of pain problems in other anatomical regions are unclear, pain in multiple regions appears to be a fairly common, yet often overlooked, experience for individuals with limb loss.

Impact of Chronic Pain on Functioning and Quality of Life

Chronic pain frequently negatively impacts not only physical functioning but also emotional, social, and vocational functioning. As with other chronic pain conditions, research suggests that chronic pain after limb loss may have serious and detrimental consequences for functioning and quality of life. For example, in a large study of individuals with lower limb amputation ($n = 437$), van der Schans and colleagues (31) found that those who experienced PLP had a poorer quality of life compared to those who did not experience PLP. Higher levels of pain in persons with limb loss have also been associated with higher overall disability

(32). Among individuals with limb loss, pain has also been associated with interference in prosthetic training and walking ability (33), employment (5,34), and social activities (27). Compared to persons with limb loss who do not experience pain, those with pain have been found more likely to report depressive symptoms (35, 36) and anxiety (22). Consistent with the biopsychosocial model, increases in depression, stress, and anxiety have been associated with intensified PLP episodes (37).

Although the impact of PLP has received the most attention in the literature, several studies suggest that RLP or back pain can also interfere significantly with functioning in persons with limb loss. For example, of the persons reporting RLP in Gallagher et al.'s (27) survey, almost 40% reported that RLP interfered "moderately" to "a lot" with activities, compared to 16.7% who reported the same level of interference from PLP. When present, chronic back pain may contribute to pain-related impairment and function as much as or more than phantom or residual limb pain (4,38).

Although pain is the norm, rather than the exception, after limb loss, pain-related disability and distress are not universally experienced. In one study of individuals with lower limb loss and PLP (3), 75% of the sample could be classified as having a low level of pain-related disability on a standardized measure of pain classification, the Chronic Pain Grade (39), demonstrating that many individuals with limb loss and pain function quite well despite their pain. Thus, although pain can potentially contribute to problems in rehabilitation, employment, daily activities, and psychosocial functioning for individuals with limb loss, one cannot assume that pain will always lead to such problems. Research is needed to explore the factors that contribute to resilience to pain after limb loss.

The Biopsychosocial Model for Understanding the Experience of Pain After Limb Loss

Significant advances in the understanding and treatment of chronic pain in persons with pain as the primary problem occurred when pain stopped being viewed exclusively from a biomedical perspective, and biopsychosocial models of chronic pain were developed (40). Biopsychosocial models of chronic pain acknowledge that although pain usually has an underlying biological basis, psychosocial factors, such as an individual's cognitions, coping responses, behaviors, and the social environment, have a significant, and sometimes a profound, impact on the experience of pain and its effects on physical and psychological functioning. The shift in thinking from an exclusively biological to a biopsychosocial perspective has had an important effect on how researchers and clinicians understand and treat chronic pain in populations where pain is typically the primary problem. This shift also provided a theoretical rationale for psychosocial pain interventions, including operant conditioning, cognitive-behavioral therapy, self-hypnosis and relaxation training, and family therapy and education, all of which have subsequently been found to be effective for decreasing perceived pain severity and decreasing the negative impact of pain on people's lives (41). Hundreds of thousands of individuals with chronic pain have benefited from these treatments (41). The field of limb loss research has been slow to adapt and incorporate biopsychosocial perspectives and interventions to pain, however. To assist clinicians and researchers in adopting a more comprehensive model for amputation-related pain, we provide a summary of the biopsychosocial correlates of pain after limb loss.

Biological Factors

Preamputation Pain

Current models regarding the biology of pain suggests that chronic or intense pain felt in the limb prior to amputation may create a somatosensory pain memory in the brain that puts an individual at risk for pain in the amputated limb after amputation. A number of studies have explored the relationship between preamputation pain and the development of PLP and RLP, producing complex and sometimes contradictory findings. An earlier prospective study of 58 patients (mainly participants with lower limb loss) found that preamputation pain intensity, but not duration, was associated with PLP during the first 6 months after amputation but was not predictive of persistent PLP at 2-year follow-up (14,42). Phantom limb pain was also more likely when the duration of preamputation pain was longer than 1 month (42). In contrast, Nikolajsen et al. (43) found that the intensity of preamputation pain was predictive of postsurgical experiences of PLP in the first 3 months after surgery but not of either PLP or RLP at 6 months. Another prospective study found that preamputation pain intensity, but not duration, was the only significant predictor of chronic PLP intensity at 2 years postamputation and was not predictive of PLP intensity earlier in the course of recovery (i.e., at 6- and 12-months post surgery) (44). These results, although somewhat contradictory and from relatively small samples (<60 participants), suggest that preamputation pain may be an important risk factor for chronic pain. Research on larger samples using prospective designs are needed to examine the relationships and mechanisms by which preamputation pain may impact chronic amputation pain.

Acute Pain

Acute pain has been suggested as a risk factor for chronic pain in several different pain populations, including persons with PLP (45). Experimental models of acute pain mechanisms have shown that sustained, high-intensity noxious input may sensitize central neural structures involved in pain perception, setting the stage for long-term pain [for a review, see Melzack et al. (46)]. In one of the only studies to examine the role of acute pain (i.e., pain in the immediate postoperative period) in chronic amputation pain, Hanley et al. (44) found that acute PLP intensity, assessed on days 4 and 5 postsurgery, was the only significant independent predictor of chronic PLP intensity at 6 and 12 months postsurgery. Hanley et al. also found that acute RLP was the best overall predictor of chronic RLP. Although preliminary and in need of replication, these findings suggest that acute pain intensity assessed immediately after amputation may help identify a subset of patients at greater risk for chronic pain. Patients thus identified as at "high risk" for bothersome chronic pain could then be targeted for early interventions aimed at preventing or managing chronic postamputation pain.

Other Biological Factors

A number of other biological risk factors for chronic PLP pain have been examined in the literature, including age, level of amputation, amputation etiology, and comorbid medical conditions. After controlling for other potential confounding factors, no consistent relationships with chronic PLP have been found (19), however, for any of these factors. In addition, PLP has been found to be equally present in persons with traumatic and persons with vascular amputations (18). Factors that appear to put individuals at increased risk for RLP are younger age, traumatic amputation, loss of a lower limb, and comorbid conditions; time since injury does not appear to increase the risk for RLP (19).

Psychosocial Factors

Although pain after limb loss is clearly not the result of psychopathology, the recent emphasis on physiological mechanisms runs the risk of overlooking the various psychosocial factors that may play a role in exacerbating pain or decreasing adaptive functioning after limb loss. The literature documents a number of psychosocial factors, particularly cognitions (thoughts, beliefs, appraisals), coping strategies, social support, and depression, that have been associated with functioning among persons with chronic pain (47, 48). Only a few studies have examined the role of psychosocial factors in adjustment to chronic pain following limb loss; these are reviewed below.

Catastrophizing Cognitions

In people with primary chronic pain, research has consistently shown that the strongest relationships are typically between maladaptive pain beliefs/cognitions and negative pain-related outcomes (49). In particular, catastrophizing has been consistently and strongly associated with virtually all pain outcomes investigated (49, 50). *Catastrophizing* can be defined as excessively negative and unrealistic thoughts or self-statements about pain. Examples of catastrophizing cognitions include thinking "this pain is awful and I feel that it overwhelms me" or "I can't stand this." Numerous studies have shown catastrophizing to be positively associated with higher levels of pain intensity, pain-related interference with activities/participation, psychological distress, analgesic use, medical services utilization, and vocational dysfunction [for reviews, see (49, 51)]. In nearly every study, the relationships between catastrophizing and adjustment variables are moderate to strong (47) and remain strong even when controlling for variables that may influence the relationship such as demographics, pain level, pain beliefs, or depressive symptoms (52,53). Although catastrophizing is related to depression, its influence on pain adjustment appears to be independent of mood (53–55).

Research on psychosocial factors has shown that pain catastrophizing stands out as a significant risk factor for poor adjustment to PLP as it does in the general pain literature. For example, strong associations between pain catastrophizing and measures of pain severity and psychological distress were seen in samples that included people with upper limb loss and people with lower limb loss (56, 57). Even when controlling for pain intensity, pain catastrophizing was the single most important predictor of PLP pain interference and depressive symptoms in the first 6 months (58) and at 1 and 2 years (59) after a lower limb amputation. One other cognitive factor often predictive of outcomes in the general pain literature, one's perceived control over pain, has not yielded empirical support thus far in the limb loss population (59,60), suggesting that perceived control over pain may have no or only a limited impact on functioning in persons with PLP.

Pain Coping Strategies

Coping strategies used to manage pain, such as diverting attention away from pain, using positive self-talk, and increasing activity levels, have shown significant associations with positive adaptation to chronic pain (49), including chronic PLP (56,57). Pain-contingent rest, in particular, has emerged as a pain coping strategy strongly related to dysfunction (61). Resting in response to pain may arise from or be reinforced by the belief that pain has been avoided by resting or by avoiding unpleasant activities (62). However, pain-contingent rest may contribute to muscle atrophy and decreased tolerance for activity, leading to greater pain dysfunction over time (62). In persons with PLP, pain-contingent rest has not been found to be a significant predictor of pain intensity, dysfunction, or distress at 1 or 2 years after lower limb amputation (59). Further research should examine pain-contingent rest and other pain coping strategies in other samples and at other time points beyond 2 years.

Social Environment

One of the most important factors contributing to functioning in the context of pain is the social environment. Numerous studies have shown that higher levels of social support have been associated with better adaptation to chronic pain (47,63). In one study of PLP, persons who reported receiving support prior to an amputation were less likely to experience PLP than those who did not receive support (27). Social support was also positively associated with improvements in and adaptation to PLP (59). Not all kinds of social support are adaptive or helpful, however. One type of environmental response to pain, solicitous responding, has been associated with poorer pain outcomes. Solicitous responding refers to solicitous behaviors, including offers of assistance, efforts to take over a task, and sympathy specific to the patient's pain or pain behavior by a significant other. Research has demonstrated that solicitous responding is positively associated with pain-related dysfunction and distress in the first 2 years after limb loss (59). Furthermore, the fact that in both of these studies perceived social support and solicitous responses made statistically independent contributions to changes in functioning over time, even when controlling for the effects of the other, suggests that the mechanisms by which these social environmental influence outcome are independent of one another. Although more research is needed confirming these relationships, current findings suggest that interventions may benefit persons with limb loss pain if they build general social support while reducing significant others' often well meaning but potentially detrimental solicitous responses to pain.

Fear Avoidance

Pain may be associated with fear of movement and described by a fear avoidance model (64). Fear avoidance can be a helpful strategy in that it may reduce the chance of immediate pain, but it is generally considered maladaptive because it often interferes with rehabilitation and the return to usual activities. Fear avoidance has been implicated as a mediator of disability measured in the laboratory as well as with daily life activities (64). Avoidance behavior has also been associated with increases in RLP and emotional distress (65,66). Despite the prevalent focus on fear of pain at early stages of pain, there is little evidence to link such fear states with poor prognosis. The evidence suggests that fear may play a role when pain has become persistent (67).

Depression

Depression is a common experience following limb loss. The reciprocal nature of the depression–pain relationship has been well established, and longitudinal studies are now beginning to investigate the directionality of this relationship. It has been established that the presence of one increases the likelihood of the other, and that co-occurrence decreases the likelihood of successful therapies, whether the target of treatment is primarily the depression or pain (68). In a recent study, nearly a third of individuals with limb loss (28.7%) surveyed were found to have depressive symptomatology; people with limb loss experiencing pain were more likely to have depressive symptoms than those not experiencing pain (19). Likewise, depression was a key predictor of both the reported intensity level and the bothersomeness of chronic pain across all pain types (RLP, PLP, back pain) after controlling for other factors. These results support the need to assess the mood of persons reporting amputation-related pain and aggressively treat depression as part of the pain control program. Possible mechanisms underlying the pathophysiology of depression and pain could be involvement of the monoamines (5-hydroxytryptamine [5-HT, serotonin] and noradrenaline (NA)) and the hypothalamic-pituitary-adrenal (HPA) axis. Further, converging evidence from brain imaging studies suggests overlapping patterns of brain activation are induced by both psychological distress and by pain nociception.

Acceptance of Pain

Another concept that is gaining recognition in the pain literature is the concept of "acceptance of pain" (69). This refers to the idea that an individual might manage better if he or she is able to reduce unsuccessful attempts to avoid or cure pain, and focus instead on the pursuit of relevant personal goals despite pain. Greater acceptance of pain is hypothesized to be a factor that may underlie adaptive pain coping. Research supports this hypothesis, and indicates that patients who are able to focus on goals other than pain reduction do better than those who do not (70–72). Moreover, research has shown that treatment designed to increase acceptance of pain results in improvements in emotional and physical functioning (73). The extent to which pain acceptance is related independently to functioning in persons with limb loss pain is not known, as this construct has not been tested in the limb loss population.

Summary

Research has shown that although biological factors may be important in the development and maintenance of chronic pain in persons with limb loss, pain-coping responses, pain-related cognitions (particularly catastrophizing), social factors, and depression also play important predictive roles in how well persons function.

Clinical Assessment of Pain

Given the prevalence of pain after limb loss and the fact that it cannot be assumed that pain will diminish over time, health care providers should routinely assess pain in their patients with limb loss. A number of reliable and valid standardized instruments are available in the general pain literature, and many of these can be used with or adapted for persons with limb loss. We will briefly highlight some of the pain dimensions that may be of particular use in clinical practice of psychoprosthetics. For more information on clinical pain assessment, the reader is referred to the *Handbook of Pain Assessment* by Turk and Melzack (74). For guidance on selecting measures for clinical research on pain, see Dworkin et al. (75).

Standardized pain intensity rating scales provide patients and clinicians with a simple method to quantify pain intensity and track changes over time. One of the most widely used rating scales is the 0 to 10 numerical rating scale, where 0 refers to "no pain" and 10 refers to "pain as bad as it can be." Research has shown that the numbers on this scale are interpreted similarly across individuals and medical conditions. When pain intensity is classified based on its interference with daily functioning, pain in the 0 to 4 range is typically classified as mild pain, 5 to 6 as moderate, and 7 to 10 as severe, among persons with limb loss (24). It may be helpful to ask patients to rate, using a numeric scale, their worst pain, least pain, and average pain over a defined time period (typically a week or a month, depending on the setting) as well as their pain at the time of the assessment. Information about various levels of pain may provide useful information not otherwise obtained by a single rating of average pain. For example, information about the worst pain may help the clinician understand the magnitude of suffering or activities or conditions that may contribute to pain flare-ups; conversely, information about least pain may point to strategies that could lead to pain relief (e.g., if someone reports low pain when relaxed, relaxation may be recommended).

Because the impact of pain on an individual's life will depend on many different factors, pain assessment extends beyond a simple rating of pain intensity. We recommend specifically asking patients to answer questions regarding PLP, RLP, back pain, and any other types of pain they may have. Clinicians will want to assess the onset, frequency, and duration of pain episodes, as well as the type of sensations experienced, which may help to pinpoint the cause of pain. For example, Sherman et al. (20) suggested that reduced blood flow to the residual limb may be described as burning, tingling, or throbbing pain and that increased muscle tension may be described as cramping or squeezing.

An excellent standardized self-report measure of pain interference is the Pain Interference Scale of the Brief Pain Inventory (76), which assesses how pain interferes with a variety of daily activities, including sleep, self-care, mood, recreational activities, work, and relationships. It uses a 0 to 10 numeric rating scale similar to the pain intensity scale, which may facilitate ease of use and provide simple, easily quantified information about pain's impact on important life activities.

Dimensions of functioning in persons with lower limb amputations can be assessed with either of two well-known validated self-report measures: the Trinity Amputation and Prosthesis Experience Scales (TAPES) (77) and the Prosthesis Evaluation Questionnaire (PEQ) (78). The TAPES was designed to measure multiple dimensions of adjustment to amputation and lower limb prostheses; items pertaining to pain assess the presence, frequency, duration, and intensity of PLP and RLP, as well as the extent to which pain interferes with daily life. The PEQ was developed to measure the prosthesis function and quality of life of persons with lower limb amputations; the 12-item pain scale assesses the frequency, intensity, and bothersomeness of NPLS, PLP, RLP, and back pain.

A number of standardized, self-report measures of pain, although not designed specifically for pain associated with limb loss, have been used successfully in many medical settings and may enable comparisons with other pain populations. The Brief Pain Inventory (BPI) in its entirety may also be used, as it also includes not only the interference scale but also 0 to 10 ratings of pain intensity and a body diagram for recording pain locations. The Chronic Pain Grade (CPG) (39) is a simple, reliable, and valid measure that can provide information about several dimensions of pain, including a classification, or grade, of an individual's level of pain-related disability. The CPG has been used with diverse pain populations, including at least one sample with limb loss (3).

A number of measures exist that assess pain-coping strategies and cognitions [see Turk and Melzack (74)]. These measures have primarily been used as research tools, and as such, tend to be long and do not have well-defined cutoffs for use in clinical practice. Nonetheless, clinicians may wish to consider examining them for ideas on measuring coping strategies, catastrophizing cognitions, or social support beyond the clinical interview.

Standardized measures can be built into assessment procedures in most clinical settings and can typically be self-administered quickly and easily. Benefits include the ability to track patient progress over time and to make comparisons between different settings and populations. We encourage clinicians to assess pain interference in order to provide a clearer picture of the impact of pain on daily activities and general functioning.

In addition, when working with patients over time, individuals with limb loss pain should be strongly encouraged to keep a pain diary for a week or more, depending on the frequency of their pain, to identify factors (e.g., prosthesis use, physical or mental stress, diet, coping strategies) associated with their pain.

A thorough medical examination is important for assessing any neurological, musculoskeletal, or vascular issues that may contribute to the experience of pain in a person with limb loss. As discussion of the medical examination is beyond the scope of this chapter; the reader is referred to other reviews (13,79). A prosthetic and orthotic assessment, including gait assessment and examination of the prosthetic socket or suspension system, is also key when a patient presents with pain, as the assessment may reveal avenues for pain relief. Pain specific to one specific area may imply regions of the socket or suspension system causing undue pressure or irritation at the anatomical site. How the prosthetic device contacts the body at rest, when sitting, and in dynamic situations should be assessed. Gait assessment should include, while standing, an observation of limb length and the levelness of the pelvis, as improper prosthetic length may cause gait deviations that may be improved with adjustment of the device in persons with lower limb amputation (80). The assessment should also include observation of symmetry, balance, proportion of time in stance and swing phase on each limb, and deviations of the trunk, hips, knees, and feet. Clinical experience suggests that chronic gait deviations may cause or aggravate back pain, although this assumption has not been empirically tested. Similarly, individuals' posture and movements during common upper limb activities should be assessed for biomechanical and other abnormalities in persons with upper limb prostheses.

Pain Interventions

More than 60 different treatment strategies for PLP have been reported in the literature (20), but few effective treatments have been identified (81,82). Although the majority of persons with chronic pain and limb loss have tried numerous treatments for pain, the treatments that have been used have tended, on average, to be rated as only somewhat helpful (81). Conclusions regarding the efficacy of most of the treatments currently in use have been hampered by a lack of randomized clinical trials and other methodological concerns, including small sample sizes, lack of control groups, lack of blinding, heterogeneous populations, and short follow-up periods. Furthermore, the treatment literature has tended to focus exclusively on phantom limb pain to the exclusion of RLP. Thus, much of what is currently known regarding the efficacy of existing amputation pain treatments is based on clinical experience, case studies, nonrandomized designs, or other populations. What follows is a brief summary of pain interventions, with emphasis on psychological interventions. Interventions for the residual limb, including early postoperative residual limb care, are crucial for managing acute pain and possibly for preventing severe long-term pain (83) but are beyond the scope of this chapter. For a review of interventions focused on postoperative residual limb care, surgery, cortical reorganization, or preemptive analgesia, the reader is referred to another review (84).

Pharmacotherapy

A number of medications are commonly used to treat PLP and RLP. The most commonly used medications for any type of chronic pain are the nonnarcotic analgesics. Research on their efficacy for amputation-related pain is unavailable, but they may serve as an initial medication for mild PLP or RLP pain due to their minimal risk for significant adverse effects (9). Tricyclic antidepressants (TCAs) and, more recently, other classes of antidepressants are commonly used to treat chronic pain conditions, including PLP. The efficacy of TCAs in the treatment of painful peripheral neuropathies has been supported (85). To our knowledge, only one randomized controlled clinical trial examined the efficacy of TCAs for relieving chronic amputation-related pain. This study of 39 adults with either PLP or RLP compared the effects of amitriptyline to an active placebo (benztropine mesylate) and found no significant benefit for either type of pain (86). The efficacy of other types of antidepressants in PLP and RLP is not known.

Antiseizure medications are commonly used to treat PLP based, in part, on clinical impressions that they may minimize the number of episodes of phantom pain. In one of two recent double-blind, placebo-controlled, crossover studies of gabapentin for PLP, Bone et al. (87) found that gabapentin resulted in significantly greater pain intensity reduction compared with placebo after a 6-week trial (there were 14 completers). In contrast, another trial with 24 participants did not find a significantly greater reduction in pain intensity comparing gabapentin to a placebo (88). However, a greater proportion of patients reported a meaningful pain reduction during the gabapentin phase. These small studies suggest that gabapentin may be effective for certain subgroups of patients, but more clinical trials are needed to explore the effectiveness of this medication.

The use of opioid analgesics for the treatment of neuropathic pain remains controversial. Opioid analgesics (also referred to as “narcotics”) are very effective in the short-term and are recommended for most patients during the immediate postsurgical period given the need for pain relief as well as the potential but unproven reduction in risk for developing chronic pain. However, long-term use of opioids can result in dependence and increasing tolerance to higher dosages, leading to poorer pain control and greater disability and depression over time (9). Common unpleasant side effects include constipation, sedation, and nausea, with more adverse effects also possible, particularly at higher doses. Many patients view the costs of opioids, including their side effects, as not outweighing their benefits. Interestingly, however, preliminary evidence exists that opioids may influence cortical reorganization in individuals whose cortical reorganization is not yet irreversibly chronic. A double-blind crossover trial ($n = 12$) of oral morphine sulfate (MST) for PLP found a significant pain reduction (50% decrease) in 42% of the patients over the 4-week trial (89). In addition, this study found evidence of reduced cortical reorganization with MST in three of the patients, concurrent with reductions in pain intensity. Although a promising line of research, larger clinical trials are needed that examine long-term benefits and consequences of narcotic use. For now, clinicians must balance the needs for pain relief with the potential for harm over time.

Rehabilitation Interventions

Early rehabilitation interventions may reduce the likelihood of chronic severe pain in persons with limb loss. Pezzin and colleagues (5) found that higher intensity inpatient rehabilitation of people with limb loss was associated with lower levels of bodily pain at long-term follow-up, as well as increased physical functioning and vitality. Early rehabilitation goals may include maintaining muscular strength and preventing contractures, both of which may decrease the likelihood of severe long-term pain. Contractures can develop as a result of inactivity (i.e., prolonged sitting), muscle imbalance, fascial tightness, protective withdrawal reflex into hip and knee flexion, and loss of plantar stimulation in extension. After lower limb amputation, it is important to maintain full mobility in the hips and knees. Overall, an exercise program that is begun early and maintained by the individual is ideal for maintaining strength and preventing pain. Patients can be encouraged to begin ambulating as early as possible with crutches or temporary prostheses (90) and to maintain regular exercise indefinitely.

As described above, back pain and pain in the contralateral limb can be a significant source of pain in persons that tends to be overlooked in the literature. Physical therapists, prosthetists, and other care providers may want to pay careful attention to gait patterns that may contribute to back or contralateral limb pain and treat back pain as indicated.

For individuals with especially high levels of suffering and disability, referral to a multidisciplinary pain rehabilitation program should be considered if such a program is available. Multidisciplinary pain rehabilitation programs are typically based on the biopsychosocial model of pain and address not only the pathophysiological processes but also the psychological, social, and behavioral factors associated with pain, distress, and pain-related disability. Modalities for rehabilitation therapies may include physical therapy, occupational therapy, vocational rehabilitation, and psychological approaches. Such programs have strong empirical support for their effectiveness when chronic pain is the primary disability (91), but have not been empirically tested for pain in individuals with limb loss.

Psychological Interventions

Self-Hypnosis Training

A growing body of research, including a number of controlled clinical trials published over the past decade, supports the efficacy of self-hypnosis training for managing both acute and chronic pain conditions (92). Case series of adults with chronic pain secondary to disability, including limb loss, are consistent with this evidence (93). Similar to analgesic medications, self-hypnosis training rarely, if ever, eliminates pain completely; nor does it benefit all patients. However, there appears to be a subgroup of persons with chronic pain, including those with amputation-related pain, who report substantial decreases in pain severity following self-hypnosis training and who are able to maintain improvements over time (93). Moreover, unlike many analgesic medications, the "side effects" of self-hypnosis training are virtually all positive. For example, in 30 patients from a case series of patients with disability-related pain (of whom six had amputation-related pain), 40 different benefits of the training were identified, with no negative effects reported (94). In addition to pain relief, these benefits included increased perceived control over pain; increased relaxation and well-being; improved sleep; and decreased stress, anxiety, and depressive symptoms. Randomized controlled trials of self-hypnosis analgesia for amputation-related pain are needed.

Relaxation Training

Pain and other stressors often result in a natural response of repeated and prolonged tensing of muscles, which tends to worsen pain. Psychologically, negative expectations related to pain and other stressors associated with limb loss can also lead to muscle tension and maladaptive coping. One of the best ways to counteract the tensing effects of pain and stress is to practice various forms of relaxation. Relaxation allows the muscles to loosen and lengthen and the mind to focus on pleasant thoughts rather than distress. There are many methods to promote relaxation that require little or no training on the part of the provider. Suggested strategies may include exercise, warm baths, listening to music, prayer, deep breathing, and imagery. While some of these strategies can be tried without any instruction (warm baths, listening to music, prayer), there are others (deep breathing, imagery) that initially may need to be practiced under the guidance of a professional to achieve optimal benefit from the skill. Individuals vary in their ability to relax, so trying a variety of relaxation techniques may be necessary to find those that have the intended response. Like self-hypnosis, it is also necessary to practice the skills on a regular basis to achieve optimal benefit from them. Relaxation techniques often work best if used as a preventative measure before pain or stress becomes too intense. In addition, relaxation exercises may work best for chronic pain and ongoing stressors when coupled with other coping strategies.

Cognitive Therapy

Given the substantial research linking cognitions, including catastrophizing, with pain severity, pain-related disability, and distress (49), it is not surprising that psychological interventions have been developed targeting maladaptive cognitions. In the context of pain treatment, cognitive therapy, or "cognitive restructuring" is an intervention designed to teach patients to (1) examine the thoughts that they have about their pain problem; (2) determine the extent to which these thoughts are adaptive and helpful, neutral, or maladaptive/unhelpful (e.g., "catastrophizing" cognitions); and (3) to replace any maladaptive thoughts with adaptive and reassuring ones. A number of studies support the efficacy of psychological interventions utilizing cognitive therapy for treating chronic pain (95, 96). Although research on the efficacy of cognitive therapy as a treatment for pain in persons with limb loss has only recently been undertaken, pilot research indicates that it benefits persons with limb loss and chronic pain as much as it does individuals with other chronic pain problems (97).

Interventions Targeting the Social Environment

The notion that chronic pain could be successfully treated by altering how others in a patient's environment responded to them when they show "pain behaviors" (behaviors that communicate pain to others, verbal reports of pain, and nonverbal behaviors such as limping, withdrawing, grimacing, etc.) was radical when it was introduced nearly 40 years ago (98). However, this idea gained gradual acceptance, especially as research demonstrated that interventions that utilized operant approaches resulted in substantial improvements in pain intensity, physical functioning, and emotional functioning. Although there is not currently much research examining the effects of the social environment on pain and functioning in persons with limb loss, what exists (27,59) is consistent with that from other pain populations and strongly supports the need to take the environment, in particular, the family environment, into account when assessing and treating pain in persons with limb loss.

Other Interventions

A number of other psychosocial interventions may be useful for treating persons with chronic pain and limb loss, including self-management interventions and behavioral activation (for a discussion of self-management and behavioral activation, see Chapter 7). For patients with a fear of pain and resulting avoidance behavior, treatment should begin with education about the pain and move to graded exposure to the feared stimulus to challenge patients' maladaptive beliefs about their condition. The goal of treatment is to alter the individual's perceptions of pain as a feared stimulus and enable confrontation of the pain and injury to facilitate recovery. Other constructs related to fear avoidance, such as catastrophizing, may require concomitant intervention in order to maximize benefits. Treatment of comorbid depression and sleep disturbances are also critical components of effective pain management, although too often persons with limb loss who are depressed are not receiving adequate treatment for these (99).

Implementation of Psychosocial Interventions

Most persons with chronic amputation pain do not obtain or participate in psychosocial interventions for chronic pain. For example, in one survey, fewer than 10% of persons with phantom limb pain (81) reported using a psychological intervention for pain. Our clinical experience is that most patients with amputation pain are offered psychosocial interventions only after all biomedical interventions have been either tried and found inadequate or otherwise ruled out. Our belief is that psychosocial interventions should be considered, and offered when appropriate, as "first-line" pain interventions that can be used concurrently with other medical and rehabilitative treatments. We hypothesize that the sooner these treatments are considered and offered, the more likely the patient will benefit from them.

A model for the integration of psychosocial interventions in the care of pain is as follows: First, it must be clear to the patient and the clinician that referral for multidisciplinary or psychosocial pain management does not preclude efforts to treat the biological aspects of the pain problem. In addition to this ongoing effort, obtaining patient input regarding their treatment goals is critical. The clinician collaborates with the patient to determine "what would be different as a result of treatment in terms of comfort, function, activities, and quality of life?" Although pain relief is often a goal of treatment, a sole focus on pain reduction may reinforce simplistic models of pain and limit the potential targets of treatment.

Patients who report amputation pain that is persistent or interferes with psychological well-being, physical functioning, participation in activities, or quality of life should be referred to an appropriately trained clinician for an assessment of (1) current pain beliefs and their impact, if any, on the patient's pain and suffering; (2) family, in particular, those with whom the patient lives, responses to pain behavior, as well as overall level of social support; (3) depression and anxiety; (4) the patient's current use of pain management techniques, if any; and (5) the patient's interest in learning pain management skills including self-hypnosis skills. To the extent that a patient engages in maladaptive cognitions ("I can't stand this! It is never going to get better!"), cognitive therapy geared toward replacing these cognitions with more adaptive and reassuring cognitions may decrease suffering, and perhaps also a focus on and awareness of pain. To the extent that those with whom a patient lives provide either solicitous ("Honey, let me do that, you shouldn't have to get up when you hurt") or aversive ("You are just looking for an excuse to avoid housework; stop being so pitiful!") responses, then either family therapy to alter such responses to more adaptive ones, or individual therapy to help buffer any negative impact of these, should be considered.

Given that persons with chronic pain are at increased risk for developing a depressive or anxiety disorder, it is important that these disorders are detected, if present, and treated (see Chapter 7 in this text for further information about treatment). Patients should be encouraged to continue with or learn new adaptive coping strategies (e.g., problem solving, engaging in pleasurable activities, exercising), and discouraged from using potentially harmful strategies (e.g., fear avoidance, alcohol abuse, pain-contingent rest). Finally, because 75% of individuals are thought to benefit from self-hypnosis training (100), patients should be offered a treatment course of self-hypnosis training.

It is important from the outset of treatment to educate patients that chronic pain after limb loss is rarely eradicated. Rather, they should be taught to expect that they can benefit from a number of strategies to help them *manage* their pain so as to reduce pain severity and suffering and improve functioning and quality of life. An important goal of patient education is to help individuals switch their model for understanding their pain problem from a biomedical perspective, where a "quick fix" may be expected, to a biopsychosocial one that involves long-term self-management.

Unanswered Questions and Future Directions

The literature reviewed strongly supports the conclusion that chronic pain is a significant problem for many persons with limb loss. However, many unanswered questions remain concerning the nature, severity, and treatment of these pain problems, pointing to directions for future research.

What Is the Scope, Etiology, and Nature of Pain Problems in Sites Beyond the Amputated Limb?

Only recently have studies of pain after limb loss considered pain beyond the phantom or residual limbs. The existing data suggest that pain problems are common in other anatomical sites. Research on the scope, etiology, and nature of pain problems in these other sites is needed if treatments are to be developed for them. Additionally, more attention to the treatment of residual limb pain is also needed.

What Is the Prevalence and Nature of Chronic Pain in Youths with Limb Loss?

There is relatively little research regarding the prevalence of pain in youths with amputations. Although a review article in 1993 suggested that children and adolescents with limb loss may not experience chronic phantom limb pain (101), more recent research suggests that chronic PLP may be as prevalent in youths with acquired amputations as it is in adults (102). Research on the scope, nature, and treatment of pain in youths with limb loss is needed to address issues such as the reduction of pain and suffering, as well as how pain impacts development, quality of life, adaptation to disability, and participation in routine daily activities such as school or play.

What Role Do Biological and Psychosocial Variables Play as Risk or Protective Factors in the Development, Maintenance, and Management of Chronic Pain Following Limb Loss?

With the exception of a few studies reviewed earlier in this chapter, the biopsychosocial model has been largely untested in samples of adults with limb loss. The few studies that have utilized a biopsychosocial model strongly support the viability of a biopsychosocial model of chronic pain in persons with phantom limb and residual limb pain, and thus there is a clear need to test these models more extensively. The results of such research not only will provide important theoretical information regarding the applicability of the biopsychosocial model of pain in limb loss but also may lead to the development of interventions based on this model. Future biopsychosocial studies should consider including some of the newer biopsychosocial constructs found in the broader pain literature, including acceptance of pain and fear avoidance. Finally, research within the biopsychosocial model needs to consider not only the factors that increase the risk for poor pain outcomes but also what factors protect individuals against the development of pain and subsequent secondary disability.

What Treatments Are Effective in Treating Pain Secondary to Limb Loss?

Perhaps the most striking gap in the relevant literature is the lack of empirically supported treatments for chronic pain after limb loss. Given the high prevalence of disability-related pain and the residual pain that persists after existing biomedical treatments, there is a compelling need to test other medical, rehabilitation, and psychosocial treatments for pain in this population. In this context, several important questions arose concerning treatment: (1) Which, if any, of the treatments that are already being utilized are effective in treating pain in limb loss as determined by randomized clinical trials? (2) Are psychosocial treatment approaches that have proven effective with persons where pain is the primary disability effective for persons with pain after limb loss? If so, which ones? (3) Do persons with amputation pain have adequate access to pain specialists and treatments? If not, what are the psychosocial and environmental barriers that interfere with access to pain treatment, and can these be modified to improve care and pain outcomes? (4) Can biomedical and psychosocial interventions be used early after limb loss to prevent the development of chronic pain, pain-related disability, and/or distress in the long-term? The answers to these critical questions will require collaboration among clinicians and researchers as well as resources to conduct large-scale clinical trials across multiple sites.

Summary of Key Points

Chronic pain after limb loss is the norm rather than the exception, with pain potentially occurring in any of several locations, including but not limited to the phantom limb. The field is only beginning to understand the biopsychosocial factors that influence the development, maintenance, and treatment of chronic pain in persons with limb loss. Given that medications often do not fully relieve pain, psychosocial interventions based on the biopsychosocial model and drawn from the broader chronic pain field warrant clinical applications and research.

Glossary

Biopsychosocial model of chronic pain: A theoretical construct or model for understanding health, including pain. It acknowledges that pain has not only a biological basis but also psychosocial factors that influence the experience of pain.

Pain: An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.

Phantom limb pain (PLP): Painful sensations perceived in the missing portion of the amputated limb.

Residual limb pain (RLP): Pain in the portion of the amputated limb that is still physically present (i.e., the residual limb or “stump”).

Acknowledgments

We gratefully acknowledge the support from the Centers for Disease Control and Prevention under grants R04/CCU322981 and R01/DD000153. The views expressed in this chapter are those of the authors. No official endorsement by the Centers for Disease Control and Prevention or the Department of Health and Human Services is intended or should be inferred. This work was also partially supported by a Management of Chronic Pain in Rehabilitation grant (PO1 HD/NS33988) from the National Institute of Child Health and Human Development and the National Institute of Neurological Disorders and Stroke.

Further Reading

Amputee Coalition of America: http://www.amputee-coalition.org/

National Pain Foundation: http://www.nationalpainfoundation.org/

Books for persons with chronic pain: A number and variety of books have been published on pain management directed toward the person with pain. Although neither of the books listed below specifically addresses pain after limb loss, they both nonetheless have valuable information and tools pertaining to pain management.

Caudill MA. Managing Pain Before it Manages You, revised edition. New York: Guilford; 2000.

Turk DC, Winter F. The Pain Survival Guide: How to Reclaim Your Life. Washington, DC: American Psychological Association, 2005.

References

1. International Association for the Study of Pain. Classification of Chronic Pain. Seattle: IASP Press; 1994.
2. Bonica JJ. The Management of Pain, 2nd ed. Philadelphia: Lea & Febiger; 1990.
3. Ehde DM, Czerniecki JM, Smith DG, et al. Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. Arch Phys Med Rehabil 2000;81(8):1039–1044.
4. Ehde DM, Smith DG, Czerniecki JM, Campbell KM, Malchow DM, Robinson LR. Back pain as a secondary disability in persons with lower limb amputations. Arch Phys Med Rehabil 2001;82(6):731–734.
5. Pezzin LE, Dillingham TR, MacKenzie EJ. Rehabilitation and the long-term outcomes of persons with trauma-related amputations. Arch Phys Med Rehabil 2000;81(3):292–300.
6. Melzack R. Phantom limbs and the concept of a neuromatrix. Trends Neurosci 1990;13(3):88–92.
7. Melzack R. From the gate to the neuromatrix. Pain 1999;suppl 6:S121–S126.
8. Nikolajsen L, Staehelin Jensen T. Phantom limb pain. Curr Rev Pain 2000;4(2):166–170.
9. Loeser JD, ed. Pain After Amputation: Phantom Limb and Stump Pain, 2nd ed. Philadelphia: Lea & Febiger; 1990.
10. Elbert T, Flor H, Birbaumer N, et al. Extensive reorganization of the somatosensory cortex in adult humans after nervous system injury. Neuroreport 1994;5(18):2593–2597.
11. Flor H, Elbert T, Knecht S, et al. Phantom-limb pain as a perceptual correlate of cortical reorganization following arm amputation. Nature 1995;357:482–484.
12. Wu CL, Tella P, Staats PS, et al. Analgesic effects of intravenous lidocaine and morphine on postamputation pain. Anesthesiology 2002;96:841–848.
13. Czerniecki JM, Ehde DM. Chronic pain after lower extremity amputation. Crit Rev Phys Rehabil Med 2003;15:309–322.
14. Jensen TS, Krebs B, Nielsen J, Rasmussen P. Phantom limb, phantom pain and stump pain in amputees during the first 6 months following limb amputation. Pain 1983;17(3):243–256.
15. Kooijman CM, Dijkstra PU, Geertzen JH, Elzinga A, van der Schans CP. Phantom pain and phantom sensations in upper limb amputees: an epidemiological study. Pain 2000;87(1):33–41.
16. Melzack R. Phantom limbs. Sci Am 1992;266:120–126.
17. Nikolajsen L, Jensen TS. Phantom limb pain. Br J Anaesth 2001;87(1):107–116.
18. Houghton AD, Nicholls G, Houghton AL, Saadah E, McColl L. Phantom pain: natural history and association with rehabilitation. Ann R Coll Surg Engl 1994;76(1):22–25.
19. Ephraim PL, Wegener ST, MacKenzie EJ, Dillingham TR, Pezzin LE. Phantom pain, residual limb pain, and back pain in amputees: results of a national survey. Arch Phys Med Rehabil 2005;86(10):1910–1919.
20. Sherman RA, Devor M, Heermann-Do K. Phantom Pain. New York: Plenum Press; 1997.
21. Parkes CM. Factors determining the persistence of phantom pain in the amputee. J Psychosom Res 1973;17(2):97–108.
22. Sherman RA, Sherman CJ, Parker L. Chronic phantom and stump pain among American veterans: results of a survey. Pain 1984;18(1):83–95.
23. Whyte AS, Niven CA. Variation in phantom limb pain: results of a diary study. J Pain Symptom Manage 2001;22(5):947–953.
24. Jensen MP, Smith DG, Ehde DM, Robinsin LR. Pain site and the effects of amputation pain: further clarification of the meaning of mild, moderate, and severe pain. Pain 2001;91(3):317–322.
25. Dijkstra PU, Geertzen JH, Stewart R, van der Schans CP. Phantom pain and risk factors: a multivariate analysis. J Pain Symptom Manage 2002;24(6):578–585.
26. Fraser CM, Halligan PW, Robertson IH, Kirker SG. Characterising phantom limb phenomena in upper limb amputees. Prosthet Orthot Int 2001;25(3):235–242.
27. Gallagher P, Allen D, Maclachlan M. Phantom limb pain and residual limb pain following lower limb amputation: a descriptive analysis. Disabil Rehabil 2001;23(12):522–530.

28. Hagberg K, Branemark R. Consequences of non-vascular trans-femoral amputation: a survey of quality of life, prosthetic use and problems. Prosthet Orthot Int 2001;25(3):186–194.
29. Smith DG, Ehde DM, Legro MW, Reiber GE, del Aguila M, Boone DA. Phantom limb, residual limb, and back pain after lower extremity amputations. Clin Orthop Rel Res 1999;361:29–38.
30. Andersson GBJ, Pope MH, Frymoyer JW, Snook S. Epidemiology and cost. In: Pope MH, et al., eds. Occupational Low Back Pain: Assessment, Treatment, and Prevention. St. Louis: Year Book; 1990:95–113.
31. van der Schans CP, Geertzen JH, Schoppen T, Dijkstra PU. Phantom pain and health-related quality of life in lower limb amputees. J Pain Symptom Manage 2002;24(4):429–436.
32. Marshall M, Helmes E, Deathe AB. A comparison of psychosocial functioning and personality in amputee and chronic pain populations. Clin J Pain 1992;8(4):351–357.
33. Carabelli RA, Kellerman WC. Phantom limb pain: relief by application of TENS to contralateral extremity. Arch Phys Med Rehabil 1985;66(7):466–467.
34. Millstein S, Bain D, Hunter GA. A review of employment patterns of industrial amputees—factors influencing rehabilitation. Prosthet Orthot Int 1985;9(2):69–78.
35. Lindesay JE. Multiple pain complaints in amputees. J R Soc Med 1985;78(6):452–455.
36. Sherman RA, Sherman CJ, Bruno GM. Psychological factors influencing chronic phantom limb pain: an analysis of the literature. Pain 1987;28(3):285–295.
37. Arena JG, Sherman RA, Bruno GM, Smith JD. The relationship between situational stress and phantom limb pain: cross-lagged correlational data from six month pain logs. J Psychosom Res 1990;34(1):71–77.
38. Marshall HM, Jensen MP, Ehde DM, Campbell KM. Pain site and impairment in individuals with amputation pain. Arch Phys Med Rehabil 2002;83(8):1116–1119.
39. Von Korff M, Ormel J, Keefe FJ, Dworkin SF. Grading the severity of chronic pain. Pain 1992;50(2):133–149.
40. Novy DM, Nelson DV, Francis DJ, Turk DC. Perspectives of chronic pain: an evaluative comparison of restrictive and comprehensive models. Psychol Bull 1995;118(2):238–247.
41. Turk DC, Gatchel RJ. Psychological Approaches to Pain Management: A Practitioner's Handbook, 2nd ed. New York: Guilford; 2002.
42. Jensen TS, Krebs B, Nielsen J, Rasmussen P. Immediate and long-term phantom limb pain in amputees: incidence, clinical characteristics and relationship to pre-amputation limb pain. Pain 1985;21(3):267–278.
43. Nikolajsen L, Ilkjaer S, Christensen JH, Kroner K, Jensen TS. Randomised trial of epidural bupivacaine and morphine in prevention of stump and phantom pain in lower-limb amputation. Lancet 1997;350(9088):1353–1357.
44. Hanley MA, Jensen MP, Smith DG, Ehde DM, Edwards WT, Robinson LR. Preamputation pain and acute pain predict chronic pain after lower extremity amputation. J Pain 2007;8(2):102–109.
45. Dworkin RH. Which individuals with acute pain are most likely to develop a chronic pain syndrome? Pain Forum 1997;6(2):127–136.
46. Melzack R, Coderre TJ, Katz J, Vaccarino AL. Central neuroplasticity and pathological pain. Ann N Y Acad Sci 2001;933:157–174.
47. Boothby JL, Thorn BE, Stroud MW, Jensen MP. Coping with pain. In: Turk DC, Gatchel RJ, editors. Psychosocial Factors in Pain. New York: Guilford; 1999:343–359.
48. Jensen MP, Turner JA, Romano JM, Karoly P. Coping with chronic pain: a critical review of the literature. Pain 1991;47(3):249–283.
49. Boothby JL, Thorn BE, Stroud MW, Jenson MP. Coping with pain. In: Gatchel RJ, Turk DC, eds. Psychosocial Factors in Pain: Critical Perspectives. New York: Guilford; 1999:343–359.
50. Geisser ME, Robinson ME, Keefe FJ, Weiner ML. Catastrophizing, depression and the sensory, affective and evaluative aspects of chronic pain. Pain 1994;59(1):79–83.
51. Keefe FJ, Rumble ME, Scipio CD, Giordano LA, Perri LM. Psychological aspects of persistent pain: current state of the science. J Pain 2004;5(4):195–211.
52. Stroud MW, Thorn BE, Jensen MP, Boothby JL. The relation between pain beliefs, negative thoughts, and psychosocial functioning in chronic pain patients. Pain 2000;84(2–3):347–352.
53. Sullivan MJ, Stanish W, Waite H, Sullivan M, Tripp DA. Catastrophizing, pain, and disability in patients with soft-tissue injuries. Pain 1998;77(3):253–260.
54. Geisser ME, Roth RS. Knowledge of and agreement with chronic pain diagnosis: relation to affective distress, pain beliefs and coping, pain intensity, and disability. J Occup Rehabil 1998;8(1):73–88.
55. Keefe FJ, Williams DA. A comparison of coping strategies in chronic pain patients in different age groups. J Gerontol 1990;45(4):P161–165.

56. Hill A. The use of pain coping strategies by patients with phantom limb pain. Pain 1993;55(3):347–353.
57. Hill A, Niven CA, Knussen C. The role of coping in adjustment to phantom limb pain. Pain 1995;62(1):79–86.
58. Jensen M, Chen C, Brugger A. Postsurgical pain outcome assessment. Pain 2002;99(1–2):101.
59. Hanley MA, Jensen MP, Ehde DM, Hoffman AJ, Patterson DR, Robinson LR. Psychosocial predictors of long-term adjustment to lower-limb amputation and phantom limb pain. Disabil Rehabil 2004;26(14–15):882–893.
60. Jensen MP, Ehde DM, Hoffman AJ, Patterson DR, Czerniecki JM, Robinson LR. Cognitions, coping and social environment predict adjustment to phantom limb pain. Pain 2002;95(1–2):133–142.
61. Turner JA, Jensen MP, Romano JM. Do beliefs, coping, and catastrophizing independently predict functioning in patients with chronic pain? Pain 2000;85(1–2):115–125.
62. Fordyce WE. Behavioral methods for chronic pain and illness. St. Louis: Mosby; 1976.
63. Feldman SI, Downey G, Schaffer-Neitz R. Pain, negative mood, and perceived support in chronic pain patients: A daily diary study of people with reflex sympathetic dystrophy syndrome. J Consult Clin Psychol 1999;67(5):776–785.
64. Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. Pain 2000;85(3):317–332.
65. Gallagher P, MacLachlan M. Psychological adjustment and coping in adults with prosthetic limbs. Behav Med 1999;25(3):117–124.
66. Desmond DM, MacLachlan M. Affective distress and amputation-related pain among older men with long-term, traumatic limb amputations. J Pain Symptom Manage 2006;31(4):362–368.
67. Pincus T, Vogel S, Burton A, Santos R, Field A. Fear avoidance and prognosis in back pain: a systematic review and synthesis of the current evidence. Arthritis Rheum 2006;54(12): 3999–4010.
68. Bair M, Robinson R, Katon W, Kroenke K. Depression and pain comorbidity: a literature review. Arch Intern Med 2003;163:2433–2445.
69. McCracken LM, Carson JW, Eccleston C, Keefe FJ. Acceptance and change in the context of chronic pain. Pain 2004;109:4–7.
70. McCracken LM, Spertus IL, Janeck AS, Sinclair D, Wetzel FT. Behavioral dimensions of adjustment in persons with chronic pain: pain-related anxiety and acceptance. Pain 1999;80(1–2):283–289.
71. McCracken LM. Learning to live with the pain: acceptance of pain predicts adjustment in persons with chronic pain. Pain 1998;74(1):21–27.
72. McCracken LM, Eccleston C. A prospective study of acceptance of pain and patient functioning with chronic pain. Pain 2005;111:1–6.
73. McCracken LM, Vowles KE, Eccleston C. Acceptance-based treatment for persons with complex, long standing chronic pain: A preliminary analysis of treatment outcome in comparison to a waiting phase. Behav Res Ther 2005;43: 1335–1346.
74. Turk DC, Melzack R. Handbook of Pain Assessment, 2nd ed. New York: Guilford; 2001.
75. Dworkin RH, Turk DC, Farrar JT, et al. Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. Pain 2005;113(1–2):9–19.
76. Cleeland CS, Ryan KM. Pain assessment: global use of the Brief Pain Inventory. Ann Acad Med 1994;23(2):129–138.
77. Gallagher P, Maclachlan M. Development and psychometric evaluation of the Trinity Amputation and Prosthesis Experience Scales (TAPES). Rehabil Psychol 2000;45:130–155.
78. Legro MW, Reiber GD, Smith DG, del Aguila M, Larsen J, Boone D. Prosthesis evaluation questionnaire for persons with lower limb amputations: assessing prosthesis-related quality of life. Arch Phys Med Rehabil 1998;79(8):931–938.
79. Ehde DM, Smith DG. Chronic pain management. In: Smith DG, Michael J, Bowker JH, eds. Atlas of Amputations and Limb Deficiencies: Surgical, Prosthetic, and Rehabilitation Principles. Rosemont, IL: American Academy of Orthopaedic Surgeons; 2004:711–726.
80. Lee RY, Turner-Smith A. The influence of the length of lower-limb prosthesis on spinal kinematics. Arch Phys Med Rehabil 2003;84(9): 1357–1362.
81. Hanley MA, Ehde DM, Campbell KM, Osborn B, Smith DG. Self-reported treatments used for lower-limb phantom pain: descriptive findings. Arch Phys Med Rehabil 2006;87(2):270–277.
82. Williams AM, Deaton SB. Phantom limb pain: elusive, yet real. Rehabil Nurs 1997;22(2): 73–77.
83. Finnoff J. Differentiation and treatment of phantom sensation, phantom pain, and residual-limb pain. J Am Podiatr Med Assoc 2001;91(1): 23–33.
84. Hanley MH, Ehde DM, Smith DG. Pain Management. Thorofare, NJ: Slack; 2006.
85. Max MB. Antidepressant drugs as treatment for chronic pain: efficacy and mechanisms. In:

Bromm M, Desmedt JE, eds. Advances in Pain Research and Therapy—Issue of Pain and the Brain: From Nociception to Cognition. New York: Raven Press; 1995: 501–515.

86. Robinson LR, Czerniecki JM, Ehde DM, et al. Trial of amitriptyline for relief of pain in amputees: results of a randomized controlled study. Arch Phys Med Rehabil 2004;85(1): 1–6.
87. Bone M, Critchley P, Buggy DJ. Gabapentin in postamputation phantom limb pain: a randomized, double-blind, placebo-controlled, cross-over study. Reg Anesth Pain Med 2002;27(5):481–486.
88. Smith DG, Ehde DM, Hanley MA, et al. Efficacy of gabapentin in treating chronic phantom limb and residual limb pain. J Rehabil Res Dev 2005;42:645–654.
89. Huse E, Larbig W, Flor H, Birbaumer N. The effect of opioids on phantom limb pain and cortical reorganization. Pain 2001;90(1–2):47–55.
90. May BJ. Assessment and treatment of individuals following lower extremity amputation. In: O'Sullivan SB, Schmitz TJ, eds. Physical Rehabilitation: Assessment and Treatment, 3rd ed. Philadelphia: FA Davis; 1994:375–395.
91. Turk DC, Okifuji A, Sinclair JD, Starz TW. Differential responses by psychosocial subgroups of fibromyalgia syndrome patients to an interdisciplinary treatment. Arthritis Care Res 1998;11(5): 397–404.
92. Patterson DR, Jensen MP. Hypnosis and clinical pain. Psychol Bull 2003;129(4):495–521.
93. Jensen M, Hanley M, Engel J, et al. Hypnotic analgesia for chronic pain in persons with disabilities: a case series. Int J Clin Exp Hypn 2005;53:198–228.
94. Jensen MP, McArthur KD, Barber J, Hanley MA, Engel JM, Romano JM, Cardenas DD, Kraft GH, Hoffman AJ, Patterson DR. Satisfaction with, and the beneficial side effects of, hypnosis analgesia. Int J Clin Exp Hypn 2006;54:432–447.
95. Hoffman BM, Papas RK, Chatkoff DK, Kerns RD. Meta-analysis of psychological interventions for chronic low back pain. Health Psychol 2007;26(1):1–9.
96. Morley S, Eccleston C, Williams A. Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. Pain 1999;80(1–2):1–13.
97. Ehde DM, Jensen MP. Feasibility of a cognitive restructuring intervention for treatment of chronic pain in persons with disabilities. Rehabil Psychol 2004;49:254–258.
98. Fordyce WE, Fowler RS Jr, Lehmann JF, DeLateur BJ. Some implications of learning in problems of chronic pain. J Chron Dis 1968;21(3):179–190.
99. Darnall BD, Ephraim P, Wegener ST, et al. Depressive symptoms and mental health service utilization among persons with limb loss: results of a national survey. Arch Phys Med Rehabil 2005;86(4):650–658.
100. Montgomery G, DuHamel K, Redd W. A meta-analysis of hypnotically induced analgesia: how effective is hypnosis? Int J Clin Exp Hypn 2000;48:138–153.
101. Wesolowski J, Lema M. Phantom limb pain. Reg Anesth 1993;18:121–127.
102. Krane EJ, Heller LB. The prevalence of phantom sensation and pain in pediatric amputees. J Pain Symptom Manage 1995;10(1):21–29.

5

Cognition and Mobility Rehabilitation Following Lower Limb Amputation

Brian O’Neill

Overview

Rehabilitation following lower limb amputation presents challenges to patients and their health care providers and social workers. The rehabilitation path involves many phases designed to help the patient acquire the new skills of wheelchair use, transferring, standing and walking without the proprioceptive feedback of the lost limb, and donning and removing the prosthesis. These tasks require fitness and the cognitive ability to problem solve and learn. Acquiring the new skills represents a series of motor-relearning tasks, often occurring in the contexts of continuing medical problems and the psychosocial impact of acquired disfigurement and disability.

The causes of amputation vary according to the sociodemographics of countries. In high-income countries, amputations are most frequently performed due to vascular insufficiency (1). The proportion of amputations primarily attributed to vascular problems is approximately 85%. Vascular surgery techniques such as angioplasty extend the viability of compromised limb circulation. As the management of circulatory problems improves, the average age at amputation is rising (1). This increasing age at amputation brings with it an elevated risk of cognitive impairment and increased rehabilitation challenges. The current estimated incidence of new amputations ranges from 8.2 per 100,000 population (2) to 25 per 100,000 (3). As such, this is not an insignificant problem.

The cognitive impairments of vascular origin can often be difficult to identify. Language and social skills are often preserved and belie the memory and executive deficits apparent in this population (4,5). New learning following amputation depends on the functioning of semantic and procedural memory systems. To identify the problem, it is important to ascertain whether it is within the range of normal aging (6), and planning an approach to the cognitive difficulty requires reliable and valid neuropsychological assessment.

Postamputation physiotherapy progresses from maximal physical support (e.g., parallel bars) and supervision structure in the early mobilization phase, through less supportive ambulation devices (walking frames, elbow crutches, walking stick) and reduced supervision to final discharge. The postdischarge phase of prosthetic care, lasting the person’s lifetime, is crucial in considering the effect of rehabilitation: Does the patient use the prosthetic limb for daily mobilization needs? This gradual move from high to low support may mask the process by which cognitive deficits impinge on outcome. For example, cognitive problems adversely affect recall of relevant information, initiation, and problem solving, yet these difficulties may not become problematic while the person is receiving the relatively high levels of support of the rehabilitation environment.

The rate of attrition in the use of prescribed prostheses is high. Approximately 50% of those undergoing amputation are fitted with a definitive prosthesis, but, of these amputees, 40% use the prosthesis infrequently or not at all at 1-year follow-up (7). On the other hand, many use their prosthesis for all mobilization and derive great benefit from rehabilitation. This indicates a substantial variability in the use of prescribed limbs. Furthermore, prosthesis prescription may be counterproductive in some cases, either raising expectations where further independent mobilization is unlikely or increasing the risk of fall-related orthopedic injuries.

The clinical rationale for identifying predictors of rehabilitation outcome is two-faceted; first, those likely to have poor outcome might benefit from interventions addressing the variable that predicts poor outcome. Second, identification of variables predictive of outcome that are nonalterable may indicate to the rehabilitation team that continued prosthetic rehabilitation is inappropriate. Thus, the team may seek other ways of meeting the person's mobility needs following amputation.

Review of the Evidence

This section reviews studies examining the psychological and demographic predictors of rehabilitation outcome, as well as a study undertaken at the West of Scotland Mobility and Rehabilitation Centre examining cognitive predictors (specific neuropsychological domains) of mobility rehabilitation outcome.

To access relevant literature, the Ovid system (http://gateway_di.ovid.com) was used to search the following databases: Ovid-Medline(R) (1966 to March 2006), Embase (1980 to March 2006), and PsychInfo (1967 to March 2006). Studies were included if they reported on patients admitted to acute or postacute facilities for prosthetic limb fitting following lower limb amputation and addressed the prediction of outcome. Articles referred to in relevant papers were also retrieved. A standardized literature review tool (8) was used to assess studies in the following areas: clarity and focus of the research question, selection and follow-up of participants, consideration of confounders in the design, and assessment and statistical analysis. The 23-question tool thus allowed assignment of a level of evidence score ranging from 2++ (highest quality for applicable study designs, as the rating 1 is relevant to randomized control trials [RCTs] and reviews only) to 4 (lowest quality).

The potential predictor variables included age, sex, ethnicity, marital status, level of amputation, etiology, balance, time from amputation to fitting of prosthesis, and diagnoses of dementias, cerebrovascular disease, or other significant comorbidities. Cognitive and affective variables included indices of general intellectual/mental function, memory function, executive function, visuospatial ability, and mental health issues. The outcomes of interest were disability, walking ability (on scaled or categorical measures) and prosthesis use. Table 5.1 lists the characteristics of study participants.

Thirteen studies were included in the review (3,9–20). In addition, a study that I initiated with Evans (21) is discussed. Five potential studies were considered but are not included due to their focus on highly selected samples and their lack of adequate operationalization of variables (22–26).

The participants in the studies are representative of the population of those who have had an amputation in high-income countries. The mean age of study participants was 66.4 years (standard deviation [SD], 6.68). Males made up 70% of samples on average. In the four studies reporting primary etiology, vascular insufficiency (including vascular problems secondary to diabetes mellitus) was the proximal cause in an average of 87.34% of patients included in the review. Transtibial amputations were most common, representing a mean 64.12% of samples in the included studies. The mean time from assessment of predictors to outcome assessment was 237.2 days (SD, 135.74).

Findings

Summaries of variables, including design, study quality, and key findings are presented in Table 5.2.

Pinzur et al. (18) asked whether psychological assessment predicted outcome for a group of 60 males (mean age 60) after a 20-day inpatient program. Psychological measures were used to categorize patients as having either good or poor rehabilitation potential, although the process was unreported. These categories were then compared with measured outcome. The authors asserted

TABLE 5.1. Sample descriptions of studies included in the review

	First author	Year	Number (in at follow-up)	Mean age (SD)	Gender	Amputation characteristics*	Comorbidity**	Time to outcome Ax
1	Barnfield	1997	29	71.03 (8.84)	52% male	TT: 59%, TF: 35%. Bilat.: 6%	DM: 61%, (total PVD 97%), CVA: 11%	20 days
2	Condie	2005	166 (143 at 1 month, 120 at 6 months)	66.73 (1.33)	69.3% male	TT: 73.5%, TF: 25.9%, HP: 0.6%.	Not reported	6 months
3	Davies	2003	357 (281 at 12 months)	68 Range: 19–95	70.1% male	TT: 50.5%, TF: 49.5%	Vascular/DM combined 87.5%	12 months
4	Fletcher	2001	81 (81—case review)	79.7 (?)	Not reported	TT: 64%, TF: 31%, TK: 4.5%.	DM: 50%, CVD: 53%	Not reported
5	Grieve	1996	20 (20)	Median 64; range: 17–92	62% male	TT: 75%, TF/TK: 25%	DM 50%, 35% >2 Dx	5 months
6	Hanspal	1991	100 (NA)	72.4 Range: 61–89	31% male	TT: 49%, TF: 51%	Not reported	Not reported
7	Hanspal	1997	50 (32)	66.4 Range: 54–74	56% male	TT: 47%, TF: 53%.	62.5% relevant comorbidity	8–14 months
8	Larner	2003	43 (43)	66.36 (15)	76.7% male	TT: 61.3%, TF: 38.7%	DM: 58.1%	1.5 months
9	Leung	1996	41 (33)	63.7 (12.3)	78.8% male	TT: 72.7%, TF: 24.3%, Bilat.: 3.0%	63.6% >2 Dx	3–12 months
10	Pinzur	1986	60 (60)	60.3 (?) Range: 34–80	100% male	Not reported	DM: 48%,(etiology PVD in 90%)	Not reported
11	Pohjolainen	1991	155 (125 at 12 months)	63Range: 14–87	71.2% male	TT: 60%, TF: 40%	PVD 81% (trauma 10%, tumor 6%, other 3%)	12 months
12	Pohjolainen	1990	175 (141 at 12 months)	62.2 (15.8)	73% male	TT: 53%, TF: 35%, Bilat.: 12%	PVD 81.2% (trauma 9.7%, tumor 5.7, other 3.45)	12 months
13	Schoppen	2003	51 (46)	73.9 (7.9)	70% male	TT: 72%, TF 11%, TK 17%.	DM 54%, CVD 67%	12 months

[*] Amputation characteristics: Bilat., bilateral; TT, transtibia; TF, transfemoral; TK, through knee; HP, Hemipelvectomy.

[**] Comorbidity: DM, diabetes mellitus; CVA, cerebrovascular accident; CVD, cerebrovascular disease.

Table 5.2. Studies included in the review by study type, sample, relationship examined, and findings

	Author/year	Study rating	Variables examined	Outcomes measured	Significant predictor variables and % variance explained if calculable
1	Barnfield (1996)	2++	Age, level of amputation, gender, ethnicity, comorbidity	Disability (FIM) at discharge	Dementia Rating Scale score, Geriatric Depression Scale score, and block design together predicted 69% of variance in Functional Independence Measure score
2	Condie (2005)	2++	Preoperative function, amputation level, illness and prosthesis related cognitions, distress, demographics	Prosthesis use at 6 months	Amputation level ($\beta = .242$, $p < .01$) and illness cognitions [Timeline cyclical ($\beta = -.364$, $p < .001$), locus of control $\beta = .251$, $p < .01$ self-efficacy $\beta = .264$, $p < .01$] predicted prosthetic indoor use at 6 months; illness cognitions (symptom fluctuation) explained 12.5% of limb use at 6 months
3	Davies (2003)	2+	Age, level of amputation, etiology	Prosthesis use at 12 months	Negative predictors of use: age (χ^2 not reported, $p < .007$) level of amputation (χ^2 not reported, $p < .000$)
4	Fletcher (2001)	2+	Age, sex, marital status, family at home, medical conditions, level of amputation	Whether Rx prosthesis; prosthesis use in those fitted	Negative predictors of fit: age (OR = 6.25, $p < .001$), CVD (OR = 3.45, $p = .001$), dementia (OR = 4.54, $p < .001$), transfemoral amputation (OR = 5.26, $p < .001$)
5	Grieve (1996)	2–	Age, sex, amputation level, smoking, comorbidity, motivation, time amputation-to-fit, pain	Disability (Sickness Impact Profile)	Age (R = ?, $p < .05$) associated with reduced physical and total Sickness Impact Profile scores
6	Hanspal (1991)	2+	Level of amputation, age, mental ability (CAPE), psychomotor function	Mobility grade	Mental ability associated with mobility ($R = 0.62$, $p < .01$), psychomotor speed ($R = 0.62$, $p < .01$), total ($R = 0.82$, $p < .01$); effect of age not reported but significant
7	Hanspal (1997)	2+	Level of amputation, age, mental ability (CAPE), psychomotor function, comorbidity	Mobility grade	Mental ability associated with mobility ($R = 0.45$, $p < .01$); comorbidity (r unreported); correlation explained 20% of variance
8	Larner (2003)	2++	Amputation level, age, duration of stay, psychological morbidity, locus of control, learning (Kendrick Object Learning Test)	Prosthetic function at 9 weeks	Amputation level (OR = 0.13, $p = .016$), KOLT (OR = .91, $p = .018$); memory and amputation level predicted 81% of variance in categoric prosthesis use
9	Leung (1996)	2–	Disability (Functional Independence Measure)	Disability (FIM)	NB: No statistics reported: FIM (motor), level of amputation, comorbidity

10 Pinzur (1986)	2–	Cognition (Test of Mental Function for the Elderly, Short-Form WAIS); Personality (16 PF, MMPI)	Whether fitted with prosthesis; prosthesis use in those fitted	NB: No statistics reported: psychologists' opinion as to whether patients were "good"/"poor" candidates predicted outcome
11 Pohjolainen (1990)	2–	Level of amputation, age, comorbidity	Function after rehabilitation; use	NB: No statistics reported: level of amp, age, comorbidity
12 Pohjolainen (1991)	2+	Sex, body mass index, comorbidity, etiology, phantom pain, time amputation to fit, stump length, occupation, smoking	Prosthetic function/use	Age (R unreported, p <.001) corr. with function/use, CVD corr. with function ($R = -0.18$, p <.05), CVD corr. with use ($R = -0.17$, p <.05), Time amp. to fit corr. with use ($R = -0.26$, p <.01)
13 Schoppen (2003)	2++	Age, amputation level, stump healing, contractures, standing balance, comorbidity (including psychological), cognition	Disability, prosthetic-function	Significant multivariate regression model (activity): age ($\beta = .25$, p <.05), standing balance ($\beta = -0.40$, p <0.05),memory, 15-word test, ($\beta = -0.32$, "); age, 1–leg balance and memory combined to predict 69% of variance in disability (SIP)

"FIM, Functional Independence Measure; CAPE, Clifton Assessment for the Elderly; Corr., Correlation; KOLT, Kendrick Object Learning Test; MMPI, Minnesota Multiphasic Personality Inventory; OR, Odds Ratio; PF, Personality Factor; PVD, Peripheral Vascular Disease"

that cognitive variables were more powerful in predicting outcome than psychiatric variables. However, poor reporting somewhat marred this ambitious early study.

Pohjolainen et al. (3) examined the level of amputation, age, and comorbidity as predictors of outcome in a follow-up cohort of 141 limb-fitted patients (mean age 62). They assert, unfortunately without statistics, that age and number of comorbidities predict the outcome. This study examined only demographic and medical characteristics of patients. In a later study, Pohjolainen and Alaranta (19) extended the examined variables to include sex, body mass index, comorbidity, etiology, presence of phantom pain, time from amputation to prosthesis fitting, stump length, occupation, and whether the patient smoked. They found in this analysis of 125 follow-up patients (mean age 63) that prosthetic function was predicted by age, cerebrovascular disease, and time from amputation to fitting. However, the report does not include any effort to control for these multiple correlations, casting doubt on their relative predictive power.

Hanspal and Fisher (14) examined level of amputation, age, mental ability (Clifton Assessment Procedures for Elderly (27)) and psychomotor function as predictors of mobility grade in a sample of 100 (mean age 72). They found that the mobility grade achieved was associated with mental ability ($r = 0.62$, p <.01), psychomotor speed ($r = 0.62$, p <.01), and a composite score of both indices ($r = 0.82$, p <.01). The effect of age was not reported as a statistic, but the authors assert that this was also significant.

Grieve and Lankhorst (13) examined the impact of age, sex, amputation level, smoking, comorbidity, motivation, time from amputation to prosthesis fitting, and stump pain in a sample of 20 patients (median age 64). They found a significant negative correlation between age and the physical scale of a measure of disability (Sickness Impact Profile (28)). No cognitive variables were included in this study.

Leung and Rush (17) found, in a study examining a single variable in a sample of 41 patients (mean age 64), that a measure of disability was associated with a scale for mobility following amputation, but did not report statistics to support this.

Hanspal and Fisher (15) examined level of amputation, age, mental ability, psychomotor function, and comorbidity in a small sample ($n = 32$, mean age 67). They found that mental ability (27) was associated with mobility at discharge ($r = 0.45$, $p < .01$) from physiotherapy.

Barnfield (9), in a small sample ($n = 29$, mean age 71), found a significant regression equation including dementia symptoms, depression, and visuospatial function that predicted a high percentage (69%) of variance in outcome disability after a 20-day inpatient rehabilitation program.

Fletcher et al. (12) examined whether the presence of comorbidities such as diabetes mellitus, cerebrovascular disease, and dementia predicted initial decision to fit in a sample of 81. Increased age, presence of dementia, above-knee amputation, and cerebrovascular disease each were predictive of limb provision. The statistics employed did not allow ascertainment of the extent of interaction of the variables, however. In terms of use of the limb, a group comparison showed that those with transtibial amputations used their limb more. No other variables were included in this analysis of limb use.

Larner et al. (16) examined whether cognitive tests predicted ability to use a prosthesis at 1.5 months in a sample of 43 (mean age 66) undergoing rehabilitation. They found that an index of memory significantly predicted ability to mobilize using the prosthesis. In a separate analysis, amputation site was also shown to be a significant predictor.

Davies and Datta (11) found, in a sample of 357, mean age 68, that prosthetic use at 12 months was negatively predicted by the age at amputation and the level of amputation. Neither age-associated diagnoses nor cognition was examined in this study. In light of previous studies, this emphasis on age to the exclusion of other potential predictors is deemed a major flaw.

Schoppen and colleagues (20) attempted to predict disability in a sample of 46 patients of mean age 74. They included the potential predictors of age, amputation level, stump healing, presence of contractures, standing balance, comorbidity (including psychological morbidity), and cognitive abilities. The finding, in this highly rated study, was that a regression model including standing balance and memory was significant and predicted a large amount of outcome variance.

Condie and colleagues (10) examined psychological predictors of outcome in a sample of 166 patients of mean age 67 where cognitive impairment was used as an exclusion criterion. They found that a regression model including an illness cognition variable (timeline—cyclical), treatment control, and emotional/psychological causal attributions predicted prosthetic use at 6 months. Timeline (cyclical) was assessed via a series of Likert-rated statements such as, "The symptoms of my condition change a great deal from day to day" and "My condition is very unpredictable." Presence of comorbid diabetes predicted poor prosthesis use (indoors) at 1 month, and amputation level predicted prosthetic use at 6 months (indoor and outdoor). No demographic variables (age, gender, deprivation index) or clinical variables predicted use at 1 or 6 months. The causal route of illness cognitions predicting outcome is uncertain, but it is possible that patients are reporting their perception of the impact of medical conditions. Unfortunately, this study did not include cognition as a predictor. However, it did include measures of both cognitive function and beliefs, so that their interrelationships could be examined.

In sum, eight studies showed that cognition or an indirect index of cognition predicted functional/motor outcome (9,12,14–16,18–20). Six studies found that age was a predictor of outcome (3,11–13,19,20), and of these, three did not include an index of cognitive function (3,11,13). One study found that, while age was not a predictor, a measure of perception of illness variables predicted use at 6 months, albeit in a sample excluding the cognitively impaired (10). One found that a measure of disability predicted outcome ability (17).

Four studies (9,10,16,20) received a SIGN rating (SIGN 2001) of 2++, the highest rating of methodological rigor in minimizing bias for cohort designs. Five of the studies (11,12,14,15, 19) received SIGN ratings of 2+. Four studies (13,17–19) received ratings of 2– (Table 5.2). As can be seen in Table 5.2, more recent studies tended to be methodologically superior. Of those rated 2+, two were published in 1991 (14,19) one in 1997 (15), and one in 2001 (12), while three of the four rated 2++ were published between 2001 and 2005 (10,16,20).

Studies rated as methodologically superior tended to include greater numbers of patients, greater number of predictor variables, direct measurement of cognitive variables, and used appropriate multifactorial statistical analyses. All the studies with the highest ratings included cognitive variables and provided indices of variance explained by their multifactorial models.

The West of Scotland Mobility and Rehabilitation Centre study

In our study (21), a battery of neuropsychological tests assessing a variety of cognitive domains was administered to participants with the aim of ascertaining whether cognitive functions, by domain, added to the variance explained by memory alone. The hypothesis was that executive function in particular would add to variance explained. The domains assessed were memory (story recall and figure recall [29]); visuospatial function (figure copy [29], line bisection [30]); executive function (key test [31]); praxis (nine-hole peg test [32]); emotional function (Hospital Anxiety and Depression Scale [33]), and language (Addenbrookes Cognitive Examination [34]). Data were also gathered on medical variables such as etiology, level of amputation, comorbidities, and pain and demographic information such as age, sex, wheelchair access, and support. The average age of participants was 60.69 years (SD, 13.98) with a range of 25 to 80 years. There were six females (18%) and 28 males (82%); 56% had undergone a transtibial amputation and 44% a transfemoral amputation (two of these were revisions), due to peripheral arterial disease in 78% of cases.

Follow-up assessments were carried out at 6 months following the primary prosthetic appointment, and measures of mobility and use of the prosthesis were carried out. A regression analysis revealed that the Locomotor Capability Index (35) score was predicted by a measure of visual memory (figure recall) (adjusted R^2= 24.8%, degrees of freedom [df] = 32, zβ = 0.52, p = .002). Hours of use was predicted by verbal fluency (letters F, A, and S) total (adjusted R^2= 17.1%, df = 26, zβ = 0.45, p = .017). Special Interest Group in Amputee Medicine mobility grades (SIGAM) (36) were predicted by a combination of a measure of immediate verbal memory (story recall), age, level of amputation, and presence of pain (adjusted R^2= 58.2, df = 30, zβ = 0.52, p = .000). The predictor variables figure copy, figure recall, immediate verbal memory, and delayed verbal memory were significantly correlated with the Locomotor Capabilities Index (LCI) and SIGAM outcome measures, although all did not enter the significant regression equations.

Our study adds to the evidence base that cognition is predictive of rehabilitation outcome, and specifically that a measure of new learning predicts outcome. Further, an index of initiation/generativity predicted total use, thus suggesting that executive function may be important in predicting gross use of the prosthesis. The results are in line with previous work demonstrating that relatively high proportions of variance can be explained by equations incorporating cognitive, medical, and demographic variables. Two previous studies included a measure of executive function (9,20) but did not find their chosen measures predictive of outcome.

Studies by Variance Explained

Condie et al. (10) found that illness cognitions (concerning the extent of fluctuation of symptoms) predicted 12.5% alone of the variance in use at 6 months. Hanspal and Fisher (15) found that cognition, when examined alone, predicted about 20% of the variance in mobility.

As might be expected when considering the complexity of the rehabilitation process, multifactorial models, where variables were combined in a regression equation, generally led to greater predictive power. In our own study we found that while approximately 25% of variance was explained by a single cognitive variable (figure recall), we also found that 58.2% of variance in use of the prosthesis (SIGAM mobility grades) was predicted by a combination of immediate verbal memory (story recall), age, level of amputation and presence of pain (adjusted R^2= 58.2, df = 30, zβ = 0.52, p = .000). Barnfield (9) found that depression, dementia rating, and a measure of visuospatial ability combined to predict 69% of variance in disability at discharge. Schoppen and colleagues (20) explained a similar extent of discharge disability (69%) using a multifactorial equation including age, one-leg balance, and memory. Finally, Larner et al. (16) found that a measure of memory and the patients' amputation level combined to predict 81% of variance in whether patients learned to walk with a prosthesis during rehabilitation.

The results of the studies described are deemed relevant and important to rehabilitation practice following amputation in an older-adult population. In sum, we see that age, level of amputation, memory function, and balance are likely to explain the majority of outcome variance in this population. Pain and attitudinal variables and perhaps executive function may account for a further small percentage.

Discussion

This review has highlighted several reliable predictors of rehabilitation outcome (decision to fit and prosthesis use) in cohorts typical of prosthetic clinics in high-income countries. These are, in order of decreasing frequency of report, (1) age at amputation, (2) amputation level, (3) direct assessment of cognition, (4) medical diagnosis of cerebrovascular disease or dementia, (5) balance, and (6) comorbidities. The case for assessing cognition postamputation is strong. The nature of tests to be included is less clear, but measures of new learning appear to be relatively robust predictors. Studies rated the highest employed multifactorial approaches, and it is suggested that large prosthetic centers should aim to routinely collect the above data along with outcome data such as ability at discharge and extent of use at 6 months. This would allow an assessment of the multifactorial model indicated by the literature to date.

The reviewed studies are historically recent, reflecting the rising age of patients at amputation and rising prevalence of cognitive difficulties. The astute reader will note that the average age of participants in the reviewed studies also showed an increasing trend. This novel area of research is impressive in its conceptual and methodological development. More recent studies sought to combine variables in explanatory equations using regression modeling. It is heartening that this process of fractionation and recombination has led to studies that have explained ever-greater amounts of variance in outcome. More recent studies also attempted to fractionate prognostic factors, from global predictors such as age and level of amputation, to specific predictors requiring careful measurement such as memory function, visuospatial function, and standing balance. It is argued that the predictive power of these specific predictors may have been masked by more global factors in studies that did not seek to fractionate prognostic factors. For example, the effect of level of amputation or age may be mediated by variables such as balance, memory, and motor control. Further detailed analyses are needed to deduce the mechanisms through which these prejudicing demographic variables have their effects on outcome, but the work has begun.

Measurement

Some studies included variables that aimed to capture psychological constructs, but they were poorly operationalized. Grieve and Lankhorst (13) included the variable motivation, rated by clinicians as either good or impaired. The authors found that their motivation variable was strongly associated with age, but they present no statistics on this relationship. The concept of motivation is often used but difficult to define. Most professionals estimate a person's level of motivation, perhaps without clear conceptualization of how this might be fractionated and measured. In the current population it is important to consider motivation as multifactorial. It is contributed to by mood, illness-related fatigue, iatrogenic lethargy, poor initiation secondary to organic cognitive problems, depression secondary to dementia, or learned behavior.

Functional activity was measured in a variety of ways as there does not appear to be a consensus on outcome assessment as yet. The Harold Wood Stanmore Mobility Grades (14,15) was used most frequently (11,14,15) and as a modified mobility grades system in O'Neill and Evans (21). The Narang Classification of Functional Level (37) was the second most frequent, used in three studies (3,19,20). Combining two or more measures was also a popular approach. Condie et al. (10), for example, used the Functional Measure for Amputees (38) in addition to the Locomotor Capabilities Index (35), while Schoppen et al.

(20) used the Groningen Activity Restriction Scale (39), Sickness Impact Profile (28), and Timed Up and Go Test (40), and Grieve and Lankhorst (13) used the Sickness Impact Profile (28) in combination with the International Classification of Impairments, Disabilities, and Handicaps based questionnaire (41). The interested reader is directed to Condie et al. (42) for a fuller discussion on outcome measures than is possible here.

Assessment of cognition as a construct is crucially important theoretically and practically. Having demonstrated a relationship between indices of cognition and outcome, the next step may be to refine the measure of cognition most closely related to the demonstrated relationship. The methods of assessment of cognition differed greatly across studies. Memory tests, cognitive screens, clinical diagnosis, and consensus opinion of the rehabilitation team were used to describe cognitive deficits. This source of heterogeneity is likely to occur due to the early stages of the endeavor to relate cognition to prosthetic outcome. In our review the Clifton Assessment Procedures for the Elderly (27) was used most frequently but only in two studies by the same authors (14,15). Other measures with established validity and reliability were used but often in single instances. The Kendrick Object Learning Test (43) was used once (16) and subtests of the Repeatable Battery for Assessment of Neuropsychological Status was also used once (21). Use of multiple tests and large batteries was common, but often without demonstrating the need for an extensive battery (18). Barnfield designed her battery with regard to cognitive domains of interest. Aiming to assess cognitive impairment due to vascular pathology, she included the Dementia Rating Scale (44), Trail Making Test (45), block design (46), and prose memory (47). Similarly examining distinct domains, Schoppen employed the Cognitive Screening Test (48), 15-Word Test (49) and the Stroop Test (50). Clinical Diagnosis of Cerebrovascular Disease or Dementia was used by two studies (12,19). Clinical classification of motivation, with descriptive details, was used by Grieve and Lankhorst. We conclude that while battery approaches have little to recommend them, reliable and valid measures of domains-of-interest such as memory, executive ability, or behavior typical of dementia is both economical and indicated.

It might be proposed that examining the impact of cognitive status on prosthetic rehabilitation outcome entails examining the impact of cerebrovascular dysfunction on rehabilitation outcome. The assessments used in studies need to be well matched to the deficits expected in these conditions. Executive function is a highly complex cognitive function, and it is possible that absence of findings implicating it as a predictor of outcome was due to the invalid measurement. In our study (21), we did find that a measure of fluency/generativity did predict outcome in terms of hours of wearing the prosthesis at 6 months. The association of verbal fluency and hours of prosthesis wearing suggests an interesting interpretation. Verbal fluency can be conceptualized as a measure of initiation. The variable "hours of wearing" is also significantly correlated with both mobility grade achieved and locomotor capability. It is a possibility that the direction of causality is such that executive impairment limits the person's rehabilitation gain by limiting the extent to which the person initiates mobilization.

Approximately 75% of major lower-extremity amputations are the result of peripheral vascular disease (PVD) including PVD secondary to diabetes mellitus (1). Although our cohorts were all mixed, it is important to note that our findings may not pertain to samples of those with amputations secondary to congenital abnormality or trauma only. The factors that predispose a patient to PVD (smoking, hyperlipidemia, diabetes mellitus) are also risk factors for the development of cerebrovascular disease. Executive function deficits are likely in the early stages of cerebrovascular deterioration (4,5,51). It thus remains likely that an adequately powered study employing a more valid measure of executive function (clinical assessment of executive function generally adopts a battery approach (31,52)), which we expect to be deficient in cerebrovascular disorders, may find an association with outcome. Memory tests have face validity in terms of lay understanding of cognitive dysfunction, but may not capture the above deficits. Sachdev and colleagues (4) examined 170 patients with stroke or transient ischemic attack (TIA) 3 to 6 months after the event and found that patients with vascular dementia had disturbance to all cognitive domains. Verbal memory, however, was relatively preserved.

Recent studies with high ratings have found that measures of cognitive ability are good predictors of rehabilitation outcome. Combination equations also explain high amounts of outcome variance. Following amputation a patient's cognitive ability should be assessed to ascertain neuropsychological difficulties that may present rehabilitation challenges. Assessment, either as routine universal cognitive screening or where cognition is of concern, should inform the clinical team's conceptualization of the patient. This should lead to setting realistic rehabilitation goals for the patient and guide management following discharge from hospital.

There are a wide variety of measures of new learning available. To suggest particular measures from this review is difficult, given the heterogeneity of the tests employed. An assessment administrable by all members of the rehabilitation team, such as the Clifton Assessment Procedures for the Elderly (27), would allow construction of a large database without specific neuropsychological expertise. However, it is also the case that a battery that gives normative values across a number of domains (e.g., Repeatable Battery for Assessment of Neuropsychological Status [29]) would allow routine assessment to contribute to clinically relevant diagnostic issues; for example, if significant impairment is noted across two or more domains, then diagnosis of a dementing condition is possible. This would obviously have a bearing on the rehabilitation approach offered or the support level to which an inpatient is discharged.

Inclusion of a measure of verbal memory in assessment protocols would allow prediction of poor prognosis. Those likely to do poorly are counseled on this risk prior to engaging in prosthetic rehabilitation. Alternative mobility rehabilitation routes such as powered wheelchair prescription might be followed for these individuals. Discharge support might be altered dependent on predicted mobility needs. Quality of life was not assessed very frequently in studies to date. It remains useful to ascertain if prosthetic rehabilitation outcome is linked to this construct. If so, those failing to achieve functional mobility on prosthetic limbs might be offered alternative assistive devices such as powered wheelchairs to see if this improves participation and quality of life.

Future Developments

Immediate recall has been shown to relate to outcome. Cognition can mediate outcome in a number of ways. We know that the patient's poor cognition influences the decision to prescribe a prosthesis. However, it may also impact on the clinicians' expectations of patients, in turn influencing the intensity of treatment offered. Acknowledging that the precise role of cognition is not fully understood, a parsimonious view is adopted that those with poor cognition are not learning effectively in rehabilitation. As such, this indicates employment of existing techniques to support encoding of information. Anecdotal evidence or yet-to-be-analyzed data suggest that poor carryover from physiotherapy gym sessions is related to scores on standardized memory tests and potentially predictive of outcome. Behavioural observation measures that are usable in the gym might be useful and predictive. We might envisage a standard presentation of a sequence to be recalled after a delay. This measure could be concurrently validated against existing neuropsychological tools already shown to be predictive.

Patients in rehabilitation need to learn complex sequences of behavior. Donning a transtibial prosthesis and then standing from a wheelchair is a fundamental example. The substeps of this task include (1) orienting the chair; (2) engaging the wheelchair brakes; (3) removing the footplate and residual limb board; (4) donning the socks, (5) the liner, (6) the socket, and (7) the suspension sleeve before (8) checking comfort, (9) sliding forward in the chair, (10) placing feet correctly, (11) moving the upper body forward, and (12) pushing up (only) from the arms of the chair. Adverse incidents may occur if all of these substeps do not proceed in the correct order, emphasizing the problems likely if a patient has difficulty encoding the stages or correctly sequencing them in reproduction. Thus sequencing difficulties may result from memory deficit or from executive dysfunction related to frontal damage.

People with episodic memory problems have difficulty remembering their behavior such that they do not learn from their mistakes. Additionally, engaging in the behavior may reinforce the mistake (53). This suggests that when the memory-impaired patient is first exposed to a task, errors should be prevented. However, such an errorless-learning approach [53,54] remains to be investigated experimentally in this population, and this indicates potential future research directions. We hypothesize that provision of an environment that supports errorless performance of new tasks would potentiate better retrieval of the sequences involved and, perhaps, a better outcome.

Practical and useful techniques might be suggested at this point. It is advisable to check for immediate recall of instructions. This will ensure comprehension and correct immediate recall. Encouraging the person to recall information also potentiates later recall. Break sequences into component parts, having the person observe the sequence, and on the next performance perform the last action, the second from last one, the next, etc., thus chaining the behavioral sequence. The importance of prevention of errorful encoding in strengthening future retrieval has been emphasized in previous work on memory rehabilitation [53,54].

Postamputation rehabilitation involves the provision of augmentative technology, the prosthesis in lieu of the amputated limb. Outcome has been found to relate to specific cognitive deficits. This suggests that external amelioration of these deficits, may, in turn, potentiate better outcome. Augmentative external supports include tried methods such as the verbal prompts of the physiotherapist and written information, as well as uninvestigated methods such as patient-held photographic/video records of correct sequences, prospective reminder systems to engage in practice, or systems to support maintenance of goal-directed behavior. When perfect performance is attained, the external supports could then be phased out. Studies examining the effect on outcome of interventions supporting cognitive deficits would be a valuable extension of the postamputation and physical rehabilitation literature.

Finally, psychological predictors of outcome include self-efficacy and illness cognitions. Two additional strands of research are suggested by the fact that neuropsychological and psychological factors have not been examined together. The first is to examine the predictive power of these factors in comparison with each other, and the second is to identify the relationship between these variables. For example, do illness cognition variables remain valid in a cognitively impaired group?

Summary of Key Points

We have seen that cognition, and in particular memory, is predictive of rehabilitation outcome following amputation in addition to variables such as age and level of amputation. Executive difficulties remain to be fully examined in the research literature but are to be expected in the cognitive profiles of the typical person undergoing amputation. Age is easy to ascertain but does not in itself explain poor outcome; rather, age-associated decline in balance and memory explains outcome. Importantly, these variables may be altered to some extent, and so careful interventions may be beneficial.

Glossary

Dementia: Demonstrable deterioration in two or more cognitive domains associated with increasing disability and attributed to disease of the brain.

Errorless learning: A set of techniques to facilitate learning. Those with memory impairments are likely to reproduce actions corrected as errors when learning. Prevention of these errors during reproduction facilitates better recall.

Executive function: A set of cognitive abilities that control and regulate goal-directed behavior. They include the ability to initiate, maintain, or stop actions, monitor behavior, and plan solutions to novel problems. Concept formation and abstract thinking are often considered components of executive function.

Figure copy: Neuropsychological assessment of visuospatial function where a person is asked to copy a complex figure. Recall of this figure after a delay forms an index of visual memory in several versions of the test.

Praxis: The organization of movement in nonhabitual tasks; also called perceptuomotor function.

Visuospatial function: Cognitive functions underpinning the formation of a representation of space from visual information.

Further Reading

Schoppen T, Boonstra A, Groothoff JW, De Vries J, Goeken LN, Eisma WH. Physical, mental and social predictors of functional outcome in unilateral lower-limb amputees. Arch Phys Med Rehabil 2003;84: 803–811. This article is a good example of research in this area, exemplifying the understanding that multi-disciplinary assessment significantly improves our predictive power.

Wilson BA. Rehabilitation of memory deficits. In: Wilson BA, ed. Neuropsychological Rehabilitation: Theory and Practice. Abingdon, UK: Swets & Zeitlinger, 2003. An overview of current understanding of the rehabilitation of memory disorder.

References

1. Cargil J, Condie ME. A survey of the lower limb amputee population in Scotland, 2002. http://www.retis.scot.nhs.uk/reports/2002SPARGReport.pdf, 2004
2. National Amputee Statistical Database for the United Kingdom. 2004/05 NASDAB Annual Report. http://www.nasdab.co.uk/steering.asp, 2005.
3. Pohjolainen T, Alaranta H, Karkkainen M. Prosthetic use and functional and social outcome following major lower limb amputation. Prostet Orthot Int 1990;14(2):75–79.
4. Sachdev PS, Brodaty H, Valenzuela M, et al. The neuropsychological profile of vascular cognitive impairment in stroke and TIA patients. Neurology 2004;62:912–919.
5. Skilbeck C. The Neuropsychology of vascular disorders. In: Halligan P, Kischka U, Marshall JC, eds. Handbook of Clinical Neuropsychology. Oxford: Oxford University Press, 2003.
6. Woodruff-Pak DS. The Neuropsychology of Aging. Oxford: Blackwell, 1997.
7. Sockalingam S, Condie ME, Treweek SP. Post-discharge functional measure for lower limb amputees. Final report submitted to REMEDI (Rehabilitation and Medical Research Trust), 1998.
8. Scottish Intercollegiate Guidelines Network. Methodology checklists. http://www.sign.ac.uk/methodology/checklists.html, 2001.
9. Barnfield K. Cognition as a predictor of rehabilitation outcome in older amputees. Diss Abstr Int 1997;Section B: Sci Eng. 57(10b): Apr.
10. Condie ME, Johnston M, Callaghan B. Predictors of prosthetic fitting, use and recovery following lower limb amputation: illness related cognitions, attitudes towards prosthetic use, psychological distress and functional limitations. Unpublished manuscript, personal communication, 2004.
11. Davies B, Datta D. Mobility outcome after unilateral lower limb amputation. Prostet Orthot Int 2003;27:186–190.
12. Fletcher D, Andrews K, Butters M, Jacobsen S, Rowland C, Hallet J. Rehabilitation of the geriatric vascular amputee patient: a population–based study. Arch Phys Med Rehabil 2001;82(6):776–779.
13. Grieve AC, Lankhorst GJ. Functional outcome of lower-limb amputees: a prospective descriptive study in a general hospital. Prostet Orthot Int 1996;20(2):79–87.
14. Hanspal R, Fisher K. Assessment of cognitive and psychomotor function and rehabilitation of elderly people with prostheses. BMJ 1991;302:940.
15. Hanspal R, Fisher K. Prediction of achieved mobility in prosthetic rehabilitation of the elderly using cognitive and psychomotor assessment. Int J Rehabil Res 1997;20:315–318.
16. Larner S, Van Ross E, Hale C. Do psychological measures predict the ability of lower limb amputees to learn to use a prosthesis? Clin Rehabil 2003;17:493–498.
17. Leung EC-C, Rush D. Predicting prosthetic rehabilitation outcome in lower limb amputee patients with the functional independence measures. Arch Phys Med Rehabil 1996;77:605–608.
18. Pinzur MS, Graham G, Osterman H., Psychologic testing in amputation rehabilitation. Clin Orthop Rel Res 1988;299:236–240.
19. Pohjolainen T, Alaranta H. Predictive factors of functional ability after lower-limb amputation. Ann Chir Gynaecol 1991;80(1):36–39.
20. Schoppen T, Boonstra A, Groothoff JW, De Vries J, Goeken LN, Eisma WH. Physical, mental and social predictors of functional outcome in unilateral lower-limb amputees. Arch Phys Med Rehabil 2003;84:803–811.
21. O'Neill B, Evans J. Cognition predicts mobility rehabilitation outcome following lower-limb amputation. Submitted 2007.
22. Hunter J, Middleton FR. Cold injury amputees—a psychosocial problem? Prostet Orthot Int 1984;8: 143–146.
23. Munin M, Guzman M, Boninger M, Fitzgerald S, Penrod L, Singh J. Predictive factors for successful early prosthetic ambulation among lower limb amputees. J Rehabil Res Dev 2001;38(4):379–384.
24. Gerhards F, Florin I, Knapp T. The impact of medical, reeducational and psychological variables on rehabilitation outcome in amputees. Int J Rehabil Res 1984;7(4):379–388.
25. Traballesi M, Brunelli S, Pratesi L, Pulcini M, Angioni C, Paolucci S. Prognostic factors in rehabilitation of above knee amputees for vascular diseases. Dis Rehabil 1998;20(10):380–384.

26. Campbell WB, Ridler BM. Predicting the use of prostheses by vascular amputees. Eur J Vasc Endovasc Surg 1996;12(3):342–345.
27. Pattie A, Gilleard V. Manual of the Clifton Assessment Procedures for the Elderly (CAPE). London: Hodder and Stoughton, 1979.
28. De Melker RA, Touw-Otten F, Jacobs HM, Luttik A. [De waarde van de "sickness impact profile" als uitkomstmeting] Ned Tidjdschr Geneeskd 1990;134:946–948.
29. Randolph C. Repeatable Battery for the Assessment of Neuropsychological Status (RBANS). London: Harcourt Assessment, 1998.
30. Wilson BA, Cockburn J, Halligan PW. Behavioural Inattention Test (BIT). London: Harcourt Assessment, 1987.
31. Wilson BA, Alderman N, Burgess PW, Emslie H, Evans JJ. Behavioural Assessment of Dysexecutive Syndrome (BADS). London: Harcourt Assessment, 1996.
32. Ability One 9–Hole Peg Test. Kirkby-in-Ashfield, UK: Ability One, 1993.
33. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. Acta Psychiatr Scand 1983;67(6):361–370.
34. Mathuranath PS, Nestor P, Berrios GE, Rakowicz W, Hodges JR. A brief cognitive test battery to differentiate Alzheimer's disease and frontotemporal dementia. Neurology 2000;55:1613–1620.
35. Gauthier-Gagnon C, Grise MC, Lepage Y. The locomotor capabilities index: content validity. J Rehabil Outcome Measures 1998;2:40–46.
36. Ryall NH, Eyres SB, Neumann VC, Bhakta BB, Tennant A. The SIGAM mobility grades: a new population specific measure for lower limb amputees. Dis Rehabil 2003;25(15): 833–844.
37. Narang IC, Mathur BP, Singh P, Jape VS. Functional capabilities of lower limb amputees. Prostet Orthot Int 1984;8:63–69.
38. Callaghan B, Sockalingam S, Treweek SP, Condie ME. A post-discharge functional outcome measure for lower limb amputees: test-retest reliability with trans-tibial amputees. Prostet Orthot Int 2002;26:113–119.
39. Kempen G, Miedema I, Ormel J, Molenaar W. The assessment of disability with the Groningen Activity Restriction Scale. Conceptual framework and psychometric properties. Soc Sci Med 1996;43:1601–1610.
40. Mathias S, Nayak US, Isaacs B. Balance in elderly patients: the "get up and go" test. Arch Phys Med Rehabil 1986;67:387–389.
41. van den Berg JP, Lankhorst GJ. Inter-rater and intrarater reliability of ratings based on modified D-code of the ICIDH. Int Disabil Studies 1990;12:20–21.
42. Condie E, Scott H, Treweek S. Lower limb prosthetic outcome measures: a review of the literature 1995–2005. Am Acad Orthot Prosthet SSC Proc 2006;6:13–45.
43. Kendrick DC, Watts G. Kendrick Assessment Scales of Cognitive Ageing. Windsor, UK: NFER-Nelson, 1999.
44. Yesavage J, Brink T, Rose T, et al. Development and validation of a geriatric depression screening scale: a preliminary report. J Psychol Res 1983;17:37–49.
45. Reitan R. Validity of trail making test as an indication of organic brain damage. Percept Motor Skills 1958;8:271–276.
46. Wechsler D. The Wechsler Adult Intelligence Scale–revised edition. San Antonio, TX: Psychological Corporation, 1981.
47. Williams J. Memory Assessment Scales: Professional Manual. Odessa, FL: Psychological Assessment Resources, 1991.
48. de Graaf A, Deelman BG. Cognitive Screening Test. Handleiding. Lisse, UK: Swets en Zeitlinger, 1991.
49. Heslinga H, Van der Burg W, Saan RJ., Die nieuwe 15–woordentest A en B in een gezonde populatie. Scriptie. Groningen, Netherlands: Rijksuniv Groningen, 1983.
50. Jensen AR, Rohwer WD. The Stroop Colour-Word Test: a review. Acta Psychol 1966;25: 36–93.
51. Phillips NA, Mate-Kole CC, Kirby RL. Neuropsychological function in peripheral vascular disease amputee patients. Arch Phys Med Rehabil 1993;74(12):1309–1314.
52. Delis D, Kaplan E, Kramer J. Delis Kaplan Executive Function System Technical Manual. London: Harcourt Assessment, 2001.
53. Wilson BA. Rehabilitation of memory deficits. In: Wilson BA, ed. Neuropsychological Rehabilitation: Theory and Practice. Abingdon, UK: Swets & Zeitlinger, 2003.
54. Jones RSP, Eayrs CB. The use of errorless learning procedures in teaching people with a learning disability. Mental Handicap Res 1992;5:304–312.

6

Psychological Adjustment to Lower Limb Amputation: An Evaluation of Outcome Measurement Tools

Dalton L. Wolfe, Jackie S. Hebert, William C. Miller, A. Barry Deathe, Michael Devlin, and Luljeta Pallaveshi

Overview

People with lower extremity amputation (LEA) face numerous physical, psychological, and social challenges associated with their limb loss and subsequent rehabilitation and community reintegration. Although care providers tend to focus on physical and medical outcomes following amputation, psychological adjustment and coping with the new reality of life with a missing limb is of paramount importance to the individual with the amputation (1). The focus on physical adjustment following amputation is reflected in the numerous studies that examine mobility-related or other physical outcomes, often at the expense of investigating psychosocial or other disability-related variables, which have a potentially significant impact on outcome (2).

Recent reviews of lower limb prosthetic outcome measures (3) and the status of outcome measurement in rehabilitation (4) have demonstrated this relative lack of utilization of measurement tools addressing psychological adjustment following amputation. Furthermore, Gallagher and MacLachlan (5) have suggested that this preoccupation with the physical aspect of amputation is reflected in the continued development of outcome measurement tools specific to the LEA population. They note that most tools that assess psychological aspects of adjustment tend to be narrowly focused on a single factor (e.g., body image or activity restriction). This chapter outlines and evaluates the most commonly employed outcome measurement tools used to assess psychological adjustment that have been investigated in subjects with LEA, in order to assist clinicians and researchers with appropriate instrument selection.

Background

There are numerous considerations for ensuring a specific instrument is appropriate for its intended use. First, it is important to have a thorough understanding of the scope of potential outcomes and, at least in the case of health status change, an appropriate matching to the component of rehabilitation that is being assessed (6). Part of this process may involve the classification of possible outcome measures into a framework understandable by potential users. For the present review, we have classified specific instruments according to the conceptual framework noted by Behel and Rybarczyk and their colleagues (7, p. 93). They identified three interrelated dimensions under which they characterized psychological adjustment responses to amputation:

1. Cognitive-affective responses (e.g., altered body image)
2. Behavioral responses (e.g., avoidance)
3. Specific adjustment problems (e.g., depression)

Cognitive-affective responses "are at the core of attempts to redefine oneself and one's environment," whereas behavioral responses "reflect efforts to negotiate the altered psychic and physical landscape" (7). These authors contend that specific responses may "coalesce into maladaptive patterns," resulting in specific psychological adjustment problems. For our own purpose we have modified this third dimension as reflecting overall status, which may or may not be maladaptive or represent problems. For example, we have included measures of health-related quality of life (HRQoL) in this category, which may reflect either positive or negative adaptations emerging from the responses in dimensions 1 and 2 above.

A second consideration in instrument selection is the purpose for which the outcome measure is used. In the context of LEA rehabilitation, outcome measurement may be related to the individual, to the amputation rehabilitation program, or the process of intervention (4). Furthermore, Feinstein et al. (8) noted six purposes of outcome measurement in assessing functional disability: to determine compensation, to predict prognosis, to plan placement, to estimate care requirements, to assist in choosing specific types of care, and to determine change in status secondary to intervention.

A third factor that should be considered is the overall quality of the instrument and the evidence, which supports its use. The degree to which a particular instrument is appropriate for its intended use can be assessed by examining its psychometric properties (i.e., reliability, validity, and responsiveness) reported in the scientific literature (9). As well, properties that describe clinical utility (i.e., practical considerations such as interpretability, acceptability, feasibility) as described by Feinstein (10) are useful in ascribing credibility to the measurement.

An important aspect of the evidence of instrument quality is that it should be relevant for the specific population for which the instrument is intended. Therefore, the present review is limited to those investigations of individuals with LEA. Demonstrations of reliability or validity in alternate patient populations (e.g., stroke) or in healthy control subjects are not adequate for ensuring the selected tool will be reliable or valid for use in LEA. It should be remembered that even within the LEA population, there is a bimodal adult population. Those receiving amputations due to trauma tend to be younger, with less comorbidity, and generally higher levels of preamputation physical function, especially as compared to those with vascular etiologies (11,12). Evaluation of the psychometric properties and clinical utility of an instrument may provide information about selecting the most appropriate tool for a particular outcome; however, this information is most relevant and useful when being used in the same population and the same context (e.g., setting) in which it was tested.

A variety of outcome measurement tools have been applied to the assessment of psychological adjustment; however, very few of these tools have been evaluated psychometrically (i.e., reliability, validity and responsiveness) within a population of people with an LEA. This chapter reviews the evidence for those tools that have undergone some form of psychometric evaluation with a sample of people with an LEA, so as to assist appropriate outcome measurement selection and also to inform future outcome measurement development.

Methodology

Search Strategy

Electronic databases (Embase, Medline, PsychInfo, CINAHL, Cochrane) were searched for the time period 1980 to September 2006 for English-language articles addressing limb amputation rehabilitation. In addition, we systematically hand-searched pertinent health care journals and existing reviews to ensure comprehensive search results. Additional forms of searching involved browsing Internet Web Sites and the electronic list of related articles as determined by PubMed. These searching techniques are a necessary adjunct given, Hopewell et al.'s (13) finding that hand-searching methods identified between 92% and 100% of randomized trials as compared to lower numbers using electronic keyword searching strategies (i.e., 49%, 55%, and 67% for Embase, Medline, and PsychInfo, respectively).

Inclusion Criteria

Articles included were those for which at least one of the psychometric properties (i.e., reliability, validity, or responsiveness) were evaluated in the LEA population. Papers that did not discuss any aspect of psychometric properties were not considered in this review.

A list of outcome measurement tools was prepared from the selected articles. To be eligible for further assessment, the tool needed to be standardized or, if customized, published in a form such that it was readily available for use. In addition, an eligible tool required that at least one article existed with a primary focus on the evaluation of psychometric properties involving subjects with LEA or that there were at least two articles that contained some psychometric information (not necessarily as the focus of the article).

Classification and Evaluation of Outcome Measures

Outcome measurement tools were then classified according to the scheme outlined previously: (1) cognitive-affective tools, (2) behavioral tools, and (3) adjustment/maladjustment tools. Following this, specific findings from individual articles were evaluated according to established criteria put forth by the Health Technology Assessment (HTA) program (9) and other sources. The eight separate evaluation criteria used are summarized in Table 6.1. These criteria consist of standard psychometric properties and properties of clinical utility, which have formed the basis for the assessment of outcome measures across a variety of fields (14–16).

In addition to the criteria and standards noted in Table 6.1, there are several methodological considerations that require further elaboration. The reader should understand that there is not universal acceptance of the underlying concepts and rationale behind these standards and criteria, and there are other methods and criteria for evaluating psychometric properties. Although several authors have advocated using this method to assign grades to indicate the level of evidence for a specific instrument (e.g., Andresen [23], and McDowell and Newell [25]), others have noted the inherent difficulty and potential for misinterpretation associated with this task. For example, Condie et al. (3), in a recent review of prosthetic-related outcome measures, chose not to assign an overall grade even to individual studies due to time constraints and the unlikelihood of a single grade capturing the complexity of the underlying evidence.

Nonetheless, our approach was to provide as much information as possible on the individual findings available for specific instruments, that is, provide a specific grade of +++, excellent; ++, adequate; or +, poor for each of the findings associated with a specific psychometric property evaluated in each study. However, overall grades collapsing all findings derived from every article for a specific psychometric property were not provided as it was felt that these would vary depending on the specific context from which the evidence was derived as compared to the specific needs and intention of the potential user. For example, if a particular instrument had several findings establishing validity in an inpatient setting but the user wanted to apply the instrument to people living in the community, an overall grade supporting its use would have less relevance. Ideally, potential users of a particular instrument can judge the appropriateness of a particular instrument based on their specific needs and the context of their investigation (i.e., specific population, setting). It is also important for the reader to understand that a single finding or study does not validate the particular instrument for use. Rather, the process of validating an instrument is an ongoing process requiring “a pattern of consistent findings involving different investigators using different theoretical structures across a number of different studies” (28, p. 25).

Therefore, we chose to present findings from individual studies with a description of the setting in which the study was conducted (i.e., inpatient, outpatient, community or laboratory) and the study population (i.e., etiology and level of amputation). The scoring criteria as noted in Table 6.1 was used for the individual findings of reliability, validity, and responsiveness (i.e., +++, ++, +), and these have been summarized in the tables throughout the Review of Evidence section, below. If more than

Table 6.1. Evaluation criteria and standards

Criteria	Definition	Standards
1. Appropriateness	The match of the instrument to the purpose/question under study. One must determine when information is required and what use will be made of the information (17).	Depends on the specific purpose for which the measurement is intended.
2. Reliability	Refers to the reproducibility and internal consistency of the instrument. **Reproducibility** addresses the degree to which the score is free from random error. Test-retest and interrater reliability both focus on this aspect of reliability and are commonly evaluated using correlation statistics including ICC, Pearson's or Spearman's coefficients, and kappa coefficients (weighted or unweighted). **Internal consistency** assesses the homogeneity of the scale items. It is generally examined using split-half reliability or Cronbach's alpha statistics.Item-to-item and item-to-scale correlations are also accepted methods.	**Test-retest interrater reliability** Intraclass Correlations (ICC): Kappa statistics, other correlation coefficients if numerically appropriate: Excellent: ≥0.75; Adequate: 0.4–0.74; Poor <0.40 (18–20). Note: Fitzpatrick et al. (9) recommend a minimum test-retest reliability of 0.90 if the measure is to be used to evaluate the ongoing progress of an individual in a treatment situation. **Internal consistency** (split-half or Cronbach's statistics): Excellent: ≥0.80; Adequate: 0.70–0.79; Poor: <0.70 (21)·Note: Fitzpatrick et al. (9) caution that values in excess of 0.90 may indicate redundancy. **Interitem and item-to-scale correlation coefficients:** Adequate levels—inter-item: 0.3–0.9; item-to-scale: 0.2–0.9 (9,22).
3. Validity	Does the instrument measure what it purports to measure? Forms of validity include face, content, construct, and criterion. Concurrent, convergent, discriminative, and predictive validity are all considered to be forms of criterion validity. However, concurrent, convergent, and discriminative validity all depend on the existence of a gold standard to provide a basis for comparison. If no gold standard exists, they represent a form of construct validity in which the relationship to another measure is hypothesized (6).	**Construct: convergent, concurrent, and predictive correlations:**Excellent ≥0.60, adequate: 0.30–0.59, poor <0.30 (9,23–25) (excellent predictive validity may also entail significance with multiple regression, ideally with prospective studies). Concurrent (known groups):Excellent: significant difference with effect size; Adequate: significant difference; Poor: no significant difference. **Receiver Operating Characteristic (ROC) analysis:** area under the curve (AUC): Excellent: ≥0.90; Adequate: 0.70–0.89; Poor <0.70 (25).There are no agreed-on standards by which to judge sensitivity and specificity as a validity index (26).
4. Responsiveness	Sensitivity to changes within patients over time (which might be indicative of therapeutic effects). Responsiveness is most commonly evaluated through correlation with other measures, through correlation with other change scores, effect sizes, standardized response means, relative efficiency, sensitivity, and specificity of change scores and ROC analysis. Assessment of possible floor and ceiling effects is included as they indicate limits to the range of detectable change beyond which no further improvement or deterioration can be noted.	**Sensitivity to change**: Excellent: Evidence of change in expected direction using methods such as standardized effect sizes: <0.5 = small; 0.5–0.8 = moderate; >0.8 = large. Also, by way of standardized response means, analysis of change scores or relative efficiency. Adequate: Evidence of moderate/less change than expected, conflicting evidence. Poor: Weak evidence based solely on *p*-values (statistical significance) (9,23–25). **Floor ceiling effects:** Excellent: No floor or ceiling effects. Adequate: floor and ceiling effects <20% of patients who strain either the minimum 20% (floor) or maximum (ceiling) score. Poor: > 20% (22).
5. Precision	Number of gradations or distinctions, e.g., Yes/no response vs. a 7–point Likert response set.	Depends on the precision required for the purpose of the measurement (e.g., classification, evaluation, prediction).
6. Interpretability	How meaningful are the scores? Are there norms available for comparison?	Jutai and Teasell (27) point out these practical issues should not be separated from consideration of the values that underscore the selection of outcome measures.
7. Acceptability	How acceptable the scale is in terms of completion by the patient. Does it represent a burden? Can the assessment be completed by proxy, if necessary?	
8. Feasibility	Extent of effort, burden, expense, and disruption to staff/clinical care arising from the administration of the instrument	

one finding was obtained for a specific psychometric property from an individual paper, then only the highest quality rating was indicated in the psychometric summary tables. General qualitative statements regarding the evidence in totality were made based on these findings in the Review of Evidence.

Review of Evidence

Following the literature review, a total of 19 outcome measurement tools addressing psychological adjustment were identified that met the inclusion criteria. Nine of these instruments were classified as being cognitive-affective tools, none as behavioral tools, and 10 as adjustment/maladjustment tools. The majority of the cognitive-affective tools (six) assessed the construct of body image, while the adjustment/maladjustment tools were composed of those focused on depression or anxiety (five) or HRQoL (five). Therefore, we have elected to summarize the results for these various tools by considering them in four groups: (1) body image tools, (2) other cognitive-affective tools, (3) depression (or anxiety) tools, and (4) HRQoL tools.

Cognitive-Affective: Body Image Tools

Self-image has been identified as one of the central themes important to persons with LEA (29), and the way one deals with a changed body image has long been recognized as an important component of adjusting to limb loss or dealing with a prosthetic replacement (30–32). There are numerous scales that have been employed to investigate the construct of body image in people with amputation including the Amputation-Related Body Image Scale (ARBIS) (33), the Amputee Body Image Scale (ABIS) (34,35), the Attitude to Artificial Limbs Questionnaire (AALQ) (36), the Body Image Questionnaire (BIQ) (36), the Engagement/Discomfort with Revealing the Body scales (EEABR, D-EEABR) (37), and the Multidimensional Body-Self Relations Questionnaire (MBSQ) (38). Pertinent details about the various studies examining each of these tools, the specific populations under investigation, and the numeric properties of each tool are summarized in Table 6.2. A summary of the quality assessment of the psychometric properties under investigation for each of these studies is shown in Table 6.3. Overall, despite the abundance of potential tools for assessing body image, there is a relatively small number of studies employing each tool (Table 6.2), with few investigations evaluating psychometric properties (Table 6.3), as is indicated by the limited number of studies identified in these tables for each tool.

All of these scales are self-report format with minimal subject burden (i.e., only 20 questions or less) with the exception of the MBSQ (69 items), which is also the only tool not developed for or initially tested with those with LEA. The questions pertinent to LEA on the BIQ were added so as to adapt a body shape questionnaire developed originally for those with eating disorders (39). Although all of the tools were developed with content validity considered (i.e., involvement of experts or patients in test construction), there is little documentation of the processes or testing undertaken and there has been no published factor analysis that may have served to confirm the dimensionality of the measures in assessing the construct of body image. It should be noted that the AALQ and the EEABR/D-EEABR were not intended to be solely measures of body image, although both contained specific questions about body image, and most questions seem somewhat related to body image as evidenced by reasonably high internal consistency. All scales also appear easily interpretable and easy to score, with a simple summing of a series of Likert-scaled questions for which the summed score represents a greater or lesser disruption to body image.

Although adequate (++) or excellent (+++) findings of internal consistency have been established in single reports for some of these tools (i.e., AALQ, BIQ, EEABR, D-EEABR), only the EEABR and D-EEABR have been assessed for some form of test-retest reliability (Table 6.3). It should be noted that true test-retest reliability is difficult to obtain in psychological self-report measures where the stability of the underlying construct is unknown and initial test administration could bias the answers upon repeated application. In addition, the EEABR demonstration of reliability involved only a single, small study ($n = 11$)

TABLE 6.2. Summary of articles examining body image outcome tools in lower extremity amputation (LEA)

Instrument, author, year	Setting	Etiology	Level	n	Data type	No. of items	Item (scale) response range
Amputation-Related Body Image Scale (ARBIS)							
Rybarcyk et al., 1995 (33)	OP	Vascular/ trauma/other	AK-BK	112	Ordinal	11	0–4 (0–44)
Amputee Body Image Scale (ABIS)							
Murray and Fox, 2002 (35)	Comm	Vascular/ trauma/other	AK-BK	44	Ordinal	20	1–5 (20–100)
Wetterhahn et al., 2002 (38)	OP + Comm	Vascular/ trauma/other	AK-BK	56			
Breakey, 1997 (34)	Comm	Trauma	AK-BK	90			
Attitudes to Artificial Limbs Questionnaire (AALQ)							
Fisher and Hanspal, 1998 (36)	OP	Vascular/ trauma/other	AK-BK	107	Ordinal	10	0–4 (0–40)
Body Image Questionnaire (BIQ)							
Fisher and Hanspal, 1998 (36)	OP	Vascular/ trauma/other	AK-BK	107	Ordinal	17	0–6 (17–102)
Engagement in Everyday Activities Involving Revealing the Body (EEARB), Discomfort-EEARB							
Donovan-Hall et al., 2002 (37)	IP + OP	Vascular/ trauma/other	BK	11	Ordinal	10, 11	0–6, 1–4 (0–60, 11–44)
Multidimensional Body-Self Relations Questionnaire (MBSQ)							
Wetterhahn et al., 2002 (38)	OP + Comm	Vascular/ trauma/other	AK-BK	56	Ordinal	69	1–5(?)

n, number of subjects with amputation only and does not include control or comparison subjects; IP, inpatient; OP, outpatient; Comm, community; AK, above knee; BK, below knee; ?, data missing or unclear.

employing a self-selected outpatient sample of convenience, which found only adequate (++) levels of test-retest reliability. The only scale with multiple reports establishing validity was the ABIS with several demonstrations of excellent (+++) convergent validity with significantly high correlations with various other measures (Table 6.3). Concurrent validity (known groups) has also been assessed for the ABIS, although these reports are limited to demonstrations of significance for between-group findings with no reporting of effect sizes. Other scales have only single reports of varying quality for convergent or concurrent validity established in persons with LEA. Responsiveness or the presence of floor or ceiling effects has not been adequately assessed for any of the scales.

Summary and Recommendations

For the most part, the tools that have been employed to assess body image have not been adequately assessed to support use in specific subpopulations of those with LEA. The ARBIS and BIQ may have potential for measuring body image following amputation (33,36), and the ARBIS has been demonstrated as a significant predictor of psychosocial adjustment (i.e., depression and quality of life) (33). However, more study is needed to determine the applicability, validity, and responsiveness of these measures.

TABLE 6.3. Quality assessment (psychometric properties) for body image outcome tools in LEA

	Quality of psychometric property						
Instrument, author, year	Reliability		Validity			Responsiveness	
	IC	Test-retest	Convergent	Concurrent	Predictive	C/F effect	Resp.
ARBIS							
Rybarczyk, 1995	+++				+++		
AALQ							
Fisher, 1998	+++		+		+		
ABIS							
Murray, 2002					++		
Wetterhahan, 2002			+++	++			
Breakey, 1997			++	++	+++		
BIQ							
Fisher, 1998	+++		++	+	+		
EEABR; D-EEABR							
Donovan-Hall, 2002	++; +++	++; ++	++; ++	+; +	++; ++		
MBSRQ							
Wetterhan, 2002			+++	++			

IC, internal consistency; C/F Effect, ceiling or floor effects; Resp., responsiveness; +++, excellent; ++, adequate; +, poor. See Table 6.1 for definition). Absence of ratings mean no findings reported.

The ABIS is the tool with the most psychometric evaluation conducted to date and appears to be associated with other measures of psychosocial well-being (34,35,38). However, some authors have questioned the psychometric validity of the scale (36), as the questionnaire includes questions on phantom limb phenomena and references to the self as "disabled," which may be considered beyond the realm of purely "body image." Factor analysis and assessments of internal consistency would be required to more fully assess these issues. Further examination of the stability and responsiveness is also needed. Despite this, the ABIS appears to have good potential for measuring self-perception of body image following amputation, and although additional study is needed to determine the reliability and responsiveness of this measure, clinical use of the tool is reasonable given the demonstrated validity and ease of administration.

Other Cognitive-Affective Tools

Three separate scales examining other cognitive-affective aspects associated with psychological adjustment to amputation were identified including the Activity-Specific Balance Confidence Scale (ABC) (40–43), the Clifton Assessment Procedures for the Elderly (CAPE) (44–46), and the Rosenberg Self-Esteem Scale (RSE) (37,47–49). The various studies examining the psychometric properties of these scales are outlined in Table 6.4 and the psychometric results for the quality assessment are shown in Table 6.5. As each of these scales measures different constructs, the results and evidence review are described separately.

The ABC Scale, based on Bandura's (50) theory of self-efficacy, is a 16-item, self-report measure of an individual's fear of falling, which is assessed over a continuum of ambulatory activities, ranging from easy to difficult. The scale was developed for and has been used extensively in the elderly population (42,43). In addition to self-report, it can also be used as a postal survey or administered by a third party (requiring no specialized training) in a variety of settings. Individuals are asked to rate their level of confidence for each activity on a scale between 0 (minimum score = no confidence) and 100% (maximum score = completely confident), and an overall mean balance confidence score is derived along the same 0 to

TABLE 6.4. Summary of articles examining other cognitive-affective outcome tools in LEA

Instrument, author, year	Setting	Etiology	Level	*n*	Data type	No. of items	Item (scale) response range
Activity-Specific Balance Confidence Scale (ABC)							
Deathe and Miller, 2005 (53)	OP	Vascular/ trauma	AK-BK	93	Ratio	16	0–100 (0–100)
Miller et al., 2004 (55)	OP-Comm	Vascular/ trauma	AK-BK	84			
Miller et al., 2003 (41)	OP+Comm	Vascular/ trauma/other	AK-BK	54+329			
Miller et al., 2002 (40)	Comm	Vascular/ trauma/other	AK-BK	435			
Miller et al., 2001 (54)	OP+Comm	Vascular/ trauma/other	AK-BK	55+329			
Miller et al., 2001 (52)	Comm	Vascular/ trauma/other	AK-BK	435			
Clifton Assessment Procedures for the Elderly (CAPE)							
Hanspal and Fisher, 1997 (45)	IP + OP	?	AK-BK	32	Various	?*	Various
Hanspal and Fisher, 1991 (44)	OP	?	AK-BK	100			(0–35)*
Rosenberg Self-Esteem Scale (RSE)							
Donovan-Hall et al., 2002 (37)	IP + OP	Vascular/ trauma/other	BK	11	Ordinal	10	1–4
Dunn, 1996 (48)	Comm	Vascular/ trauma/other	AK-BK-U	138			(10–40)
Christ et al., 1995 (47)	Comm	Other	?	45			

n, number of subjects with amputation only and does not include control or comparison subjects; IP, inpatient; OP, outpatient; Comm. community; AK, above knee; BK, below knee; U, upper limb; ?, data missing or unclear; *Hanspal and Fisher (44,45) employed the Orientation and Mental Ability sections and a Psychomotor test (Spiral Maze) from the CAPE.

TABLE 6.5. Quality assessment (psychometric properties) for other cognitive-affective outcome tools in LEA

	Quality of psychometric property						
Instrument, author, year	Reliability		Validity			Responsiveness	
	IC	Test-retest	Convergent	Concurrent	Predictive	C/F effect	Resp.
ABC							
Deathe, 2005			++				
Miller, 2004			++				
Miller, 2003	+++	+++	+++	++			
Miller, 2002				++			
Miller, 2001			+++				
Miller, 2001				++	+++		
CAPE							
Hanspal, 1997		+++			++		
Hanspal, 1991					+++		
RSE							
Donovan-Hall, 2002		++	+++	++			
Dunn, 1996	+++		+++				
Christ, 1995				+			

IC, internal consistency; C/F effect, ceiling or floor effects; Resp., responsiveness; +++, excellent; ++, adequate; +, poor; see Table 6.1 for definition). Absence of ratings mean no findings were reported.

100 scale, thus providing an easily interpretable outcome. There is also a threshold score of 80, below which mobility capability, performance, and social activity appear to be affected as identified in a series of studies of older adults (51). This cutoff value has been used but not assessed in LEA (52). The ABC scale has minimal patient burden, taking only about 5 minutes to complete. Patients must have adequate abstract cognitive functioning to imagine themselves in certain circumstances and respond appropriately. Preliminary analysis of repeatability has indicated that a real change would occur if test-retest scores were different by 6, but the minimal important clinical difference on the scale has not been determined (41).

Although there have been numerous evaluations of the psychometric properties in individuals with LEA, these have all been conducted by the same group of investigators (40,41,52–55). These reports have included single findings of excellent reliability and internal consistency as well as multiple demonstrations of various forms of validity in patients with LEA from both vascular and nonvascular causes. It should be noted that the scale was not shown to distinguish between those with transtibial versus transfemoral level of amputation as might be expected (41). In addition, responsiveness of the tool to assess individual change over time has not yet been evaluated. A ceiling effect may exist, as higher repeatability was seen at higher scores of balance confidence (41).

The CAPE is a brief psychogeriatric assessment procedure to assess cognitive ability (46). The original developers have suggested its usefulness in a broad range of psychogeriatric patients, providing significant differentiation between groups receiving varying degrees of care and with differing outcome expectations (56). Hanspal and Fisher (44,45) have employed these assessment procedures in older patients with LEA to predict achievement of successful rehabilitation as reflected by attainment of higher mobility grades. It was not clear if these authors employed the entire CAPE or just specific subsections. They administered sections assessing orientation and mental ability as well as measuring the time taken and errors associated with the performance on a psychomotor task (i.e., spiral maze task).

The authors employed the CAPE, as they felt it could be administered by professionals relatively unskilled in psychometric techniques (45). In each case, Hanspal and Fisher conducted this assessment in older individuals only (i.e., over 60 and mean age of 66). Excellent (+++) test-retest reliability ($r = 0.93$) was achieved despite a retest period of 1 year. This finding is exceptional given that one might expect some cognitive decline over that time frame in an elderly population. In the original investigation, excellent (+++) correlations were obtained between the cognitive assessment and mobility grades indicative of predictive validity, although both assessments were conducted after the subjects had already achieved a stable mobility outcome (44). A better indication of predictive validity was obtained in a subsequent investigation in which adequate (++) correlations were achieved between early cognitive assessments (i.e., at 2 to 4 weeks postamputation) and later mobility assessments (i.e., 8 to 14 weeks), although higher correlations were found for those patients having no medical comorbidities (45).

The RSE is a widely used self-report scale employed in general psychological studies assessing perceived self-esteem, which can be thought of as a positive or negative orientation toward oneself and is part of the wider construct of self-concept (49). It was originally developed for use in assessing this construct in adolescents. The scale is easily scored and readily interpretable, with 10 Likert-scaled questions scored from 1 to 4, providing a summed score from 10 to 40. High scores indicate high self-esteem, and normal values are available, although the largest sample involves only adults up to the age of 65 (37).

The tool is easy to administer, takes very little time, and can also be conducted as part of a postal survey. Although we report only three evaluations of its use in LEA, these studies have been conducted over a variety of settings ranging from groups of patients with varying etiologies across the care continuum (37,48) to a more specific application examining psychosocial adaptation of long-term survivors of bone sarcoma (47). Internal consistency was found to be excellent (+++) with a postal version of the RSE mailed to a sample obtained from a sports association (i.e., amputee golf) mailing list (138 of 275 responded) (48). A small study ($n = 11$) showed adequate (++) test-retest reliability ($r = 0.64$), although interpretation is uncertain as the test-retest interval was assessed 1 month prior to receiving a prosthesis versus 3 months after receiving the prosthesis, a testing model more appropriate for examining responsiveness (37). This study also provided adequate (++) evidence of concurrent validity in that significant differences (p <.05) were obtained on the RSE between healthy controls and individuals with an amputation at either time period. Conversely, Christ et al. (47), in their examination of psychosocial adaptation following bone cancer treatment, noted that there were no significant differences in the RSE between those who were treated with a limb salvage approach versus those receiving amputation, and no differences between males and females. As well, other investigations provided demonstrations of convergent validity with excellent (+++) associations noted between the RSE and measures of anxiety and depression (37,48).

Summary and Recommendations

ABC Scale

The ABC Scale provides useful clinical information about the confidence with which individuals feel capable in moving throughout their environment, which directly relates to their return to participation in social and community activities. The routine use of this tool in both clinical and research applications is recommended in persons with LEA amputation, particularly in older adults, although validation is required from additional investigators. In particular, more information about the predictive qualities of the ABC Scale relative to psychosocial and physical outcomes as well as further evaluation of the responsiveness and potential ceiling effects for the tool would be useful.

CAPE

Identifying specific factors to predict eventual success of LEA rehabilitation can provide useful information for the clinician (57,58). Fisher and Hanspal (36) have employed the CAPE for this purpose and have demonstrated that a cognitive assessment including a psychomotor component can predict mobility outcomes for those over 60 years of age. Similar findings were achieved by Schoppen et al. (58) over a wider age range using a battery of cognitive function tests to significantly predict a broader range of outcomes including HRQoL and activity restrictions, and by Larner et al. (59), who used the Kendrick Object Learning Test (60) to predict the likelihood of successfully using a prosthesis. Based on these findings, it is clear the overall concept of cognitive screening has clinical merit, but further evaluations involving direct comparisons between tools may better determine the cognitive instruments that best serve this purpose.

RSE

In addition to examining self-esteem as an outcome of social forces, self-esteem is often analyzed as an independent or intervening variable. Rosenberg, the primary developer of the construct of self-esteem (and the RSE), noted that self-esteem should be thought of as a generally stable characteristic of adults and not easily manipulated (61). Dunn (48) and Christ et al. (47) each employed the RSE as a measure of an outcome or criterion variable, which was predicted by other demographic or psychosocial variables, whereas Donovan-Hall et al. (37) used the RSE as a criterion measure of psychological well-being to assess convergent validity. The RSE is well established as a measure of self-esteem in a variety of populations, although evidence for the use of the RSE in individuals with LEA would be enhanced with additional demonstrations of validity. This is especially the case for findings of predictive validity in which the RSE may be useful in predicting psychological or other functional outcomes.

Adjustment/Maladjustment Tools: Depression and Anxiety

Depression is diagnosed with the standard clinical interview and the use of appropriate diagnostic instruments (e.g., using *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition [DSM-IV] criteria) (62). Anxiety and other depressive symptoms may be assessed using a variety of screening scales that were developed originally for general psychiatric use. These include the Beck Depression Inventory (BDI) (63,64), the Center for Epidemiological Studies–Depression Scale (CES-D) (65), the General

Table 6.6. Summary of articles examining depression outcome tools in LEA

Instrument, author, year	Setting	Etiology	Level	n	Data type	No. of items	Item (scale) response range
Beck Depression Inventory (BDI)							
Schoppen et al., 2003 (58)	IP + OP	Vascular	AK-BK	51	Ordinal	21	0–3 (0–63)
Frank et al., 1984 (74)	IP + OP	Vascular/ trauma/other	AK-BK	66			
Kashani et al., 1983 (70)	IP + OP	Vascular/ trauma/other	AK-BK	65			
Center for Epidemiological Studies - Depression Scale (CES-D)							
Behel et al., 2002 (7)	OP	Vascular/ trauma/other	AK-BK	84	Ordinal	20	0–3 (0-60)
Dunn, 1996 (48)	Comm	Vascular/ trauma/other	AK-BK-U	138			
Christ et al., 1995 (47)	Comm	Other	?	45			
Rybarcyk et al., 1995 (33)	OP	Vascular/ trauma/other	AK-BK	112			
Rybarczyk et al., 1992 (75)	OP	Vascular/ trauma/other	AK-BK	89			
General Health Questionnaire (GHQ)							
Fisher and Price, 2003 (76)	IP + Comm	Vascular/ Trauma/Other	?-U	122	Ordinal	12* 28 & others	Likert 0–3 or Scaling 0,0,1,1 (varies)*
Lindesay, 1986 (73)	OP	?	?-U	35			
Thompson and Haran, 1983 (77)	Comm	Vascular/ trauma/other	AK-BK	134			
Geriatric Depression Scale (GDS)							
Robinson-Whelan and Bodenheimer, 2004 (78)	Comm	Vascular	AK-BK	44	Ordinal	30	Y/N, 1/0 (0-30)
Schubert et al., 1992 (79)	IP	?	AK-BK	17			
Hospital Anxiety and Depression Scale (HADS)							
Donovan-Hall et al., 2002 (37)	IP + OP	Vascular/ trauma/other	BK	11	Ordinal	14	0–3 (0–21)
Fisher and Hanspal, 1998 (36)	OP	Vascular/ trauma/other	AK-BK	107			
Carrington et al., 1996 (80)	OP	Vascular	AK-BK	13			

n, number of subjects with amputation only and does not include control or comparison subjects; IP, inpatient; OP, outpatient; Comm., community; AK, above knee; BK, below knee; U, upper limb; ?, data missing or unclear; *,several variants of the GHQ exist (e.g., GHQ-12, GHQ-28) and the scoring system can be varied between summing of a Likert-based system or by transforming responses to 0 or 1.

Health Questionnaire (GHQ) (66,67), the Geriatric Depression Scale (GDS) (68,69), and the Hospital Anxiety and Depression Scale (HADS) (69). Table 6.6 outlines details about the studies examining each of these tools and Table 6.7 provides a summary of the quality assessment of the psychometric properties for each of these studies. Estimates of the prevalence of depression vary widely in LEA, ranging from none or very low (36), to other reports of 35% (62,70) and 51.4% (62). Despite the relatively large number of tools for assessing depressive symptoms, there are few investigations employing each tool (Table 6.6), with the psychometric properties of each remaining relatively unstudied in LEA (Table 6.7).

Each of these self-report measures have minimal patient burden with no more than 30 items requiring either Likert-scale–type responses or a selection of the most appropriate statement. Several of these have several shorter or longer

Table 6.7. Quality assessment (psychometric properties) for depression outcome tools in LEA

Instrument, author, year	Quality of psychometric property						
	Reliability		Validity			Responsiveness	
	IC	Test-retest	Convergent	Concurrent	Predictive	C/F effect	Resp.
BDI							
Schoppen, 2003					+++		
Frank, 1984				++			
Kashani, 1983			++	++			
CES-D							
Behel, 2002			+++				
Dunn, 1996	+++		+++				
Christ, 1995				+			
Rybarczyk, 1995			+++				
Rybarczyk, 1992			++				
GHQ							
Fisher, 2003				++			+
Lindesay, 1986			+++				
Thompson, 1983				+			
GDS							
Robinson-Whelan, 2004	+++				+		
Schubert, 1992					++		+
HADS							
Donovan-Hall, 2002		++	++	++			
Fisher, 1998			++				
Carrington, 1996				++			

IC, internal consistency; C/F effect, ceiling or floor effects; Resp., responsiveness; +++, excellent; ++, adequate; +, poor; see Table 6.1 for definition). Absence of ratings mean no findings were reported.

versions (e.g., GHQ-12, GHQ 28, or GHQ-60), although the present report deals with the versions that have been tested in those with LEA. Interpretation is typically straightforward, with greater scores reflecting a greater prevalence of depressive symptoms or behaviors and therefore a higher likelihood of having depression or anxiety. There are several variants of scoring methodology for the GHQ, which makes this scale marginally more complex in interpretation. Normative data are available for various clinical populations for most of the scales, and several investigators have suggested cutoffs and guidelines for categorizing scale scores into the degree of depressive symptomatology (e.g., BDI [63], CES-D [71], GHQ [66], GDS [68,72], HADS [69]). Of particular note, Lindesay (73) noted a specific cutoff in discriminating between cases and noncases with 100% sensitivity and 86% specificity for the GHQ-28 in detecting psychiatric disturbance in individuals with an amputation with phantom pain.

Although the quantity of psychometric testing is relatively sparse for these measures, each of the scales has evidence for at least two forms of validity or reliability. The CES-D, in particular, demonstrated excellent (+++) internal consistency and convergent validity with excellent (+++) correlations between the CES-D and an assortment of related constructs such as HRQoL (7,33), optimism, and self-esteem (48). Other notable findings include Lindesay's (73) demonstration of an excellent (+++) correlation ($r = 0.88$) between the GHQ-28 and the specific blinded diagnoses made with the Present State Examination (9th edition).

Similarly, Kashani et al. (70) provided evidence of convergent validity for the BDI with higher scores for those with a diagnosis of depression as based on DSM-III criterion (adequate, ++). Several other demonstrations of a priori between-group significant differences as hypothesized were indicative of concurrent validity (adequate, ++) for the BDI (70,74). In addition, the BDI, when administered at 2 or 6 weeks following amputation, has been demonstrated to have excellent ability to predict various outcomes including activity restriction, mobility, and HRQoL at 1-year postamputation (58). Adequate (++) convergent and concurrent validity and test-test reliability have been demonstrated for the HADS (37,76,80), while findings of adequate (++) and poor (+) predictive validity were noted for the GDS (78,79).

Summary and Recommendations

Depression represents the psychological variable most frequently studied following amputation. Estimates of the prevalence of depression vary widely, ranging from none or very low (36) to estimates of up to 50% (62). In the present analysis, the CES-D was the measure with the most demonstrations of convergent validity, although these were typically conducted as comparisons with other self-report measures and not against a suitable criterion measure to assess specificity and sensitivity. Conversely, the 28-item GHQ scale was shown to have impressive values for sensitivity and specificity (100% and 86%, respectively) as compared to the criterion measure of the Present State Examination (9th edition) (73). The HADS is the only other measure with multiple demonstrations of convergent validity. The CES-D, the GHQ, and the HADS are most recommended for use in those with LEA, although certainly more validation is warranted. In addition, the CES-D and GHQ appear to be among the most widely used measures in assessing depressive symptomatology following LEA.

Horgan and MacLachlan (81) have noted that attention to the time frame of measurement is important, in that a depressive reaction is common immediately after amputation followed by relatively high level of depression for up to 2 years after which lower rates of depression are reported. Reports associated with 10 years or greater postamputation are mixed with some indicating increased prevalence and others reporting closer to normal rates. Horgan and MacLachlan note that the reporting of higher rates may also be linked to the use of the CES-D to measure depressive symptoms, and they suggest that this tool may lead to a tendency for overreporting, as was found in a validity study comparing CES-D results with the results of a standard clinical interview in a population of older adults. Others have noted that four CES-D items may be influenced by aspects of certain disease processes rather than depression (82), and at least two of these seem especially relevant to the person with an amputation ("I felt everything that I did was an effort," and "I could not get going").

As with most screening tools, there is a tendency to err on the side of overestimating positives, with the rationale that it is better to have extra false positives than risk false negatives. Also, it may not be the tool but rather the cutoffs that need resetting; this provides additional rationale for conducting more appropriate validation studies against a suitable criterion measure in those with LEA. As with other instruments noted throughout this chapter, investigations of the responsiveness of these instruments are sorely lacking.

Adjustment/Maladjustment Tools: HRQoL

Health-related quality of life is a multidimensional concept that focuses mostly on physical and mental health, social and role achievements, and thus is more oriented toward functional performance and objective measurement than is subjective QoL, albeit these most certainly influence subjective QoL (83,84). A variety of measurement tools have been employed to examine the construct of HRQoL, which is increasingly being realized as an important component in assessing overall adjustment following amputation. An important distinction with these tools is made between those that have been developed and used as HRQoL tools in a variety of clinical or other populations (i.e., generic tools) and those developed to address the specific issues and concerns of the person with an amputation (i.e., condition-specific tools).

Although we provide comment and data for each type of tool evaluated in LEA, we focus particularly on the tools specific to people with an amputation: the Orthotics and Prosthetics Users' Survey (OPUS) (85), the Prosthesis Evaluation Questionnaire (PEQ) (86), the Questionnaire for Persons with a Trans-Femoral Amputation (Q-TFA) (87), and the Trinity Amputation and

Prosthetic Experience Scales (TAPES) (5), each of which was developed considering the theoretical framework of HRQoL. Other amputee-specific tools such as the Prosthetic Profile of the Amputee (PPA) (2) were excluded from this review as the content concerning psychological adjustment was considered to be limited.[1]

Generic tools examined were the Nottingham Health Profile (NHP) (88), the SF-36 Health Survey (SF-36) (89), and the Sickness Impact Profile (SIP) (90). Details about the various studies examining each of these tools are summarized in Table 6.8, and a summary of the quality assessment of the psychometric properties is provided in Table 6.9. As might be expected with relatively recently developed tools such as the OPUS, PEQ, Q-TFA, and TAPES, there are few investigations to date examining the psychometric properties.

The OPUS (64 items), Q-TFA (70 items), and the TAPES (54 items) represent relatively minor subject burden as self-report questionnaires that typically take 20 minutes or less to complete (5, 86,87). Although completion rates for the PEQ for most items were reported to be very high (86), Miller et al. (54) altered the scoring system for the PEQ mobility subscale from the original visual analogue scale (VAS) format to a numerical scale ranging from 0 to 10 based on a pilot study in which subjects unfamiliar with the VAS reported that it was difficult to understand. Ferriero et al. (91) reported only a 70.5% completion rate for an Italian version of the PEQ, and noted that that this may have been due to the questionnaire length (i.e., 82 items).

With respect to the generic instruments, there is also fairly minor subject burden, although it should also be noted that the SIP version employed in the investigations of those with LEA included the longer 136 item version (92–94), although these questions are very straightforward and require only yes/no responses. A shorter version of the SIP (i.e., SIP-68) has been used as a dependent measure of outcome in a study of physical, mental, and social predictors following unilateral LEA (58).

All scales are uniformly easy to understand in terms of their interpretability with several inherent subscales and typically an overall composite score representing a total summed or average score from the subscales, although this is not always appropriate conceptually. Each of the amputee-specific tools was developed after consultation with appropriate stakeholders and pilot testing. In addition, the OPUS, PEQ, and TAPES have undergone various statistical procedures to facilitate development including factor, correlational, or Rasch analyses (5,85,86).

The OPUS consists of four domains: lower limb functional status (20 items), quality of life (23 items), satisfaction with devices (11 items), and satisfaction with services (10 items) (85). The PEQ consists of four domains, each containing several subscales (86). There are two physical domains: prosthetic function and mobility. The third domain is psychological and social, including perceived responses (five items), frustration (two items), and social burden (three items). The last domain is global with a single scale of well-being (two items). The Q-TFA is comprised of four domains: prosthetic use (two items), prosthetic mobility (19 items), problems (30 items), and global (three items). The remaining 16 items address issues pertinent to the first two of these domains but were not included in the domain subscores because of statistical redundancy or other reasons (87). The Q-TFA was designed for nonelderly persons with transfemoral amputations and was also developed to study outcomes when individuals change from a conventional socket prosthesis to a bone-anchored prosthesis. The TAPES contains three main sections that were identified using expert and patient consultation, pilot testing, and factor analysis (5). The first section focuses on psychosocial adjustment, consisting of three subscales (general adjustment, social adjustment, and adjustment to limitation), with five items in each subscale. Scores of psychosocial adjustment range from 5 to 25 for each subscale, with higher scores indicating greater levels of adjustment. The other sections assess activity restriction and prosthesis satisfaction, with a fourth section assessing the experience of phantom limb and stump pain, as well as other medical conditions not related to the amputation. Unlike most of the generic instruments, OPUS, PEQ, Q-TFA, and TAPES do not have cutoff points or reference values available for comparison, although an

---

[1] Some items on the PPA relate to adjustment: adjustment to the amputation, adjustment to the prosthesis, and phantom limb phenomena.

TABLE 6.8. Summary of articles examining health-related quality of life outcome tools in LEA

Instrument, author, year	Setting	Etiology	Level	n	Data type	No. of items	Item (scale) response range
Nottingham Health Profile (NHP)							
Demet et al., 2003 (95)	Comm	Vascular/trauma/other	AK-BK-U	539	Ordinal	38*	y/n, 1/0 (0–100 for each of 6 subscales)*
Demet et al., 2002 (96)	Comm	Vascular/trauma/other	AK-BK-U	542			
Hoogendoorn and van der Werken., 2001 (97)	IP + OP	Trauma	BK	21			
Orthotics and Prosthetics Users' Survey (OPUS)							
Heinemann et al., 2003 (85)	OP	? (includes orthotic clients and children)	?	66 + 154	Ordinal	64	Likert, various(varies)
Prosthesis Evaluation Questionnaire (PEQ)							
Ferriero et al., 2004 (91)**	Comm	Vascular/trauma/other	AK-BK	95	Ordinal	42 + 40	VAS(0-100)
Legro et al., 1998 (86)	Comm	Vascular/trauma/other	AK-BK	92			
Questionnaire for Persons with a Transfemoral Amputation (Q-TFA)							
Hagberg et al., 2004 (87)	Comm	Vascular/trauma/other	AK	156	Ordinal	70	Likert, various (0–100)
SF-36 Health Survey (SF-36)							
De Godoy et al., 2002 (98)	OP	Vascular/trauma	?	30	Ordinal	36	Likert, various (0–100)***
Hagberg and Branemark, 2001 (99)	OP + Comm	Vascular/trauma/other	AK	197			
Pezzin et al., 2000 (100)	OP	Trauma	AK-BK	78			
Sickness Impact Profile (SIP)							
MacKenzie et al., 2004 (92)	IP	Trauma	AK-BK	161	Ordinal	136	Y/N 1/0
Peters et al., 2001 (94)	OP	Vascular	AK-BK	35		****	(0-100)****
Marshall et al., 1992 (93)	OP + Comm	Vascular/?	AK-BK-U	47			

Trinity Amputation and Prosthetic Experience Scales (TAPES)							
Gallagher and MacLachlan., 2004 (101)	Comm	Vascular/trauma/other	AK-BK	63	Ordinal	54 *****	Likert, various (varies)*****
Gallagher and MacLachlan., 2000 (5)	OP + Comm	Vascular/trauma/other	AK-BK	104 / 60			
Gallagher and MacLachlan., 2000 (102)	Comm	Vascular/trauma/other	AK-BK	104			

n, number of subjects with amputation only and does not include control or comparison subjects; IP, inpatient; OP, outpatient; Comm., community; AK, above knee; BK, below knee; U, upper limb; ?, data missing or unclear; *Part 1 only, Part II consists of 7 distinct Y/N questions; **Italian translation of PEQ; ***Each of 8 subscales and 2 overall dimensions (physical or mental) may be transformed into scores from 0 to 100; ****Although several variants of the SIP exist (e.g., SIP-68, SIP-30) a scoring and weighting system allows a total score of 0–100 for the total and each of 3 dimensions (and further subdivided into 12 categories); *****3 of 9 subscales deal with psychosocial adjustment, each consisting of 5, 5–point items, resulting in total subscale scores of 5–25.

TABLE 6.9. Quality assessment (psychometric properties) for health-related quality of life outcome tools in LEA

Instrument, author, year	Quality of psychometric property						
	Reliability		Validity			Responsiveness	
	IC	Test-retest	Convergent	Concurrent	Predictive	C/F effect	Resp.
NHP							
Demet, 2003				++			
Demet, 2002		+++					
Hoogendoorn, 2001			+	++			
OPUS							
Heinemann, 2003	+++						
PEQ							
Ferriero, 2004	+++		+++*	+*			
Legro, 1998	+++	+++	+++	++			
Q-TFA							
Hagberg, 2004	+++	+++	+++			+++ (F)+ (C)**	
SF-36							
De Godoy, 2002				++			
Hagberg, 2001				++			
Pezzin, 2000				++			
SIP							
MacKenzie, 2004				++			
Peters, 2001				++			
Marshall, 1992				++			
TAPES							
Gallagher, 2004			+++				
Gallagher, 2000	+++		+++		+++		
Gallagher, 2000				++			

IC, internal consistency; C/F effect, ceiling or floor effects; Resp., responsiveness; +++, excellent; ++, adequate; +, poor; see Table 6.1 for definition). Absence of ratings mean no findings were reported.
*Findings limited to mobility subscale or various PEQ subscales correlated with each other; **Poor ceiling effect for Prosthetic Use subdomain only, others were excellent.

international norm bank is currently in development for the TAPES (103).

The OPUS, PEQ, Q-TFA, and TAPES developers have reported excellent (+++) findings of internal consistency for the vast majority of the subscales of the respective tools (5,85–87). In addition, excellent (+++) test-retest reliability has been reported for the PEQ and Q-TFA for each of the subscales by their developers (86,87). In examining the PEQ, the investigators overcame the difficulty in assessing test-retest reliability for the PEQ for such a multidimensional construct as HRQoL by only including participants with stable prosthetic status (86). In this investigation excellent (+++) to adequate (++) findings of convergent validity were demonstrated in correlations between appropriate subscales of the PEQ and the SF-36, the SIP, and the Profile of Mood States–Short Form (86). Gallagher and MacLachlan (5,101) provide a systematic and rigorous demonstration of excellent (+++) convergent validity using multivariate analysis to show that various TAPES subscales predicted a significant proportion of the variance for each of the four domains of the World Health Organization Quality of Life Questionnaire–Brief Version (WHOQoL). Similarly, Hagberg et al. (87) reported generally excellent (+++) correlations between the various domains of the Q-TFA and the SF-36, especially for those domains related to physical functioning, indicative of convergent validity for the Q-TFA. However, both the problem and global domains of the Q-TFA demonstrated relatively similar levels of association for both physical and mental components of the SF-36 as well as across all subdomains (although reduced for mental components), suggesting a limited ability to discriminate between physical and mental function especially in characterizing psychological adjustment following transfemoral amputation.

Investigations of generic HRQoL tools have resulted in at least two or more adequate (++) findings of concurrent validity for each of the SIP, SF-36, and the NHP, with demonstrations of significant between group differences among those with LEA as grouped by numerous factors such as age, gender, etiology, and amputation level (92–95, 97–100).

Summary and Recommendations

The adjustment to amputation requires both functional and psychosocial adjustments, and therefore the multidimensional concepts of HRQoL seem well suited to capture this process. The HRQoL within the LEA population remains poorly researched, with the majority of measurement tools used being generic (101). Although generic tools such as the NHP, the SIP, and the SF-36 have reasonable application in examining HRQoL in individuals with LEA, four tools have been developed specifically for use in LEA: OPUS, PEQ, Q-TFA, and TAPES. Each of these tools has been developed on a conceptual framework consistent with HRQoL, and has been developed using an appropriate and rigorous process with stakeholder involvement, pilot testing, and iterative statistical testing with factor and other analyses. In particular, the OPUS, PEQ, and TAPES have subsections that specifically address psychosocial adjustment following amputation and all are recommended for further testing and use, although the development of the TAPES seems especially useful for assessing psychosocial adjustment. None has been used extensively, other than by the tool developers, as would be expected for such recently developed tools, although the PEQ has more evaluation in this respect (54,104,105).

Validation of the PEQ, Q-TFA, and TAPES with existing generic HRQoL measures has been initiated, although continuing research is required to build the body of evidence validating each tool. Gallagher and MacLachlan (101) acknowledge that the validation of the TAPES would benefit from additional evidence including longitudinal studies to explore possible causal relationships, more fully assess clinical meaningfulness, and demonstrate responsiveness to a change in clinical status. Similar statements would also apply to the PEQ, Q-TFA and the OPUS.

Discussion

This chapter reviewed the various outcome measurement tools addressing psychological adjustment following LEA, with a view to aiding clinicians and researchers in selecting the most appropriate tool for their specific purpose. Specific summary statements and recommendations for each outcome measurement area have been presented. However, there are several common discussion points that the reader should consider.

In general, although it has been noted that there is a tendency to address the physical consequences of the amputation at the possible expense of the psychological responses (1,2), there are several outcome measurement tools that can and have been used to assess pertinent psychological issues. Most notably, these exist in the areas of body image, anxiety, depression, and HRQoL, although more study is required in these areas to more fully validate the measures and to determine if the excellent reliability (for the most part) is replicable. Without exception all of the measurement tools need to be assessed for responsiveness if they are to be considered useful for evaluating rehabilitation interventions. Therefore, longitudinal prospective studies are required. This type of study design would also be appropriate to assess predictive validity and allow investigation of the particular factors that explain the various psychological and functional outcomes of people as they adjust to LEA.

A specific limitation of our methodology is that ratings for the quality assessment were limited to the single highest finding from any specific article. Therefore, it might appear that there is a similar strength of evidence for tools for which there is actually quite a divergent body of evidence. This is especially important in the area of validity for which the overall array of findings that serve to validate a particular instrument should be considered rather than any single finding (28). For example, the papers by Gallagher and MacLachlan

(5,101) describing the relationships between the various subscales of the TAPES and the separate domains of the WHOQoL provide a more robust demonstration of convergent validity than that established in the paper by Wetterhahn et al. (38), in which the ARBIS was evaluated against the various subscales of the MBSRQ with varying levels of association found, only one of which reached the threshold of excellent (+++). Despite this, each of these articles achieved an excellent (+++) rating for convergent validity. This shortcoming was accounted for somewhat in this chapter by ensuring that the text descriptions acknowledge more robust demonstrations of support for specific psychometric evaluations.

Overall, a considerable amount of work has been conducted by the various tool developers, and they should be commended for important contributions to the field of LEA rehabilitation. The ability to obtain important and generalizable research findings and to assist with clinical decision making depends on the continued development of reliable, valid, responsive, and clinically sound outcome measures.

Summary of Key Points

- Studies examining the psychometric properties of outcome measurement tools related to psychological adjustment following LEA were reviewed and assessed for psychometric properties and clinical utility.
- Specific tools were identified that involved the assessment of body image, balance confidence, cognitive function, self-esteem, depression and anxiety, and HRQoL. Notably, amputee-specific tools have been developed to assess body image and HRQoL, and these permit specific insight to psychological adjustment following LEA. Other constructs involved the utilization of generic tools.
- In general, all tools require further psychometric testing in individuals with LEA. Initial demonstrations of internal consistency, test-retest reliability, or various forms of validity have been provided for most tools reviewed, whereas responsiveness has rarely been addressed. Future prospective longitudinal studies are required to overcome this shortcoming.
- The ARBIS, the BIQ and especially the ABIS have good potential for measuring self-perception of body image following amputation.
- Only generic measures of depression and anxiety have been evaluated in individuals with LEA, with the CES-D, HADS, and GHQ having the most psychometric validation. Comparison studies are required to more fully understand the specific advantages or limitations for each of these tools in assessing depression.
- A variety of amputee-specific measures including the OPUS, PEQ, Q-TFA, and TAPES have recently been developed for assessing HRQoL following LEA, although further testing is required for each of these to more fully characterize their utility in assessing adjustment following LEA. The TAPES seems to be the most appropriate for assessing issues relating to psychological adjustment following LEA.

Glossary

Acceptability: A measure of the clinical utility of a measurement tool that refers to the burden it places on those being assessed, which may be reflected by the degree to which it is completed or tolerated.

Amputee-specific measures: Outcome measurement tools that were developed for and tested initially within a population composed of individuals with amputations.

Concurrent validity: A form of construct validity (see Validity and accompanying footnote) that reflects the ability of a measurement tool to distinguish between groups (i.e., known groups) that it should theoretically be able to distinguish between.

Convergent validity: A form of construct validity (see Validity and accompanying footnote) that reflects the degree to which a measurement tool measures the same construct as another tool that is purported to measure the same construct (i.e., that it theoretically should be similar to).

Feasibility: A measure of the clinical utility of a measurement tool that refers to the burden experienced by the assessors in its administration and scoring.

Generic measures: Outcome measurement tools that were developed (or subsequently validated) for a variety of clinical populations.

Health-related quality of life (HRQoL): A multidimensional concept that refers to a person or group's perceived physical and mental health over time and the resultant impact on functional performance including social and role achievements.

Internal consistency: A form of reliability that is concerned with the degree to which different items of a measurement tool measure the same construct (see Table 6.1 for operational details).

Predictive validity: A form of construct validity (see Validity and accompanying footnote) that reflects the ability of a measurement tool to predict something it should theoretically be able to predict.

Psychometric properties: The inherent features of a measurement tool that are viewed as essential elements for determining its quality. Classically, these have consisted of the "properties" of reliability and validity. More recently, responsiveness has been suggested as a distinct property, although others view it as a form of construct validity.

Reliability: The overall property of a measurement tool that describes its ability to measure something consistently (see Table 6.1 for operational details).

Reproducibility: The extent to which repeated measurements yield the same outcome (see Table 6.1 for operational details).

Responsiveness: The degree to which a measurement tool detects a change in an outcome that actually changes and no or only small changes in an outcome that remains stable over time (see Table 6.1 for operational details).

Validity[†]*:* The overall property of a measurement tool that describes its ability to measure what it is intended to measure (See Table 6.1 for operational details).

Acknowledgements

The authors would like to acknowledge the assistance provided by Heather Askes, Nicole Elfring, Ayala Gorodzinsky, and Giselle Rodrigues in reviewing and assessing manuscripts as part of the AmpEBR project. Dr. Miller gratefully acknowledges the support provided by the Canadian Institutes of Health Research in the form of a New Investigator Award.

Further Reading and Other Information Sources

Health Technology Assessment Guide: see ref. 9.

OPUS (Promoting Outcomes Management in Prosthetics Practice: Overview). Rehabilitation Institute of Chicago, http://www.ric.org/research/centers/cror/projects/outcomes

PEQ (Questionnaire, Guide, and Use Survey along with background information). Prosthetics Research Study, http://www.prs-research.org/htmPages/PEQ.html

Q-TFA (Items and coding of each score of Q-TFA). Hagberg, See ref. 87.

SF-36 (A community for measuring health outcomes using SF tools). http://www.sf-36.org/

Systematic review of lower limb prosthetic outcome measures: see ref. 3.

TAPES (Questionnaire and guide to using TAPES and scoring along with background information). Dublin Psychoprosthetics Group, http://www.tcd.ie/Psychoprosthetics/pages/tapes.html

References

1. Scherer MJ. The change in emphasis from people to person: introduction to the special issue on assistive technology. Disabil Rehabil 2002;24(1–3):1–4.
2. Grise MC, Gauthier-Gagnon C, Martineau GG. Prosthetic profile of people with lower extremity amputation: conception and design of a follow-up questionnaire. Arch Phys Med Rehabil 1993;74(8):862–870.
3. Condie E, Scott H, Treweek S. Lower limb prosthetic outcome measures: a review of the literature 1995 to 2005. J Prosthet Orthot 2006;18(1S):13–45.
4. Deathe B, Miller WC, Speechley M. The status of outcome measurement in amputee rehabilitation

---

[†] Although there are varying definitions and classifications of validity, we have considered the major forms of validity to include face, content, construct and criterion validity with only construct and criterion validity able to be assessed objectively. Convergent or discriminative concurrent and predictive validity are all considered to be forms of criterion validity. However, these all depend on the existence of a gold standard to provide a basis for comparison. If no gold standard exists, they represent a form of construct validity in which the relationship to another measure is hypothesized, and it is in this context that our assessments of the various forms of validity were conducted (i.e., convergent, concurrent, and predictive).

in Canada. Arch Phys Med Rehabil 2002;83(7): 912–918.

5. Gallagher P, MacLachlan M. Development and psychometric evaluation of the Trinity Amputation and Prosthesis Experience Scales (TAPES). Rehabil Psychol 2000;45(2):130–154.
6. Finch E, Brooks D, Stratford PW, Mayo NE. Rehabilitation Outcome Measures. A Guide to Enhanced Clinical Decision-Making. Toronto, Ontario: Canadian Physiotherapy Association, 2002.
7. Behel JM, Rybarczyk B, Elliott TR, Nicholas JJ, Nyenhuis D. The role of perceived vulnerability in adjustment to lower extremity amputation: a preliminary investigation. Rehabil Psychol 2002;47(1):92–105.
8. Feinstein AR, Josephy BR, Wells CK. Scientific and clinical problems in indexes of functional disability. Ann Intern Med 1986;105(3):413–420.
9. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Health Technol Assess 1998;2(14):i–iv, 1–74.
10. Feinstein AR. An additional basic science for clinical medicine: IV. The development of clinimetrics. Ann Intern Med 1983;99(6):843–848.
11. Buijk CA. Use and usefulness of lower limb prostheses. Int J Rehabil Res 1988;11(4):361–367.
12. Dillingham TR, Pezzin LE, MacKenzie EJ. Limb amputation and limb deficiency: epidemiology and recent trends in the United States. South Med J 2002;95(8):875–883.
13. Hopewell S, Clarke M, Lusher A, Lefebvre C, Westby M. A comparison of handsearching versus MEDLINE searching to identify reports of randomized controlled trials. Stat Med 2002;21(11):1625–1634.
14. Salter K, Jutai JW, Teasell R, Foley NC, Bitensky J, Bayley M. Issues for selection of outcome measures in stroke rehabilitation: ICF Participation. Disabil Rehabil 2005;27(9):507–528.
15. Salter K, Jutai JW, Teasell R, Foley NC, Bitensky J. Issues for selection of outcome measures in stroke rehabilitation: ICF Body Functions. Disabil Rehabil 2005;27(4):191–207.
16. Salter K, Jutai JW, Teasell R, Foley NC, Bitensky J, Bayley M. Issues for selection of outcome measures in stroke rehabilitation: ICF activity. Disabil Rehabil 2005;27(6):315–340.
17. Wade DT. Measurement in Neurologic Rehabilitation. New York: Oxford University Press, 1992.
18. Hseuh IP, Lee MM, Hsieh CL. Psychometric characteristics of the Barthel activities of daily living index in stroke patients. J Formos Med Assoc 2001;100:526–532.
19. Wolfe CD, Taub NA, Woodrow EJ, Burney PG. Assessment of scales of disability and handicap for stroke patients. Stroke 1991;22(10):1242–1244.
20. Fleiss JL. Statistical Methods for Rates and Proportions. New York: Wiley, 1981.
21. Nunnally JC. Psychometric Theory. New York: McGraw-Hill, 1967.
22. Hobart JC, Lamping DL, Freeman JA et al. Evidence-based measurement: which disability scale for neurologic rehabilitation? Neurology 2001;57(4):639–644.
23. Andresen EM. Criteria for assessing the tools of disability outcomes research. Arch Phys Med Rehabil 2000;81(12 suppl 2):S15–S20.
24. Cohen ME, Marino RJ. The tools of disability outcomes research functional status measures. Arch Phys Med Rehabil 2000;81(12 suppl 2):S21–S29.
25. McDowell I, Newell C. Measuring Health: A Guide to Rating Scales and Questionnaires. New York: Oxford University Press, 1996.
26. Riddle DL, Stratford PW. Interpreting validity indexes for diagnostic tests: an illustration using the Berg balance test. Phys Ther 1999;79(10):939–948.
27. Jutai JW, Teasell RW. The necessity and limitations of evidence-based practice in stroke rehabilitation. Top Stroke Rehabil 2003;10(1):71–78.
28. Frytak J. Measurement. J Rehabil Outcomes Meas 2000;4(1):15–31.
29. Gallagher P, MacLachlan M. Adjustment to an artificial limb: a qualitative perspective. J Health Psychol 2001;6(1):85–100.
30. Bhojak MM, Nathawat SS. Body image, hopelessness and personality dimensions in lower limb amputees. Indian J Psych 1988;30:161–165.
31. Frierson RL, Lippmann SB. Psychiatric consultation for acute amputees. Report of a ten-year experience. Psychosomatics 1987;28(4):183–189.
32. Furst L, Humphrey M. Coping with the loss of a leg. Prosthet Orthot Int 1983;7(3):152–156.
33. Rybarczyk B, Nyenhuis DL, Nicholas JJ, Cash SM. Body image, perceived social stigma, and the prediction of psychosocial adjustment to leg amputation. Rehabil Psychol 1995;40(2):95–110.
34. Breakey JW. Body image: the lower-limb amputee. J Prosthet Orthot 1997;9(2):58–66.
35. Murray CD, Fox J. Body image and prosthesis satisfaction in the lower limb amputee. Disabil Rehabil 2002;24(17):925–931.
36. Fisher K, Hanspal R. Body image and patients with amputations: does the prosthesis maintain the balance? Int J Rehabil Res 1998;21(4):355–363.

37. Donovan-Hall MK, Yardley L, Watts RJ. Engagement in activities revealing the body and psychosocial adjustment in adults with a trans-tibial prosthesis. Prosthet Orthot Int 2002;26(1):15–22.
38. Wetterhahn KA, Hanson C, Levy CE. Effect of participation in physical activity on body image of amputees. Am J Phys Med Rehabil 2002;81(3):194–201.
39. Cooper PJ, Taylor MJ, Cooper Z, Fairburn CG. The development and validation of the Body Shape Questionnaire. Int J Eating Disord 1987;6:485–494.
40. Miller WC, Speechley M, Deathe AB. Balance confidence among people with lower-limb amputations. Phys Ther 2002;82(9):856–865.
41. Miller WC, Deathe AB, Speechley M. Psychometric properties of the Activities-specific Balance Confidence Scale among individuals with a lower-limb amputation. Arch Phys Med Rehabil 2003;84(5):656–661.
42. Powell LE, Myers AM. The Activities-specific Balance Confidence (ABC) Scale. J Gerontol A Biol Sci Med Sci 1995;50A(1):M28–M34.
43. Tinetti ME, Richman D, Powell L. Falls efficacy as a measure of fear of falling. J Gerontol 1990;45(6):239–243.
44. Hanspal RS, Fisher K. Assessment of cognitive and psychomotor function and rehabilitation of elderly people with prostheses. BMJ 1991;302(6782):940.
45. Hanspal RS, Fisher K. Prediction of achieved mobility in prosthetic rehabilitation of the elderly using cognitive and psychomotor assessment. Int J Rehabil Res 1997;20(3):315–318.
46. Pattie AH, Gilleard VJ. Manual of the Clifton Assessment Procedures for the Elderly (CAPE). London: Hodder and Stoughton, 1979.
47. Christ GH, Lane JM, Marcove R. Psychosocial adaptation of long-term survivors of bone sarcoma. J Psychosoc Oncol 1995;13(4):1–22.
48. Dunn DS. Well-being following amputation: salutary effects of positive meaning, optimism, and control. Rehabil Psychol 1996;41(4):285–302.
49. Rosenberg M. Society and Adolescent Self-image. Revised edition. Middletown, CT: Wesleyan University Press, 1989.
50. Bandura A. Self-efficacy mechanism human agency. Am Psychol 1982;37:122–147.
51. Myers AM, Fletcher PC, Myers AH, Sherk W. Discriminative and evaluative properties of the Activities-Specific Balance Confidence scale. J Gerontol 1998;53:M287–294.
52. Miller WC, Deathe AB, Speechley M, Koval J. The influence of falling, fear of falling, and balance confidence on prosthetic mobility and social activity among individuals with a lower extremity amputation. Arch Phys Med Rehabil 2001;82(9):1238–1244.
53. Deathe AB, Miller WC. The L test of functional mobility: measurement properties of a modified version of the timed "up & go" test designed for people with lower-limb amputations. Phys Ther 2005;85(7):626–635.
54. Miller WC, Deathe AB, Speechley M. Lower extremity prosthetic mobility: a comparison of 3 self-report scales. Arch Phys Med Rehabil 2001;82(10):1432–1440.
55. Miller WC, Deathe AB, Harris J. Measurement properties of the Frenchay Activities Index among individuals with a lower limb amputation. Clin Rehabil 2004;18(4):414–422.
56. Pattie AH, Gilleard CJ. The Clifton Assessment Schedule—further validation of a psychogeriatric assessment schedule. Br J Psychiatry 1976;129:68–72.
57. Hanley MA, Jensen MP, Ehde DM, Hoffman AJ, Patterson DR, Robinson LR. Psychosocial predictors of long-term adjustment to lower-limb amputation and phantom limb pain. Disabil Rehabil 2004;26(14–15):882–893.
58. Schoppen T, Boonstra A, Groothoff JW, De Vries J, Goeken LN, Eisma WH. Physical, mental, and social predictors of functional outcome in unilateral lower-limb amputees. Arch Phys Med Rehabil 2003;84(6):803–811.
59. Larner S, van RE, Hale C. Do psychological measures predict the ability of lower limb amputees to learn to use a prosthesis? Clin Rehabil 2003;17(5):493–498.
60. Kendrick DC. Kendrick Cognitive Tests for the Elderly. Windsor: NFER-Nelson, 1998.
61. Blascovich J, Tomaka J. Measures of self-esteem. In: Robinson JP, Shaver PR, Wrightsman LS, eds. Measures of Personality and Social Psychological Attitudes, 3rd ed. Ann Arbor: Institute for Social Research, 1993:115–160.
62. Cansever A, Uzun O, Yildiz C, Ates A, Atesalp AS. Depression in men with traumatic lower part amputation: a comparison to men with surgical lower part amputation. Mil Med 2003;168(2):106–109.
63. Beck A, Steer RA, Ball R, Ranieri W. Comparison of Beck Depression Inventories -IA and -II in psychiatric outpatients. J Pers Assess 1996;67(3): 588–597.
64. Beck A, Ward C, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry 1961;4:561–571.

65. Radloff LS. The CES-D scale: a self-report depression scale for the general population. Appl Psychol Measurement 1977;1:385–401.
66. Goldberg DP, Blackwell B. Psychiatric illness in general practice. A detailed study using a new method of case identification. Br Med J 1970;1(5707):439–443.
67. Goldberg DP, Cooper B, Eastwood MR, Kedward HB, Shepherd M. A standardized psychiatric interview for use in community surveys. Br J Prev Soc Med 1970;24(1):18–23.
68. Yesavage JA, Brink TL, Rose TL et al. Development and validation of a geriatric depression screening scale: a preliminary report. J Psychiatr Res 1982;17(1):37–49.
69. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67(6):361–370.
70. Kashani JH, Frank RG, Kashani SR, Wonderlich SA, Reid JC. Depression among amputees. J Clin Psychiatry 1983;44(7):256–258.
71. Myers JK, Weissman MM. Use of a self-report symptom scale to detect depression in a community sample. Am J Psychiatry 1980;137(9):1081–1084.
72. Norris JT, Gallagher D, Wilson A, Winograd CH. Assessment of depression in geriatric medical outpatients: the validity of two screening measures. J Am Geriatr Soc 1987;35(11):989–995.
73. Lindesay J. Validity of the General Health Questionnaire (GHQ) in detecting psychiatric disturbance in amputees with phantom pain. J Psychosom Res 1986;30(3):277–281.
74. Frank RG, Kashani JH, Kashani SR, Wonderlich SA, Umlauf RL, Ashkanazi GS. Psychological response to amputation as a function of age and time since amputation. Br J Psychiatry 1984;144:493–497.
75. Rybarczyk BD, Nyenhuis DL, Nicholas JJ, Schulz R, Alioto RJ, Blair C. Social discomfort and depression in a sample of adults with leg amputations. Arch Phys Med Rehabil 1992;73(12): 1169–1173.
76. Fisher K, Price EM. The use of a standard measure of emotional distress to evaluate early counseling intervention in patients with amputations. Journal of Prosthetics and Orthotics 2003; 15(1):31–34.
77. Thompson DM, Haran D. Living with an amputation: The patient. Int Rehabil Med 1983;5:165–169.
78. Robinson-Whelen S, Bodenheimer C. Health practices of veterans with unilateral lower-limb loss: Identifying correlates. J Rehabil Res Dev 2004;41(3B):453–460.
79. Schubert DS, Burns R, Paras W, Sioson E. Decrease of depression during stroke and amputation rehabilitation. Gen Hosp Psychiatry 1992;14(2):135–141.
80. Carrington AL, Mawdsley SK, Morley M, Kincey J, Boulton AJ. Psychological status of diabetic people with or without lower limb disability. Diabetes Res Clin Pract 1996;32(1–2): 19–25.
81. Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: a review. Disabil Rehabil 2004;26(14–15):837–850.
82. Vahle VJ, Andresen EM, Hagglund KJ. Depression measures in outcomes research. Arch Phys Med Rehabil 2000;81(12 suppl 2):S53–S62.
83. Dijkers MP. Individualization in quality of life measurement: instruments and approaches. Arch Phys Med Rehabil 2003;84(4 suppl 2):S3–14.
84. Wood-Dauphinee S, Exner G, Bostanci B et al. Quality of life in patients with spinal cord injury—basic issues, assessment, and recommendations. Restor Neurol Neurosci 2002;20(3–4):135–149.
85. Heinemann AW, Bode RK, O'Reilly C. Development and measurement properties of the Orthotics and Prosthetics Users' Survey (OPUS): a comprehensive set of clinical outcome instruments. Prosthet Orthot Int 2003;27(3):191–206.
86. Legro MW, Reiber GD, Smith DG, Del Aguila M, Larsen J, Boone D. Prosthesis evaluation questionnaire for persons with lower limb amputations: assessing prosthesis-related quality of life. Arch Phys Med Rehabil 1998;79(8):931–938.
87. Hagberg K, Branemark R, Hagg O. Questionnaire for persons with a transfemoral amputation (Q-TFA): initial validity and reliability of a new outcome measure. J Rehabil Res Dev 2004;41(5):695–705.
88. Hunt SM, McKenna SP, McEwen J, Backett EM, Williams J, Papp E. A quantitative approach to perceived health status: a validation study. J Epidemiol Community Health 1980;34(4): 281–286.
89. Ware JE Jr, Sherbourne CD. The MOS 36–item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992;30(6):473–483.
90. Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. Med Care 1981;19(8):787–805.
91. Ferriero G, Dughi D, Orlandini D, Moscato T, Nicita D, Franchignoni F. Measuring long-term outcome in people with lower limb amputation: cross-validation of the Italian versions of the Prosthetic Profile of the Amputee

and Prosthesis Evaluation Questionnaire. Eura Medicophys 2005;41(1):1–6.

92. MacKenzie EJ, Bosse MJ, Castillo RC et al. Functional outcomes following trauma-related lower-extremity amputation. J Bone Joint Surg Am 2004;86–A(8):1636–1645.
93. Marshall M, Helmes E, Deathe AB. A comparison of psychosocial functioning and personality in amputee and chronic pain populations. Clin J Pain 1992;8(4):351–357.
94. Peters EJ, Childs MR, Wunderlich RP, Harkless LB, Armstrong DG, Lavery LA. Functional status of persons with diabetes-related lower-extremity amputations. Diabetes Care 2001;24(10):1799–1804.
95. Demet K, Martinet N, Guillemin F, Paysant J, Andre J-M. Health related quality of life and related factors in 539 persons with amputation of upper and lower limb. Disabil Rehabil 2003;25(9):480–486.
96. Demet K, Guillemin F, Martinet N, Andre JM. Nottingham Health Profile: reliability in a sample of 542 subjects with major amputation of one or several limbs. Prosthet Orthot Int 2002;26(2):120–123.
97. Hoogendoorn JM, van der WC. Grade III open tibial fractures: functional outcome and quality of life in amputees versus patients with successful reconstruction. Injury 2001;32(4):329–334.
98. de Godoy JMP, Buzatto SHG, Longo OJR, Fontes OA, Braile DM. Quality of life after amputation. Psychol Health Med 2002;7(4): 397–400.
99. Hagberg K, Branemark R. Consequences of non-vascular trans-femoral amputation: a survey of quality of life, prosthetic use and problems. Prosthet Orthot Int 2001;25(3): 186–194.
100. Pezzin LE, Dillingham TR, MacKenzie EJ. Rehabilitation and the long-term outcomes of persons with trauma-related amputations. Arch Phys Med Rehabil 2000;81(3): 292–300.
101. Gallagher P, MacLachlan M. The Trinity Amputation and Prosthesis Experience Scales and quality of life in people with lower-limb amputation. Arch Phys Med Rehabil 2004;85(5):730–736.
102. Gallagher P, MacLachlan M. Positive meaning in amputation and thoughts about the amputated limb. Prosthet Orthot Int 2000;24(3): 196–204.
103. Gallagher P. Introduction to the special issue on psychosocial perspectives on amputation and prosthetics. Disabil Rehabil 2004;26(14–15): 827–830.
104. Dillingham TR, Pezzin LE, MacKenzie EJ, Burgess AR. Use and satisfaction with prosthetic devices among persons with trauma-related amputations: a long-term outcome study. Am J Phys Med Rehabil 2001;80(8): 563–571.
105. Harness N, Pinzur MS. Health related quality of life in patients with dysvascular transtibial amputation. Clin Orthop Relat Res 2001;(383):204–207.

7

Interventions for Psychological Issues in Amputation: A Team Approach

Stephen T. Wegener, Susan E. Hofkamp, and Dawn M. Ehde

Overview

Attention to the psychological needs of persons with limb loss and their families is part of comprehensive rehabilitation. In addition to services provided by psychologists, social workers, and other mental health service providers, the entire rehabilitation team can have impact on the psychological health of the individual and family after limb loss. This chapter provides (1) guiding principles for psychological intervention, (2) a brief overview of the psychological issues encountered in psychoprosthetic work, (3) a model for team involvement in psychological care, and (4) an overview of a range of psychological interventions that may be used by members of the rehabilitation team. Using these principles, models, intervention approaches, and the entire rehabilitation team, we can improve psychological care of persons with limb loss.

Guiding Principles

Clinicians approach the care of persons with limb loss with a variety of assumptions, beliefs, and organizing principles. Often we are unaware of the unstated schemas that guide our interactions with patients and their families. By adopting certain guiding principles, based in the empirical literature, clinicians will likely be more attentive to the psychosocial aspects of limb loss and more successful in improving patient outcomes.

The *biopsychosocial model* recognizes that there are biological, psychological, and social dimensions of medical conditions and that it is necessary to consider all relevant factors when assessing a patient (1). Some of the elements that impact the individual's experience with limb loss are physical, emotional, cognitive, or behavioral, as well as the physical and social environments. To fully understand a person's health or quality of life, all of these areas must be examined. For example, if a patient is suffering from residual limb pain, the tendency may be to focus on the physical or mechanical aspects of the problem. While these are important, the biopsychosocial model reminds us that that we need to consider how this pain problem impacts social functioning and how psychological issues may affect the pain experience.

Patient-centered care was recommended as one solution to the health care problems identified by the Institute of Medicine in their report on *Crossing the Quality Chasm* (2). Patient-centered care widens the focus from the patient's medical needs to the needs of the patient as a whole. Six dimensions define patient centered care: (1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support; and (6) involvement of family and friends (3). While these domains capture important aspects of patient centeredness, empowering patients through increasing self-efficacy and activation are the central distinctions between this approach and other health care quality improvement initiatives.

While mood disturbances and other psychological conditions are more prevalent in persons with limb loss than the general population (4), serious distress is not a universal response. The existing literature suggests that (1) many individuals with physical impairments do not develop mood disturbances or other psychological symptoms, (2) most do not develop major psychiatric disorders, and (3) professionals are likely to overestimate the level of mood disturbances in persons with disability (5,6). There is a range of psychological responses from diagnosable psychiatric illness to resilience and positive growth following limb loss. While recognizing that psychological distress is not universally experienced by all persons with limb loss, psychological evaluation and intervention can improve mood, increase adaptive behaviors, reduce cognitive dysfunction, and facilitate the rehabilitation process.

A final guiding principle is to recognize and build on the patient's strengths. Often our assessment and interventions are focused on what is wrong with the person. While problems often demand our attention, effective assessment and interventions include noticing, bringing to the awareness of the patient, and building on the strengths of the patient and family. Patients are the central workers in the rehabilitation process and they come to the point of amputation with abilities, resources, and experience. Recognizing and capitalizing on these strengths lays the foundation for a successful patient–provider relationship and identifies the personal and social resources the individual can use to manage psychosocial problems that may arise.

Clinical Issues

Affective complaints such as depression, anxiety, and posttraumatic stress disorder are among the most common psychological issues present in individuals with limb loss. For some, negative body image, social stigma, and intimacy problems may occur. While some psychological distress is common following amputation, persistent or severe symptoms, or those that interfere with recovery and rehabilitation, may require intervention. It is important to recognize signs of these problems so that they can be appropriately and effectively addressed to minimize the negative effect they may have on adjustment to limb loss.

Affective Disturbances

The rates of affective distress symptoms and mood disorders vary but are higher in rehabilitation populations than the general population (7) and are similar to those found in other medical populations (8). Depression has been the most carefully studied affective disturbance, with post–lower limb amputation depression rates ranging from 20% to 35% (4,9). More recently in a sample of over 900 community-dwelling individuals with an amputation, approximately 28% reported significant depressive symptoms, and those with pain issues were at an increased risk (10). A review by Horgan and MacLachlan (11) cited evidence that the time since amputation may be an important factor in the prevalence of depression. Those in the initial 2 years postamputation time frame had the highest rates. The primary symptoms of a depressive disorder are depressed mood, loss of interest, changes in appetite, sleep disturbance, poor concentration, loss of energy, and feelings of worthlessness or hopelessness (12). Other symptoms that are not used to diagnose depressive disorders, but often occur with them include headaches, digestive problems, sexual problems, pessimistic attitude, and low self-esteem. Experiencing some depressive symptoms is common, but having multiple symptoms that are present nearly every day for weeks or longer may be a sign of a depressive disorder that requires professional assistance. Unfortunately, research suggests that many persons with limb loss and depression may not be receiving the mental health services they need to cope with psychological distress (10).

Symptoms of anxiety may also be a problem following loss of a limb, particularly for those in the early phase of adjustment (11). Panic attacks, worry, fear, avoidance behavior, irritability, trouble sleeping, difficulty concentrating, and muscle tension may all be symptoms of anxiety. For individuals with traumatic limb loss, it is especially important to assess for an acute stress disorder or posttraumatic stress disorder, depending on the length of time since the traumatic event. For either disorder the individual must have been exposed to a traumatic event and have symptoms in the following three categories: (1) reexperiencing the event, (2) avoidance and numbing symptoms, and (3) physiological hyperarousal (12). These symptoms presenting for 1 month or less are indicative of an acute stress response, while symptoms that persist for a longer period of time are diagnosed as posttraumatic stress.

Intrapersonal Issues

An individual's body image may be closely related to the presence of affective issues described above. Individuals with depression or anxiety may be more likely to have a negative body image, and those with a distorted self-image may be more likely to be depressed or anxious (4). In addition, body image has been shown to predict depression and adjustment to amputation (13). Rybarczyk and colleagues (14) note that the person with limb loss must reconcile the three different images of the preamputation body and the body with and without a prosthesis in order to develop a new sense of self (see Chapter 3). Changes in the physical body and abilities can lead to a negative self-image in some persons with limb loss. Some may also develop a negative body image due to social discomfort or internalization of stigma expressed by society. The individual with a negative self-image may demonstrate distorted views of the body and reluctance to participate in social activities.

Interpersonal Issues

Social stigma results when those with disabilities are viewed differently than nondisabled individuals and negative assumptions are made about functioning and personality based on those beliefs. In the case of persons with limb loss, there is a visible impairment, which may increase the amount of associated stigma. Perceptions of social stigma are related to depression and adjustment to amputation, such that increased levels of stigma have a negative effect on individuals targeted by the stigma (13). It is unclear whether individuals who report a high level of perceived social stigma are accurate in their perceptions or are distorting their own negative thoughts as coming from others (4).

Another interpersonal area of potential difficulty for individuals with amputations is intimacy and sexual functioning. During the acute phase of limb loss, it may be reasonable to focus on physical and emotional aspects of recovery. However, as rehabilitation and adjustment become a long-term issue, individuals will likely want to return to their previous pattern of functioning. Areas of concern that need to be addressed include comfort level, body image, and role expectations (15). Communication between the patient and his or her partner about these issues is important in order to remain sexually healthy and active. The comfort level of health care providers in addressing sexual issues may also be a barrier to appropriate assessment and interventions (14).

Substance Use

The rates of alcohol abuse among people with limb loss have not been carefully studied. Given that the rate of alcohol problems in consecutive trauma admissions is as high as 44% (16), and that the prevalence of problem drinking in persons with chronic disabling conditions is higher than in the general population, persons with limb loss may be at increased risk for alcohol abuse pre- or postamputation. Alcohol use not only might contribute to the development of a number of chronic conditions but also might slow the rate of recovery and produce secondary complications, and thus alcohol use warrants assessment and, when indicated, intervention.

Model for Team Involvement in Psychological Care

Attention to psychosocial health is a responsibility shared by all members of the rehabilitation team beginning with the patient and family and including clinicians who are not formally identified as mental health providers. A useful model for the involvement of the entire team in improving psychosocial functioning following limb assessment can be found in the work by Annon (17). This approach, the PLISSIT model, defined in Table 7.1, calls for team members to provide graded interventions based on the needs of the patient and skills and training of the clinician.

Table 7.1. The PLISSIT model

Level of intervention	Intervention activities and characteristics	Provider characteristics
Permission	Proactively providing opportunity for discussion of psychosocial issues—part of assessment or ongoing care	Willingness to ask questions, empathy, knowledge of available services and treatment options, ability to make referral
Limited **I**nformation	Providing general information, peer interactions	Above plus knowledge of condition, communication skills, educational materials
Specific **S**uggestions	Making person specific recommendations to prevent or resolve a problem	Above plus skill in teaching specific techniques, ability to form therapeutic relationship
Intensive **T**herapy	In-depth intervention to addressing ongoing psychosocial problems	Above plus advanced training in psychotherapeutic and behavioral strategies and techniques; knowledge of specific condition

Patients vary in their needs or interest in addressing psychosocial concerns and require different levels of intervention. Some patients and families have few concerns, while others have compelling needs that require intensive treatment. Similarly, there is variation in providers' interest, comfort level, and skills, with some professionals having limited interest or skills while others are highly trained in advanced interventional strategies. Adopting the PLISSIT model accommodates this variation among patients and team members while ensuring psychosocial needs are addressed by the appropriate clinician. The PLISSIT model is composed of a continuum of care, and each step is characterized by intervention activities that are based on the skills and comfort of the providers and the needs of the patient.

The interventions that follow are arranged based on this continuum of care. There are not clear boundaries between these various activities, and clinicians may engage in multiple activities along the continuum with a particular patient. What is critical is to recognize that all patients are to be given permission to address psychosocial issues by the clinicians involved in their care. Based on that interaction, the clinician arranges for or provides additional services along the continuum to the patient if indicated. Based on reimbursement patterns, access to mental health services and availability of some services—notably peer support and self-management training—the entire continuum of care may not be available to all who are in need. Thus, the PLISSIT model also serves as a guide to the limb loss community as to what services need to be developed in a particular system of care to meet the needs of the patients and family.

Using the Stages of Change Model to Tailor Interventions

The stages of change model, or transtheoretical model (18–20), has been widely used to help understand an individual's readiness to engage in specific health behaviors (e.g., use of prosthesis, adaptive coping strategies, smoking cessation). The model is based on the notion that individuals vary in the degree to which they are prepared to make changes. The stages are meant to represent specific attitudes, intentions, and behaviors that are related to the individual's position in the change process. There are generally five stages in the transtheoretical model: precontemplation, contemplation, preparation, action, and maintenance. A linear progression through these stages is possible, but does not often occur with health behaviors. Instead, a spiral pattern generally occurs, in which people can move through the stages while suffering periodic relapses that result in regression to an earlier stage. Recognition of an individual's readiness to engage in a specific health care behavior can used to guide what type of PLISSIT intervention is most likely to be accepted by, and effective for, the patient. Table 7.2 outlines the relationship among the stages of change, the PLISSIT model, and the interventions discussed in this chapter. The model is theoretically, not empirically, driven and is not meant to be prescriptive. It is meant to provide a depiction of how the

TABLE 7.2. Linking the PLISSIT model and examples of interventions with the patients' stage of change

Stage	Characteristics of stage	Key PLISSIT principles	Potential intervention examples
Precontemplation	Lack of awareness of problem/Lack of intention to change behavior	Permission/Limited information	Education/Peer involvement/Motivational interviewing
Contemplation	Aware of problem and thinking about changing in next 6 months	Permission/Limited information	Education/Motivational interviewing
Preparation	Plan to change in next month/Unsuccessful attempts to change in last year	Limited information/Specific suggestions	Behavioral activation/Problem solving/Motivational interviewing
Action	Successful change in behavior for up to 6 months	Specific suggestions/Intensive therapy	Assertiveness/social skills training/Relaxation training/Psychotherapy
Maintenance	Successful behavior change for more than 6 months/Working to stabilize change and prevent relapse		Self-management approaches/Peer involvement

models and interventions discussed in this chapter are related, and show that awareness of stage of change can be used to guide the approach and tactics used to treat patients. This is consistent with recent trends in tailoring interventions to the individual, rather than using the same strategies for all patients with a certain diagnosis.

Integrating Psychological Care in the Clinical Setting: Permission

The permission aspect of PLISSIT emphasizes giving permission to the patient and the family to have, and to discuss, psychosocial concerns. Persons with limb loss interact with a series of clinicians as they move from acute care through rehabilitation. The assessment by each team member is an opportunity to give permission. The clinician needs to introduce the topic, which provides patients with the opportunity to voice their concerns. It is not sufficient to make general statements such as, "Is there anything else we need to talk about?" It is more helpful to make a statement that normalizes having psychosocial concerns and asking specifically how the amputation impacted the person's social and psychological functioning. Providing permission can occur by alerting patients to the availability of peer and professional services that address psychosocial concerns, providing information in the waiting room about available services, and informing patients about confidentiality. Clinicians (e.g., nurses, prosthetists, physicians) who have ongoing relationships with people with limb loss need to proactively provide ongoing permission in future consultations. Providing permission to discuss these issues is accompanied by the recognition that patients have the right to decline discussion. It is also important not to communicate the myth that all persons with limb loss must experience severe distress, concerns, or psychopathology or follow any prescribed pattern of grief or loss.

Having knowledge of community resources and referral option is also critical so that the clinician feels prepared to respond to any concerns that arise. Without the knowledge of these resources or skills, the clinician is likely to avoid addressing psychosocial issues. For many patients, permission to have concerns and an opportunity to discuss them is sufficient, and no further intervention is needed; for those who evidence greater need additional steps can be taken.

Peer Interventions and Motivational Interviewing: Limited Information

The limited-information aspect of PLISSIT emphasizes the provision of general knowledge and strategies regarding psychosocial issues, their prevention, and management. However, this process involves more than providing information; it also includes more active methods and strategies such as peer interactions and motivational interviewing.

Peer Interactions

Peer interactions and support groups are grounded in modeling theory, which states that individuals are likely to learn best from those whom they identify as being most like themselves. Wright (21) has long advocated the importance of the "insider perspective" when interacting with persons with disabilities. It is believed that through exposure to successful individuals with similar disabilities, less experienced persons can develop hope, learn, and adopt more effective behaviors, and have increased social support. Peer role models or support groups are sometimes part of formal rehabilitation programs (22), and in other cases are part of consumer organizations. For example, one national consumer program for persons with limb loss is the Peer Visitor Program offered by the Amputee Coalition of America (http://www.amputee-coalition.org). Peer support groups are becoming widely available and are state-of-the-art care for persons with limb loss and other chronic conditions (23). There is evidence linking support group participation with reduced depression and distress (24,25), increased knowledge (25,26) and increased quality of life (27). However, while this type of peer support is often welcomed by patients, there are limited reports of improved outcomes, and the appropriate timing of the visits and benefits have yet to be empirically established.

Motivational Interviewing

Individuals with limb loss are presented with a variety of issues that may require substantial changes in behavior. Based in part on the stages of change model (19), Miller and Rollnick (28) developed motivational interviewing (MI) as a brief, client-centered counseling approach to changing behaviors such as substance abuse. The approach has since been adapted and validated in randomized clinical trials aimed at promoting behavior change with a variety of health care problems. Motivational interviewing is designed to enhance internal motivation to engage in, or change, a behavior by assisting the individual with recognition, exploration, and resolution of ambivalence about change. A basic assumption of MI is that the motivation to engage in a new behavior, or make changes to an established one, is modifiable and can be increased through interpersonal, supportive, client-centered interactions. Four key components of motivational interviewing are (1) expressing accurate empathy, (2) developing discrepancy between current behavior and personal values or goals, (3) accepting and flowing with resistance to change, and (4) supporting the individual's self-efficacy to make a change (28).

Systematic reviews (29,30) and a meta-analysis (31) of the MI literature have supported its effectiveness across a variety of health care populations and behaviors. It has been shown to be more effective than providing no treatment conditions or giving advice (31). Given its efficacy to date, MI is increasingly being utilized as a way to educate patients and change their behaviors across a variety of health care problems, settings, and interactions. Strong empirical evidence exists that health care professionals at varying levels of training can successfully learn MI skills via instructional workshops of 1 or 2 days in length (32). Given its efficacy across a broad range of health behaviors, its ability to promote change with even brief interactions, and its ability to be taught with brief instruction, MI can be a valuable tool in increasing patients' willingness to engage in recommended treatment strategies and behaviors. Further information about motivational interviewing can be found at http://www.motivationalinterview.org/.

Psychological and Behavioral Strategies: Specific Suggestions

The specific-suggestion aspect of PLISSIT emphasizes providing a focused intervention strategy to address a particular problem. This class of intervention may be most appropriate for individuals who exhibit problems in a limited area and are capable of initiating the strategy with limited professional support and input. As discussed, symptoms of psychological or social distress may be a temporary response to the stressor of amputation and may not be severe enough to warrant intensive interventions. In those cases, some specific suggestions of psychological and behavioral strategies may be adequate to resolve the issue. Many of these techniques can be administered by a provider with minimal training and are intended to be taught and practiced by the individual on their own. These strategies may also be part of more intensive therapy provided to individuals with greater need.

Self-Management

In conditions associated with pain, distress, and functional impairments, many individuals interpret these associated consequences of their conditions as uncontrollable. The decreased self-efficacy and perceived lack of control are thought to increase pain and negative emotional responses, leading to further physical and psychosocial disability. Self-management (SM) interventions have gained widespread application with chronic conditions to address these maladaptive patterns. Self-management incorporates the principles of cognitive-behavioral theory (CBT), described later in this chapter. Other key elements in self-management include knowledge, self-monitoring, skills acquisition, and problem solving (33). The SM interventions have targeted not only persons who have identified problems with self-efficacy, pain, or negative emotions, but also persons at risk for such problems by virtue of their chronic health condition.

The literature indicates that SM interventions have improved outcomes in many conditions, including rheumatologic diseases (34), fibromyalgia (35), diabetes (36), and depression (37). Although these overall results are encouraging, a recent meta-analyses of SM interventions for older adults indicates that the magnitude of the improvement varies depending on the condition and the end point chosen (38). The SM interventions appear to achieve long-term reductions in pain and disability primarily through increases in self-efficacy (39) and changes in negative thinking rather than via specific behavior changes (40). The SM literature indicates that interventions incorporating social support and peer interaction may have the greatest effect in changing behavior and maintaining gains (41). Thus, delivering the SM program in small groups may enhance the person's ability to carry out the self-care regimen necessary to achieve positive outcomes. The SM interventions can be provided by professionals, laypersons, or peers. More recently SM interventions using Internet and telecommunication technologies have achieved successful outcomes in persons with chronic impairments (38). Using new technologies, SM interventions have the potential to improve outcomes for individuals who do not have ready access to other psychosocial or peer support interventions.

Recently, an SM course designed by and for persons with limb loss was developed and evaluated. The Promoting Amputee Life Skills (PALS) self-management course consists of nine sessions focused on maintaining adaptive behaviors and relapse prevention. Each session focuses on a specific topic and set of skills and includes (1) introduction to self-management (goal setting, problem solving, the road to recovery); (2) dealing with aches and pains; (3) how to bounce back, part I (recognizing signs of depression); (4) how to bounce back, part II (building on strengths and promoting positive mood); (5) interacting with family and friends (mobilizing your support network); (6) communicating and networking; (7) healthy "me" (self-managing medical and improving overall health); (8) staying on track (maintaining progress and relapse prevention); and (9) booster session. The intervention is delivered in a group format with eight to 12 participants per group. The groups are led by trained leaders, one of whom is a person with limb loss.

An analysis of the immediate post- and 6-month postintervention data demonstrated that participant satisfaction was high and the benefits of participation equaled or outweighed the effort involved. In comparison to the control group PALS participants were 2.5 times less likely to report symptoms of depression, reported better function, were less bothered about limitations of everyday function, reported higher levels of general self-efficacy, and reported more positive mood. Individuals who participated earlier following their amputation or who started the program with psychosocial problems had larger effect sizes and more improved outcomes. The impact of the PALS intervention is comparable to those found in other evaluations of SM courses designed for chronic diseases (38).

Coping Strategies

How the individual copes with amputation and the subsequent rehabilitation process likely mediates outcome (see Chapter 2). Research indicates that the coping abilities of individuals with amputations and those without physical disability do not differ significantly (11). According to Lazarus and Folkman (42), effective coping strategies should accomplish the following: (1) reduction of the environmental stressor; (2) adjustment to, or tolerance of, negative events; (3) maintenance of emotional homeostasis; (4) continuation of healthy self-image; and (5) resuming of normal activities. Coping strategies may be categorized as active versus passive and helpful versus maladaptive. In general, coping behaviors that are active and goal-oriented are more helpful to the patient. Interventions focused on building coping skills should include (1) analysis of the situation and current coping techniques, (2) description of the problem, (3) goal setting, and (4) modification of the coping strategies. These steps can be accomplished though brief, structured interventions with the patient (43).

Catastrophizing is a cognitive response to an event that is marked by exaggerated negative expectations and concerns. Higher levels of catastrophizing predict increased pain interference and depressive symptoms in persons with phantom limb pain (44). Catastrophizing is known to predict pain intensity, disability, and psychological distress independent of the level of physical impairment for persons with chronic back pain (45) and for people with limb loss with phantom limb pain (46,47). A person with limb loss may exhibit catastrophizing, for example, by focusing on the negative aspects of amputation, being unable to see hope for resuming previous activities, and stating that there is nothing that can be done to help the situation. Changes in catastrophizing achieved through cognitive behavioral treatment have been associated with decreases in self-reported disability, pain intensity, and depression (48). As discussed in Chapter 4, interventions for catastrophizing focus on monitoring, challenging, and making changes to negative thoughts as well as behavioral activation to increase self-efficacy.

Coping strategies such as distraction, positive self-talk, and increasing activity levels are associated with adjustment to chronic pain such as phantom limb pain (49) and are thought to promote psychological health following limb loss. In addition, individuals who can find some positive meaning from the amputation may have less depression and increased activity levels and better adjustment (50,51). Therefore, interventions aimed at finding positive meaning, increasing positive self-talk, and stimulating activity may be beneficial in many facets of recovery and rehabilitation from amputation. These may include specific suggestions such as engaging in an exercise program to provide distraction from negative mood and thoughts while increasing activity levels, suggestions to pursue recreational activities that promote a positive mood or social interactions, or more intensive therapy such as cognitively based psychotherapies designed to increase positive mood and thoughts.

Assertiveness and Social Skills Training

Individuals with overt disabilities, such as those with limb loss, may face difficult social situations due to factors such as functional limitations, social stigma, prejudice, and body image anxiety. Research indicates that assertiveness training can improve social skills and problem solving related to social situations (52–54). Furthermore, social skills training can help the individual manage anxiety related to communicating with others about disability issues. Assertiveness training teaches individuals to express their feelings and personal rights without violating the rights of others (55). This is different from a passive behavior style where the individual is too intimidated to express thoughts and feelings, or from an aggressive behavior style where manipulation, intimidation, and trying to be in control are common. The goal of assertiveness is to be more relaxed in interpersonal situations while expressing personal likes and interests, talking about oneself without feeling self-conscious, accepting compliments, openly disagreeing with others, and saying no to requests. Assertiveness means being able to confront issues that are fear or anxiety provoking, and being able to communicate feelings of anger without making others feel attacked. Outcomes related to depression, anxiety, and anger have shown improvement following training in assertiveness skills, but treatment gains may be difficult to maintain over a longer period of time (54).

The individual with poor assertion skills may be either too passive or too aggressive. Passive behavior may be reflected in persons with limb loss not communicating their dissatisfaction with a prosthetic device because they have been through several fittings and do not want to upset the prosthetist by complaining. An equally unhelpful response to the same situation, coming from an individual with aggressive behavior, includes yelling and being confrontational with the prosthetist. Neither of these behavior styles is likely to be effective in meeting the patient's needs. Modeling desired behaviors is an important part of teaching social skills, so the provider must have some knowledge of the techniques. Role playing with the patient can be helpful and reduce the anxiety involved implementing the skills. Some of the key components of assertiveness training include learning to use "I" statements when discussing thoughts and feelings, making eye contact and being aware of other body language, practicing peaceful confrontation, and avoiding aggressive acts toward others (56). Some individuals are able to successfully use assertiveness skills after a few sessions of instruction, but others require a slower approach with substantial practice.

Problem Solving

Individuals with amputations must manage ongoing medical regimens as well as barriers to adherence and daily stressors. Effective problem-solving skills are essential in coping with such issues. Problem solving is associated with a reduction in depressive symptoms and anxiety in patients with lower limb loss (57). Poor problem-solving abilities may be related to the use of maladaptive coping strategies such as avoidance and passivity (58). D'Zurilla and Chang (58) have proposed a multidimensional model of problem solving that includes a person's problem orientation and the application of skills to find a solution to the problem. Problem orientation is described as a motivational process based on an individual's belief system that influences how that individual thinks and feels about problems and his/her self-efficacy for problem solving. Problem solving includes five basic steps: (1) identify and describe the problem, (2) generate ideas and solutions, (3) refine and select a potential solution, (4) implement the idea, and (5) evaluate the outcome and return to step 2 if necessary. This technique operates on the principle that there generally is not a single solution to a problem and it may take several attempts to find a viable plan.

Persons in the acute phase of adaptation to limb loss are often confronted with a number of issues and can easily become overwhelmed by the number of stressors. Someone who makes statements such as, "I just don't know where to start" or "Nothing I've tried seems to help," would likely benefit from instruction in effective problem-solving skills. Assistance from providers experienced with rehabilitation from limb loss can be helpful in prioritizing issues to be addressed before engaging in the problem-solving steps. The generation of possible solutions requires some creativity, which may be difficult for individuals faced with multiple new problems associated with the loss of a limb or the ongoing struggle of adaptation to a prosthetic. Enlisting help from a provider, peer with limb loss, family member, or friend may facilitate the problem-solving and decision-making process.

Behavioral Activation

As discussed above, avoidance of feared stimuli (e.g., activities that may cause pain, anxiety-provoking social situations) can be a disabling problem for individuals with limb loss. Symptoms of depression may also lead to decreased participation in activities. Using early intervention to counteract avoidance and depression and increase levels of activity optimizes physical and psychological outcomes related to pain (59). Behavioral activation is one method for confronting those fears and breaking the negative cycle of disuse that can result from avoidance. It entails tracking activities throughout the day, along with mood to provide a link between behaviors and emotions. This monitoring of mood and activity can help show that there is a relationship between what one does and how one feels.

Another component of behavioral activation is identifying behaviors that promote positive mood and increasing engagement in those activities and social interactions. Through monitoring, individuals may recognize that, despite concerns about body image, they feel happier when they engage in social activities than when they are isolated at home. Graduated exposure to feared situations is necessary to challenge the individual's dysfunctional beliefs, while minimizing the experience of anxiety or fear. For example, suppose a person has been avoiding going to busy, public places due to fears about being able to navigate the situation with a new prosthetic device. Gradual exposure to the situation, such as going to the place when it is less crowded or practicing in a more familiar area, may build confidence. This type of intervention is very easy to explain to a patient and can be suggested by providers with less formal training than is required for more intensive therapy options.

Intensive Therapy

The intensive-therapy aspect of PLISSIT emphasizes providing psychotherapeutic intervention often in the context of addressing a particular problem. More intensive therapy strategies may be necessary for more severe symptoms, chronic problems, or issues that have not improved with other treatments. Included in this category are psychotherapy and use of medications to manage emotional distress and improve coping skills. These interventions require a higher level of knowledge, skill, and training than the specific suggestions previously discussed. That may include formal schooling to obtain a degree or professional licensure, or attending a training program for a particular skill. For other members of the team it is essential that they identify provider services to which patients can be referred.

Psychotherapy

Psychotherapy can take many forms and utilize a variety of techniques. All successful forms of psychotherapy provide for (1) a caring, competent therapist, whom the patient believes can help; (2) an opportunity for cognitive, emotional, and experiential learning; (3) instillation and revitalization of hope; (4) success experiences that increase the sense of mastery over oneself and the environment; and (5) alleviation of negative/dysphoric feelings (60). The beneficial effects of psychotherapy for the typical mental health patient are well established (61). Recently there has been growing emphasis on evidenced-based therapies to allow for matching of interventions to specific problems. Most, but not all, of the evidence-based treatments use cognitive-behavioral, behavioral, or interpersonal techniques (62). Along with the data that supports specific treatment approaches, there is also strong documentation in the literature of aspects of the therapeutic relationship that contribute to positive treatment outcome. The therapy relationship appears to account for as much of the treatment outcome as the specific treatment technique used (63). Thus, there is as much need to attend to the quality of the therapeutic relationship, as there is to choosing the specific intervention.

Cognitive-behavioral therapy (CBT) is designed to (1) help patients appreciate the relationship among their thoughts and feelings and behaviors, and (2) identify self-defeating patterns of thought and replace them with adaptive thoughts and behaviors to achieve better outcomes (64). The behavioral component focuses on activation and development of coping skills such as relaxation or assertiveness. The CBT-based interventions use two broad approaches: coping skills training and cognitive restructuring techniques (64). Coping skills training includes teaching new skills or enhancing existing ones. Cognitive restructuring strategies focus on modifying negative cognitive/evaluative responses and cultivating more adaptive responses and problem-solving skills. Cognitive-behavioral therapy is conducted by a specially trained professional, usually in individual sessions with at-home practice of activities in between visits.

Primary targets of CBT interventions are affective problems such as depressive symptoms, anxiety, and anger. High rates of both major depressive disorder and depressive symptoms have been observed in persons with limb loss (10). Consequently, a cognitive therapist might ask patients with limb loss and symptoms of depression to keep a diary of their thoughts and feelings in various situations throughout the day in order to identify patterns. Then, they would discuss those patterns together and work on developing more helpful thoughts. For the behavioral component of therapy, the patient may be asked to engage in one pleasurable activity per day. Social problems, such as dealing with social stigma and increasing social skills, may also be addressed effectively with CBT.

Interpersonal psychotherapy (IPT) was designed as a brief, individual treatment for depression (65), but has been refined and adapted for use with other psychological diagnoses as well. It is appropriate for treatment of acute psychological distress as well as long-term maintenance of symptoms that are mild to moderate in severity. The therapy focuses on relationship issues, but also takes into account the biopsychosocial factors that contribute to the problem. The goal of IPT is to assist the individual with identifying and changing unhelpful interpersonal interactions.

Medication

There are a variety of medications that may offer relief for symptoms of psychological distress associated with limb loss; however, few randomized clinical trials have been completed to provide evidence of their efficacy in the limb-loss population. Many of the medications act on multiple problems such as mood disorder, anxiety, sleep, and pain. A full discussion of medications that may be appropriate for psychological distress is beyond the scope of this chapter, but the following information serves as an introductory overview of some options for psychopharmacological treatment.

Medications commonly used to treat depression include selective serotonin reuptake inhibitors (SSRIs), selective serotonin and norepinephrine reuptake inhibitors (SSNRIs), and tricyclic antidepressants (TCAs). Although not designed to treat pain, antidepressants may also be prescribed for this purpose in patients with or without depression. The SSRIs aid in the release of serotonin in the body, while the SSNRIs help raise levels of serotonin and noradrenaline. The TCAs also increase the amount of serotonin in the body, which raises the efficacy of endorphins (66). Sedation, although considered a side effect, can be helpful for those who also suffer from sleep problems. Antidepressant medications require some time to build up in the body before they are effective, so the patient should be told not to expect immediate results. It can also take several trials of different medications to find the best treatment strategy for an individual. Unfortunately, depressive disorders are frequently inadequately treated in primary and specialty care medical settings (67). Therefore, clinicians should follow the practice guidelines available regarding antidepressant medication to ensure proper dosing, monitoring, and follow-up when using antidepressants (67).

Some antidepressants are also used to treat symptoms of anxiety, particularly SSRIs and TCAs (68,69). Both are prescribed for the diagnosis of posttraumatic stress disorder, and SSRIs are also used for issues related to social anxiety. As discussed previously, some of these medications may take several weeks to take effect, so they are often started in combination with an anxiolytic that will work more quickly. Anxiolytics are drugs that are more specific to anxiety. The most commonly used medications in this class are benzodiazepines, which may act by enhancing the effects of γ-aminobutyric acid (GABA). They have a greater potential for addiction, however, so long-term use is generally not recommended. Anticonvulsant medications may also be used to augment the treatment regimen. They may also help manage pain, particularly neuropathic pain such as phantom limb pain.

The use of hypnotic medication, typically benzodiazepines, for sleep problems is appropriate for short-term or recent-onset insomnia. Their efficacy and safety for chronic insomnia is less clear. If chronic use is anticipated and the sleep disturbance is related to pain, other classes of medications such as TCAs should be considered. The decision to use a hypnotic should consider whether the intended effect is to reduce time to sleep onset, nighttime awakenings, or anxiety related to sleep disturbance. Antidepressants such as TCAs and SSRIs appear to improve self-reported sleep parameters, pain, fatigue and well-being. However, it is not clear if these improvements are independent of depression (70).

Effective Consultation

Making a referral for more intensive therapy to another team member or provider outside of the team is appropriate once the problem has been identified and other avenues of treatment (e.g., specific suggestions such as relaxation or problem solving) have been attempted. Early detection of potential problems is one of the most important components of making a good referral. There is evidence that early intervention for psychological issues enhances outcome (59). Having a good network of referral sources is important, particularly for an independent provider, in order to facilitate the necessary services for a patient. There are providers in a variety of fields that specialize in working with limb-loss disability and rehabilitation populations. They should be the first choice when looking for a referral for a patient with amputation-related problems. When making a referral, the question should be clear and focused and include relevant information about the patient, including strengths that may be emphasized during treatment.

Response to a referral should always be in a timely manner, based on the urgency of the situation. In general, psychologists include the following components in their assessment and response: (1) evaluation of mental status, affect, mood, life stressors, substance use, and threat of harm to self or others; (2) information about the patients' understanding of their medical condition and concerns regarding the current situation, coping style and effectiveness, pain issues, expectations for recovery, and goals for rehabilitation; (3) diagnostic formulation; and (4) recommendations and treatment plan (71, 72). This information needs to be synthesized into a concise response to the consulting provider and documented in an appropriate manner. In the rehabilitation setting, this may include presenting a plan at a team meeting and facilitating interventions with various providers.

Future Developments

The number of persons with limb loss and other impairments is increasing (73). Our work and that of others has identified secondary conditions of depression and pain as significant problems for community-dwelling persons with limb loss (10, 74–76). These secondary conditions are often associated with activity limitations, participation restrictions, and reduced quality of life. Programs and services that empower patients and consumers to become active participants in their lifelong care are needed to meet the increasing demands placed on them by an evolving health care system that holds both consumers and their providers accountable for successful outcomes. Further, development of the continuum of care beyond the acute time period is needed. Several lines of research suggest approaches that may enhance outcomes and expand the continuum of care. There is growing recognition that utilization of peer mentors may be helpful in assisting individuals with new impairments with successful adaptation (4). Motivational interviewing techniques have been developed and shown to be efficacious in increasing participation in a variety of health behaviors (29). Training providers in the importance of SM and how to better support individuals in their use of these techniques should increase enrollment in SM programs (72). Finally, it is well recognized that computer-based health information and support systems can be used to disseminate information, link people to needed resources, connect people on-line who are facing similar challenges and develop communities of individuals with common interests, aspirations, and needs. While only recently being developed, these programs and services have the potential to be successfully utilized by patients with a variety of chronic illnesses, including individuals in underserved populations. These areas provide ample opportunities for clinicians and researchers to focus the efforts for the benefit of persons with limb loss.

Summary of Key Points

Attention to the psychological needs of persons with limb loss and their families is part of comprehensive rehabilitation. Effective clinicians providing psychological care are guided by the biopsychosocial model; they follow patient centered-care principles, remember that serious distress is not a universal response, and recognize and build on the patient's strengths. Attention to psychosocial health is a responsibility shared by all members of the rehabilitation team beginning with the patient and family and including clinicians who are not formally identified as mental health providers. Adopting the PLISSIT model allows for the involvement of the entire team in providing graded interventions based on the needs of the patient and skills and training of the clinician. There are a variety of interventions ranging from peer interactions and self-management training to intensive psychotherapy that have the potential to improve outcomes for persons with limb loss.

Glossary

Catastrophizing: A cognitive response to an event that is marked by exaggerated negative expectations and concerns.

Self-efficacy: The belief that one is able to perform specific tasks or activities.

Self-management: A strategy where patients take responsibility for managing their care and become active consumers of health care. Key elements in self-management include knowledge, self-monitoring, skills acquisition, and problem solving.

Stages of change: A model based on the notion that individuals vary in the degree to which they are prepared to make changes. There are generally five stages in the model: precontemplation, contemplation, preparation, action, and maintenance.

Acknowledgments

We gratefully acknowledge the support from the Centers for Disease Control and Prevention under grants R04/CCU322981 and R01/DD000153. The views expressed in this chapter are those of the authors. No official endorsement by the Centers for Disease Control and Prevention or the Department of Health and Human Services is intended or should be inferred.

Further Reading

Amputee Coalition of American. http://www.amputee-coalition.org (1-888/AMP-KNOW [1-888/267-5669])

References

1. Engel GL. The need for a new medical model: a challenge for biomedicine. Science 1977;196: 129–136.
2. Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: Institute of Medicine, 2001.
3. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care. Jossey-Bass Health Series. San Francisco, CA: Jossey-Bass, 1993.
4. Rybarczyk BD, Nyenhuis DL, Nicholas JJ, Schulz R, Alioto RJ, Blair C. Social discomfort and depression in a sample of adults with leg amputations. Arch Phys Med Rehabil 1992;73:1169–1173.
5. Frank RG, Elliott TR, Corcoran J, Wonderlich S. Depression after spinal cord injury: is it necessary? Clin Psychol Rev 1987;7:611–630.
6. Richards JS. Psychologic adjustment to spinal cord injury during first postdischarge year. Arch Phys Med Rehabil 1986;67:362–365.
7. Weissman MM, Myers JK. Affective disorders in a US urban community: the use of research diagnostic criteria in an epidemiological survey. Arch Gen Psychiatry 1978;35:1304–1311.
8. Rodin G, Voshart K. Depression in the medically ill: an overview. Am J Psychiatry 1986;143: 696–705.
9. Kashani JH, Frank RG, Kashani SR, Wonderlich SA, Reid JC. Depression among amputees. J Clin Psychiatry 1983;44:256–258.
10. Darnall BD, Ephraim P, Wegener ST, et al. Depressive symptoms and mental health service utilization among persons with limb loss: results of a national survey. Arch Phys Med Rehabil 2005;86:650–658.
11. Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: a review. Disabil Rehabil 2004;26:837–850.
12. American Psychological Association. Diagnostic and Statistical Manual for Mental Disorders. Washington, DC: American Psychiatric Association Press, 1994.
13. Rybarczyk B, Nyenhuis DL, Nicholas JJ, Cash SM, Kaiser J. Body image, perceived social stigma, and the prediction of psychosocial adjustment to leg amputation. Rehabil Psychol 1995;40:95–110.
14. Rybarczyk B, Szymanski L, Nicholas JJ. Limb amputation. In: Frank RG, Elliott TR, eds. Handbook of Rehabilitation Psychology. Washington, DC: American Psychological Association, 2000:29–47.

15. Liddle SA, Sands JK. Changes in sexuality. In: Sands JK, ed. A Guide to Arthritis Home Health Care. New York: Wiley, 1988:119–141.
16. Soderstrom C, Smith G, Dischinger P, et al. Psychoactive substance abuse disorders among seriously injured trauma center patients. JAMA 1997;277:1769–1774.
17. Annon J. The PLISSIT model: a proposed conceptual scheme for the behavioural treatment of sexual problems. J Sex Educ Ther 1976;2:1–15.
18. Prochaska J, DiClemente C. The Transtheoretical Approach: Towards a Systematic Eclectic Framework. Homewood, IL: Dow Jones Irwin, 1984.
19. Prochaska JO, DiClemente CC, Norcross JC. In search of how people change. Applications to addictive behaviors. Am Psychol 1992;47:1102–1114.
20. Prochaska JO, Norcross JC. Systems of Psychotherapy: A Transtheoretical Analysis. Pacific Grove, CA: Brooks/Cole, 1999.
21. Wright BA. Physical Disability: A Psychological Approach. New York: Harper & Row, 1983.
22. Tate DG, Rasmussen L, Maynard F. Hospital to community: a collaborative medical rehabilitation and independent living program. J Appl Rehabil Counsel 1992;23:18–21.
23. Davison KP, Pennebaker JW, Dickerson SS. Who talks? The social psychology of illness support groups. Am Psychol 2000;55:205–217.
24. Bright JI, Baker KD, Neimeyer RA. Professional and paraprofessional group treatments for depression: a comparison of cognitive-behavioral and mutual support interventions. J Consult Clin Psychol 1999;67:491–501.
25. Brodaty H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. J Am Geriatr Soc 2003;51:657–664.
26. van Dam HA, van der Horst FG, Knoops L, Ryckman RM, Crebolder HF, van den Borne BH. Social support in diabetes: a systematic review of controlled intervention studies. Patient Educ Couns 2005;59:1–12.
27. Rehse B, Pukrop R. Effects of psychosocial interventions on quality of life in adult cancer patients: meta analysis of 37 published controlled outcome studies. Patient Educ Couns 2003;50:179–186.
28. Miller W, Rollnick S. Motivational Interviewing: Preparing People to Change Addictive Behavior. New York: Guilford Press, 2002.
29. Rubak S, Sandbaek A, Lauritzen T, Christensen B. Motivational interviewing: a systematic review and meta-analysis. Br J Gen Pract 2005;55:305–312.
30. Dunn C, Deroo L, Rivara FP. The use of brief interventions adapted from motivational interviewing across behavioral domains: a systematic review. Addiction 2001;96:1725–1742.
31. Burke BL, Arkowitz H, Menchola M. The efficacy of motivational interviewing: a meta-analysis of controlled clinical trials. J Consult Clin Psychol 2003;71:843–861.
32. Miller WR, Yahne CE, Moyers TB, Martinez J, Pirritano M. A randomized trial of methods to help clinicians learn motivational interviewing. J Consult Clin Psychol 2004;72:1050–1062.
33. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003;26:1–7.
34. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999;37:5–14.
35. Sandstrom MJ, Keefe FJ. Self-management of fibromyalgia: the role of formal coping skills training and physical exercise training programs. Arthritis Care Res 1998;11:432–447.
36. Norris SL, Engelgau MM, Narayan KM. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. Diabetes Care 2001;24:561–587.
37. Smith NM, Floyd MR, Scogin F, Jamison CS. Three-year follow-up of bibliotherapy for depression. J Consult Clin Psychol 1997;65: 324–327.
38. Chodosh J, Morton SC, Mojica W, et al. Meta-analysis: chronic disease self-management programs for older adults. Ann Intern Med 2005;143:427–438.
39. Lorig K, Holman H. Arthritis self-management studies: a twelve-year review. Health Educ Q 1993;20:17–28.
40. Lorig K, Seleznick M, Lubeck D, Ung E, Chastain RL, Holman HR. The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. Arthritis Rheum 1989;32:91–95.
41. Boutaugh M, Lorig K. Patient education. In: Wegener S, ed. Clinical Care in the Rheumatic Diseases. Atlanta: American College of Rheumatology, 1996:53–58.
42. Lazarus RS, Folkman S. Stress, Appraisal, and Coping. New York: Springer, 1984.
43. Heim E. Coping-based intervention strategies. Patient Educ Couns 1995;26:145–151.
44. Jensen MP, Ehde DM, Hoffman AJ, Patterson DR, Czerniecki JM, Robinson LR. Cognitions, coping and social environment predict adjustment to phantom limb pain. Pain 2002;95:133–142.

45. Severeijns R, Vlaeyen JW, van den Hout MA, Weber WE. Pain catastrophizing predicts pain intensity, disability, and psychological distress independent of the level of physical impairment. Clin J Pain 2001;17:165–172.
46. Hill A, Niven CA, Knussen C. The role of coping in adjustment to phantom limb pain. Pain 1995;62: 79–86.
47. Hill A. The use of pain coping strategies by patients with phantom limb pain. Pain 1993;55:347–353.
48. Jensen MP, Smith DG, Ehde DM, Robinsin LR. Pain site and the effects of amputation pain: further clarification of the meaning of mild, moderate, and severe pain. Pain 2001;91:317–322.
49. Jensen MP, Turner JA, Romano JM, Karoly P. Coping with chronic pain: a critical review of the literature. Pain 1991;47:249–283.
50. Dunn DS. Well-being following amputation: salutory effects of positive meaning, optimism and control. Rehabil Psychol 1996;41.
51. Gallagher P, MacLachlan M. Positive meaning in amputation and thoughts about the amputated limb. Prosthet Orthot Int 2000;24:196–204.
52. Galassi MD, Galassi JP. Assertion training: a critical review. Psychother Res Pract 1978;15:16–29.
53. Heimberg R, Montgomery D, Madsen C, Heimberg JS. Assertion training: a review of the literature. Behav Ther 1977;8:953–971.
54. Glueckauf RL, Quittner AL. Assertiveness training for disabled adults in wheelchairs: self-report, role-play, and activity pattern outcomes. J Consult Clin Psychol 1992;60:419–425.
55. Alberti RE, Emmons ML. Your Perfect Right: Assertiveness and Equality in Your Life and Relationships. Atascadero, CA: Impact, 2001.
56. Seaward BL. Behavior modification. Managing Stress: Principles and Strategies for Health and wellbeing. Boston: Jones and Bartlett, 1994: 153–163.
57. Desmond DM, MacLachlan M. Coping strategies as predictors of psychosocial adaptation in a sample of elderly veterans with acquired lower limb amputations. Soc Sci Med 2006;62:208–216.
58. D'Zurilla TJ, Chang EC. The relations between social problem solving and coping. Cog Ther Res 1995;19:547–562.
59. Keefe FJ, Rumble ME, Scipio CD, Giordano LA, Perri LM. Psychological aspects of persistent pain: current state of the science. J Pain 2004;5:195–211.
60. Frank JD. Persuasion and Healing. Baltimore: The Johns Hopkins University Press, 1973.
61. Kendall PC, Chambless DL. Empirically supported psychological therapies. J Clin Consult Psychol 1998;66:3–167.
62. Chambless DL. Compendium of empirically support therapies. In: Koocher GP, Norcross JC, Hill SS, eds. Psychologist Desk Reference. Oxford: Oxford University Press, 2005.
63. Wampold BE. The Great Psychotherapy Debate: Models, Methods, and Findings. Mahwah, NJ: Erlbaum, 2001.
64. Turk DC, Meichenbaum D, Genest M. Pain and Behavioral Medicine. New York: Guilford Press, 1983.
65. Klerman GL, Weissman MM, Rounsaville BJ, Chevron ES. Interpersonal Psychotherapy of Depression. New York: Basic Books, 1984.
66. Arthritis Foundation. Relieving symptoms: treatments for fibromyalgia. The Arthritis Foundation's Guide to Good Living with Fibromyalgia. Atlanta, GA: Arthritis Foundation, 2001:17–28.
67. Practice guidelines for the treatment of patients with major depressive disorder (revision). Am J Psychiatry 2000;157:1–45.
68. Zohar J, Westenberg HG. Anxiety disorders: a review of tricyclic antidepressants and selective serotonin reuptake inhibitors. Acta Psychiatr Scand Suppl 2000;403:39–49.
69. Feighner JP. Overview of antidepressants currently used to treat anxiety disorders. J Clin Psychiatry 1999;60(suppl 22):18–22.
70. O'Malley PG, Balden E, Tomkins G, Santoro J, Kroenke K, Jackson JL. Treatment of fibromyalgia with antidepressants: a meta-analysis. J Gen Intern Med 2000;15:659–666.
71. Bronheim HE, Fulop G, Kunkel EJ, et al. The Academy of Psychosomatic Medicine practice guidelines for psychiatric consultation in the general medical setting. The Academy of Psychosomatic Medicine. Psychosomatics 1998;39:S8–30.
72. Leis AM, Haines CS, Pancyr GC. Exploring oncologists' beliefs about psychosocial groups: implications for patient care and research. J Psychosoc Oncol 1994;12:77–87.
73. National Limb Loss Information Center. Frequently Asked Questions: Amputee Coalition of America, 2006.
74. Ephraim PL, MacKenzie EJ, Wegener ST, Dillingham TR, Pezzin LE. Environmental barriers experienced by amputees: the Craig Hospital inventory of environmental factors-short form. Arch Phys Med Rehabil 2006;87:328–333.
75. Ephraim PL, Wegener ST, MacKenzie EJ, Dillingham TR, Pezzin LE. Phantom pain, residual limb pain, and back pain in amputees: results of a national survey. Arch Phys Med Rehabil 2005;86:1910–1919.
76. Ehde DM, Jensen MP, Engel JM, Turner JA, Hoffman AJ, Cardenas DD. Chronic pain secondary to disability: a review. Clin J Pain 2003;19:3–17.

8

Anthropology and Its Individual, Social, and Cultural Contributions to Psychoprosthetics

Seth D. Messinger

Overview

Understanding psychosocial issues is important in enhancing outcomes for people with amputations [1,2]. Nonetheless, there has as yet been only limited research "conducted on the relationships among functioning, limitations, and identity in people with amputations" [3]. This chapter addresses the contributions made to the study of the psychosocial world of prosthetic limbs users by discussing qualitative research approaches, with a special emphasis on the specific contributions that have been made by sociocultural anthropology. This chapter also discusses current anthropological work among United States military personnel who sustained limb loss as a result of the ongoing conflict in Afghanistan and Iraq.

One way to address the question of the psychosocial world of people with amputations and prosthesis users is to draw on the contributions by medical anthropology toward understanding the cultural and social life of health and illness. Medical anthropology, a subfield of sociocultural anthropology, is broadly concerned with the relationship of health and illness to culture. Historically, medical anthropologists have worked to understand the meaning and function of health beliefs, to critique social disparities that are obstacles to individuals or communities having access to health resources, and to understand how individual experiences with suffering and affliction both complement and confound biomedical practice. This holistic approach to the person and body in distress grounds the research in the lived experience of people in their individual, political, economic, and cultural contexts. The strength of the holistic approach is that it addresses the whole life not only of users but also of clinicians, as well as exploring the social and cultural meanings generated by prosthesis technology. Anthropological understandings of the psychosocial life of prosthesis users provide a new and important way to understand the clinical, rehabilitative, and day-to-day lives of prosthesis users.

The "Three Bodies" of Prosthetics and Users

In a key contribution to medical anthropology, Nancy Scheper-Hughes and Margaret Lock [4] engage an anthropological approach to health and illness by attending to what they term the "three bodies" that individuals inhabit. The first of these is the *individual body*, which they write is "understood as the lived experience of the body-self" (p. 7). The second is the *social body*, which is situated at the intersection of nature, culture, and society. Finally, there is the *body politic*, a metaphor that indexes the control of bodies by social and political regulators who are concerned with, for example, appropriate and inappropriate forms of sexual behavior and drug and alcohol use, among other social and body practices (4). These three bodies can be mapped onto the study of the psychosocial world of people with amputations and prosthesis use. Individual bodies are altered through disease or injury and are eligible for and fitted with prostheses. Patients comply with their treatment, work with their prosthetist, and utilize their prosthetic limb, or they do not. The reasons patients do or do not wear their prosthetic limbs has much to do with their beliefs and values, the expectations of their wider social system, and their place in a political economy that structures the health care system of which they are a part. All of these issues need to be considered in any inquiry into the psychosocial world of people with amputations and prostheses. The following sections discuss the clinical and practice literature as addressing the individual body, the research literature on patients' reactions to prostheses as addressing the social body, and the way that prosthetics are interpreted as cultural symbols as addressing the political body. I will then draw these three discussions together in a discussion of current research into the world of military personnel with amputations in a military medical center.

Review of the Evidence

The writing and research on the psychosocial world of prosthetics that I am particularly interested in discussing occurs on three different registers that map onto the "three bodies" of Scheper-Hughes and Lock that I introduced above. The first explores the question of how individuals with different kinds of amputations do after they receive prosthetic limbs. How do they respond to their prostheses and how do they integrate them into their sense of self and their way of being in the world? The second register focuses on the social aspect in terms of how people with amputations with prostheses interact with the so-called normal world, how culture influences acceptance or rejection of people with amputations, and how people with amputations practice a form of refusal of prosthetic technology while simultaneously being socially integrated into the broader society. Lastly, I will discuss the cultural world that produces both prosthetics and the psychosocial world of prosthesis users. At this level the specificity of prosthetics begins to lose focus as the term is applied to such diverse social products as maquiladora factories on the U.S.–Mexican border, but despite the opacity of some of these discussions I will argue below that they provide both the framing and the ground of the psychosocial world of prosthesis use at least in the contemporary U.S. context.

The Individual Body of the Prosthesis User

Research into the psychosocial world of people with amputations and prosthetics has focused on clinical issues such as acceptance of prosthetic technology and compliance. As in all medical situations the question of compliance is an important one for both practitioners and clients. Three relatively recent publications establish the ground for addressing more complex issues regarding prosthesis users. These three studies investigate user satisfaction with prosthetics and develop a mixed picture depending on the user and the nature of the injury that led to amputation. One recent study looked at the combination of use and satisfaction with prosthetic limbs by users with trauma-related amputations. While nearly all the people with amputations in the study reported using their prosthetic limbs, the majority reported dissatisfaction with some element of either their amputation or their prosthesis. User dissatisfaction emerged from a couple of key sources. The first was pain associated with nerves, residual limb, or phantom sensation (5). Another source of dissatisfaction was frustration with prosthesis fit and discomfort. This study was limited, however, by its focus on people with lower extremity amputations only. In a subsequent study of users with both upper and lower extremity amputations, researchers had substantially the same results regarding prosthesis use (6). One difference between this study and the earlier one was the more detailed attention to sources of patient dissatisfaction with their prosthetics. Again, as in the earlier study, prosthesis fit and comfort were key issues. However, also significant was the users relationship with their prosthetist. This relationship was shown to be less than ideal for patients depending on characteristics associated with race, gender, and socioeconomic status, with black men with less schooling demonstrating higher levels of dissatisfaction (6). This study demonstrates the significant role that social factors as well as cultural ones play in users' perceptions of their prostheses and the environment available for their successful use. This is discussed in greater detail below.

In a study focused solely on people with upper extremity amputations, the authors noted that satisfaction rates for this population are mixed to low. Upper extremity prosthetic limbs were not found to increase "patient satisfaction with their ability to be functional in the community" (7, p. 68). As is the case with people with lower extremity amputation, people with upper limb amputations complained about nerve, phantom, and residual limb pain. They also complained about discomfort with the fit of the prosthetic limb as well as excessive sweating associated with the limb socket. All users had difficulties with using their prosthesis when cooking, dressing, and in recreation and work-related activities. Upper extremity amputation was also associated, in this paper, with a change by users in the forms of recreation and leisure activities, from active to more passive pursuits. I note this because it challenges the goals of the amputee patient care program that I am currently studying, which explicitly encourages patients to return as close as possible to premorbid levels of activity. I will discuss this in greater detail below.

Prosthesis users face enormous challenges as they transition from limb loss. These include pain issues, which may afflict them lifelong. Users struggle with learning to use their limb, managing their gait (if they have a lower extremity amputation), and dealing with physical discomfort and sweating associated with wearing the prosthetic socket. They also suffer from assaults to their sense of themselves as they struggle to accommodate their remembered body image to their dismembered body. Finally, they struggle with anxieties over their vulnerability and disability, questioning how they will be able to fulfill gender and other role expectations. These are all individual bodily concerns, but as the last point illustrates they are also social ones. How one's body looks; how it ambulates, feels, and smells; and how one is able to comport oneself in the world are situated in social and cultural constructions of appropriate bodies that situate people in complicated social systems.

Social Life of Prostheses and Users: The Social Body

There has also been considerable research into exploring the theoretical world of, and social life of, prosthesis technology outside the clinical encounter and environment. In a study conducted 30 years ago, many people with amputations reported that perceived social exclusion and stigma constrained their feelings of social acceptance (8). This conclusion is supported by a more recent study conducted by Rowlands (9) on the social life of a young woman with a traumatic brain injury. The mother of the young woman at the center of Rowlands's study noted that while friends of her daughter made efforts to remain in contact, they did so in a highly structured and formal way, which only underscored the absence of the give-and-take of normal social relations. Research in recent years among people with amputations has not wholly supported this social exclusion model. Rybarczyk et al. (10), in a study exploring mood disorders and anxiety among people with amputations, noted that while depression and anxiety are more frequent than in the general population, they are concentrated in patients who have lost lower limbs at a relatively young age and from traumatic causes. A decade later, a study conducted by Cacciapaglia and her coauthors (11) found that obstacles to social interaction by people with disabilities were influenced by whether the disability was visible or not. The authors conclude that "people were more willing to interact with a person with a visible disability" (p. 181). The authors credit laws like the Americans with Disabilities Act of 1991 with making the social environment more hospitable to people with amputations than it perhaps had been previously. Interestingly, this is not always the case cross-culturally. Cambodian people with amputations face obstacles reintegrating into their social lives after suffering limb loss for reasons that have to do with both the scarcity of resources available to them and to Buddhists notions of bodily wholeness (12).

The question of user acceptance of prosthetic technology has been linked by researchers to both perceived social exclusion as well as to how individuals integrated prostheses into their senses of self. Murray (13) notes that most research into satisfaction with prostheses has emerged from a concern with affective responses to amputation and prosthesis use. Murray's work has explored individual cases rather than groups (see Chapter 9). In his study he focused on the embodied perceptual experience of the body; that is, he closely observed and interviewed respondents on the relationship of prosthesis technology to their bodies. Prosthesis users report that their prosthetic limbs become a part of their body. He notes that this perceptual experience may correlate with successful prosthetic use. In a subsequent study Murray (14) raises important issues about the role that prosthetics play in individual and group meaning making. He discussed how the role of bodies is highly significant for people with amputations. Limb loss can mean that certain forms of nonverbal communication are foreclosed by certain kinds of amputations. For instance, in the U.S. losing a right hand eliminates the ability to shake hands appropriately, while the loss of a left hand may interfere with signaling one's marital status. The use of prosthetics may restore far more than some functionality to the body by allowing the body to generate greater communicative force in the world through the restoration of the ability to present symbols.

Recognizing that prostheses may restore some semblance of a preamputation sense of self needs to be considered in light of the changes to the basic sense of self that can accompany the loss of a limb. Behel and coauthors (15) found that while depression and anxiety were not automatic comorbidities associated with adjustment to limb loss and prosthesis use, where they were found in patients it was among those who had other issues with adjustment. What was interesting in this research was that while fear of crime was the stated cause of anxiety and depression among the individuals studied, Behel and coauthors attributed the depression and anxiety to cognitive affective or behavioral responses to one's disability. This seems to be a reluctance on the part of the researchers to address the social context of living with an amputation.

Finally, the issue of adjustment through prosthesis refusal also merits discussion. Geyla Frank (16), an anthropologist, has devoted much of her career to chronicling and interpreting the life history of Diane DeVries, who is a remarkable woman by any standard. She is a congenital quadrilateral amputee who has refused, seemingly since birth, to accept the notion that she is disabled. In the life history she and Frank constructed, DeVries explains that she has had a lifelong lack of interest in prosthetics, which stems from two sources. The first is a generalized recognition that the available technology for people with upper-extremity amputations is not sufficient for her to be independent in all activities of daily living. The second issue though is more personal to DeVries and has to do with feelings of self-mastery or a strong sense of internal locus of control. DeVries notes that she never *felt* herself to be abnormal or disabled. Despite her sense that she is not abnormal or disabled, DeVries relies on an intensely supportive social network to assist her in maintaining her independent life. These include either significant others willing to take on the tasks of assisting DeVries in toileting, bathing, dressing, and undressing, or home health aides who are hired to assist her. Both the help of significant others and the presence of home health aides require some degree of social acceptance of disability at the level of individual attitudes, but it also requires social structural accommodation of the kind represented by the Americans with Disabilities Act, as well as state and local initiatives that encourage the social integration of people with disabilities. However, this social integration is not seamless and is grounded in many of the social, racial, and class tensions that permeate social life. For instance, DeVries was herself involved in a conflict over whether or not her disability constrained her ability to work. DeVries, who won her law suit, has maintained that attempts to remove her from work stemmed much less on her ability to perform her job (she has advanced degrees in social work and was working as a case manager) than on how others perceived her as a quadrilateral amputee.

While DeVries's experiences are an explicit example of how stigma can shift into prejudicial thoughts and discriminatory action, there are other environments and encounters where the social tensions that percolate in contemporary U.S. society emerge. Steve Kurzman (17) is both an anthropologist and has had a unilateral transtibial amputation. He conducted a study of rhetorical negotiations between prosthetists and clients over questions of socket fit, balance, and mobility issues. What Kurzman found was that prosthetists and patients acknowledge that, as he puts it, "there is no language for this" (p. 229). This has the effect of turning the questions of fit and alignment of prostheses into a collaborative venture jointly constructed by patients and prosthetists specifically involving a shared schema for what "fit" is. A major discursive challenge is struggling to produce a shared language that links the subjective experience of fit with the biomedical and biomechanical language of gait and alignment. What is infused through these discussions, though, is a subtle acknowledgment of social class (Kurzman does not discuss female patients and its unclear if any patients are nonwhite). Prosthetists have to adjust their communication strategies in light of their experience or expectations of their patients' educational and social backgrounds. In one telling example, a working-class patient preferred a heavier prosthesis to a lighter one. Kurzman writes that the "senior instructor took the opportunity to point out the importance of occupation and implicitly, class as a factor influencing choice of occupation, and physical activity level as a consideration for prosthesis design" (p. 239) While biomedicine and the biomechanical world of prosthetists opt for a socially neutral language of practice, social status and social life is recuperated in the clinical encounter. This is explicitly the case in military prosthetics where issues of gender are often foregrounded.

Cultural Life of Prosthetics and Users: The "Body Politic"

Providing rehabilitative technology like prosthetics has been an important task undertaken by governments in the wake of war (18–20). While much attention has been paid to the functional help prostheses afford their wearers, in the aftermath of World War II, especially in the U.S., considerations over the social role of dismembered veterans became increasingly prominent. During and after World War II many American veterans with an amputation underwent rehabilitation at Walter Reed Army Medical Center. The physicians and administrators at Walter Reed made the successful performance of gender roles an unspoken but integral part of the rehabilitation process. This was made especially clear in news accounts from the period, which tell triumphal stories of patients being returned to a kind of functional normalcy through the use of prosthetic limbs (21). Photographs of veterans with an amputation often accompanied these news stories and provided vivid demonstration of the normalizing power of prosthetics. In one image, taken in 1952, an individual with a transhumeral amputation in a T-shirt lights a cigarette using his "hook" and intact hand. The image is strikingly reminiscent of a model of masculinity derived from 1950s icons like James Dean (21). In a second image a man in a suit sits reading a newspaper with his trouser legs pulled up showing his prosthetic legs crossed. A careful observer, Serlin (21) tells us, will discern images of dancing girls painted on the prosthetic socket. This image sends two carefully crafted messages: one is a reminder of how soldiers decorated their jeeps, tanks, artillery shells, and aircraft. The second message is that despite this virile past, this newspaper-reading man with his pants legs appropriately pulled down would be indistinguishable from any other contemporary corporate "warrior"; thus he fulfills two models of able bodied masculinity simultaneously (21).

Serlin notes that these images fostered a dual role for prosthetic limbs. First, they demonstrated how prosthetic limbs served as functional replacements of flesh and blood limbs. Second, these images did the work of introducing social acceptance of dismembered veterans through a multilayered symbolic system which reinforced the sacrifices made by these veterans (the pinup girls painted on the prosthetic sockets in the second image as described above), and demonstrated that far from having been emasculated by dismemberment, these veterans were, through the prosthesis technology produced by a victorious national economy, hypermasculine. A third role for these images was played out over a larger political dynamic, which demonstrated to the rest of the world the level of technology and social support offered by the U.S. in contrast to what was proclaimed (at least through propaganda) as the deprivations of both the defeated and our erstwhile World War II ally, Communist Russia (21). Prosthetic technology would begin to play a symbolic role in these larger national and transnational tropes, which are present today (discussed below) but which also ground the social field within which prosthetics and prosthesis users are figured at the level of culture.

When Scheper-Hughes and Lock introduced their idea of the third body being the body politic, they observed that individuals' relations to their selves and to social life were structured, or shaped, by a macrolevel of regulation. Here they were noting that the body politic was both a metaphor for the regimes of control that govern individual and social bodies in their relations as well as a metaphor for the way that healthy or sick bodies come to stand for their societies. Within the broader anthropological theoretical literature, there has been some consideration of how prosthetics serve as metaphors for social questions that would fall under the rubric of the body politic.

At its most abstract and emerging out of theoretical interests in cyborgs and cybernetic social systems, which were prominent in the 1990s, this work pushed the boundaries of prostheses to their definitional limit as tools that extend bodies beyond their own boundaries. One example is Diane Nelson's (22) paper, which argues that Mayan women represented a prosthetic identity for post–civil war Guatemala because they served as a symbolic ground for an authentic identity for different, previously at odds, communities. Alternately, Melissa Wright (23) argues that the women workers in the Mexican border factories (maquiladoras) served as a prosthesis for both an American and a global economy that pushes its manufacturing sector beyond its national body politic and served as a prosthesis for a Mexican national economy struggling to catch up to its northern neighbor (23).

While this work is quite provocative, it was also almost immediately criticized for pushing the notion of prosthesis past the point of utility or specificity (see ref. 24 for a critique that anticipates ref. 25). In the same issue of *Cultural Anthropology* that published the Nelson and Wright papers, Stephen Kurzman wrote that both Nelson and Wright had ignored the "figure for the ground" and by emphasizing the prostheses had shifted attention away from their users. Furthermore, Kurzman noted that Nelson and Wright had simultaneously granted and withdrew subjectivity from prostheses.

In Nelson's piece on the Maya Mujer, Mayan women stand in for a "stumped" Guatemalan identity but seem to have no identity themselves. Similarly, in Nelson's piece female maquiladora factory workers provide a prosthetic identity for global capital or Mexican manufacturing but are themselves silent and inert. Kurzman (25) argues that prostheses and their users should be the figure rather than the ground of analysis. Vivian Sobchak (26), like Kurzman, is both a researcher and prosthesis user. In a recent essay she criticized what she argues are the uses and misuses of prosthetic tropes to describe social life. She makes the point, in slight contrast to Kurzman's, that prosthetic limbs can stand (intentional pun) as both the figure and the ground in these discussions. She makes a point that is similar to Scheper-Hughes and Lock's, that prosthetic limbs are embedded in three levels of subjective experience. At the individual level her prosthetic leg can be simply something upon which to stand and ambulate. But the social level quickly intrudes in several ways. First is the intimate physical relationship that she has with her prosthetists. As a person with a unilateral high transfemoral amputation, she is used to a relative stranger's hands moving across and around her upper thigh. Second is how she is perceived in social settings based on the quality of her gait and how that influences others' perceptions of her. Finally, she is embedded in a cultural context, which will circumscribe the extent to which she stands as a gendered and sexual being based on her disability as well as limit her access to specific kinds of prosthesis technology. As a middle-aged woman with a limited interest in physical exertion, her insurance company limits her access to such limbs as Otto Bock's C-leg.

Sobchak's contribution to this discussion improves on Nelson's and Wright's work about the saliency of looking at prosthesis technology as a cultural artifact that structures social relations. Prostheses should be seen as embedded in a context that devotes research funding to their development, a marketing program for their distribution, and a cultural role. Prosthetics cannot be totally divorced from who uses them and where they are used. This is a point that arose earlier in my discussion of David Serlin's work on the postwar role that prostheses were asked to play in restoring expected economic and gender functionality to military servicemen maimed in World War II.

In a subsequent piece, Serlin (27) explicitly links prostheses with the cultural assumptions attendant on the ongoing military operations associated with the U.S. war on terror in Afghanistan and Iraq. Serlin writes that military medicine is implicated in the same project of empire as are military deployment and U.S. foreign policy. Serlin describes a press account of a patient recuperating at Walter Reed Army Medical Center with a transradial amputation sustained in Iraq. In the article the patient notes that he has a hundred terminal devices for his myoelectric and body-powered prosthetic arm. Serlin notes that the function these attachments provide to military patients goes beyond the opportunity to "write, play golf, shoot pool, and even go fishing without any compromise to their lifestyles" (27, p. 178). In addition they also fulfill military and cultural expectations of what it is to be a normal or super-normal American male, which he claims links the "privileges accorded to American able-bodied masculinity" (p. 179) to components of American political power, particularly its foreign policy. Serlin is focusing on the excess of the clinical distribution of prosthetic limbs and terminal devices as a metaphor for an American culture that links commodity abundance with transcendent power.

Future Developments

Here I want to move onto a discussion of present and future research, which has linkages to the literature that I have discussed above. At the beginning of this chapter I noted that while issues of identity are bound up in issues of function, there has as yet been little research "conducted on the relationships among functioning, limitations, and identity in people with amputations" (3). I am currently involved in just such research. I will now illustrate how the intellectual and methodological underpinnings of the work that is currently being done is informed by Scheper-Hughes and Lock's idea about the three bodies: the individual, the social, and the political. This is a valuable perspective, which sheds light on how individuals respond to their prosthetic limbs.

Since the summer of 2006 I have been investigating the culture of rehabilitation in the Military Amputee Patient Care Program of the Walter Reed Army Medical Center in Washington, DC. The program primarily addresses the rehabilitative needs of military personnel who have lost a limb or limbs as a result of the ongoing military operations in Afghanistan and Iraq. Since October 2001 about 600 U.S. military personnel have lost limbs as a result of injuries sustained in the ongoing conflicts in both Afghanistan and Iraq. There are several characteristics that distinguish military patients from civilian ones that affect rehabilitative trajectories. These characteristics are both physical and, for lack of a better term, ideological. In terms of the physical, military patients are distinguished from their civilian counterparts by their relative youth, their athleticism, and the health care system within which they are embedded. The medical system has consequences for patient outcome in the military system, because military patients are treated in a group setting. While not group therapy per se, military patients have the benefit of seeing others with similar injuries at all stages of the rehabilitative process. There are studies that support the notion that therapy in groups is more effective than receiving therapy alone. One study of a chronic pain therapeutic group demonstrates that patients can develop and encourage good outcomes for themselves through their collective work adapting to therapeutic goals and routines (28). Another study on Alcoholics Anonymous demonstrates that the group effort in constructing appropriate narratives of alcoholism is instrumental in the recovery process (29). Another consequence of the military medical system is that its funding allows patients to have top-of-the-line prosthetic limbs for a variety of activities. Contrast this with the limits that Sobchak reports she encountered, where the prosthetic limb she received was tracked toward her presumed need and level of activity.

Ideologically, military patients are placed in a social position near but not within the status of disability. Because of the way that military patients have lost their limbs, they are pulled into a discourse of heroism (whether they like it or not). The structure of rehabilitation is not organized around finding occupations or activities that these patients can do, but is instead organized around providing them with the means to return as closely as possible to their preinjury functioning. In addition, in the Walter Reed program, patients are subtly encouraged to see their prosthetic limbs as possible enhancements that might improve functioning rather than a substitute for missing limbs. This is obviously easier for patients who have below-knee amputations, but it is a common theme both in the military and in the prosthetic research and development field. Hugh Herr (30), the developer of Ossür's Rheo Knee, reported in a recent presentation that by extending the pylons of his below-knee prostheses, he has been able to enhance his ability to rock climb. Military patients are encouraged to think that because of their military background they are going to receive an overabundance of the latest technology and that they will have an advantage over other populations in using it at the edge of its abilities.

I am currently looking at how military patients at Walter Reed collectively experience both the formal rehabilitation activities they participate in daily in occupational therapy, physical therapy, the prosthesis service, and with physicians from rehabilitative medicine and orthopedic surgery, as well as in their out-of-clinic activities. I argue that attention must be paid to the knowledge produced by patients as they move through different phases of their recovery from injury. By focusing on the production of knowledge developed by clinicians about patients, and by patients about themselves and each other, my study explores the complex activities and negotiations that occur on the trajectory from acute injury to the resumption of the life course beyond the gates of a military medical center.

The second broad issue that I am following at Walter Reed is how patients experience and describe what it is like to integrate mechanized limbs into their bodies and their selves. This builds on work already done by Kurzman and Sobchak, which I have described above. What my work will contribute to theirs, as well as to the broader literature on the psychosocial world of prosthetics users, is a rich mine of data that is derived by interviews and observations and is interpreted through phenomenological approaches to the subtle and incremental changes to the self that changes to the body produce.

Phenomenology as a philosophic tradition has focused on the nature of experience. One school, inspired by the work of Maurice Merleau-Ponty, has explored how experience shapes the body as a knowing agent. One way to understand this approach is to consider an activity well known to researchers: typing. Experienced typists, generally without looking, can type with few spelling errors. However, ask them to draw a keyboard or to describe all the letters, in order, on each row, and the task is almost impossible. Merleau-Ponty (31) suggested that this "is knowledge in the hands, which is forthcoming only when bodily effort is made, and cannot be formulated in detachment from that effort." My study moves beyond this to the social level by utilizing Alfred Schutz's social phenomenology.

Alfred Schutz (32) shares Merleau-Ponty's concern with the body as a knowing agent. But as he is interested in a broader theory of human action, he shifts his focus to this idea of experience, to integrating the human body into the broader social and natural world within which it interacts. He does this by demarcating both levels of community interaction and levels of sharing temporal experience. *Consociate* is the name he gives to the most intimate social level. Consociates share the same time together while having spatial access to each other and thus partake of each other's inner sense of time and duration, and furthermore partake in the building of each other's experience. What this means, according to Schutz, is that through the joint participation in a lifeworld (such as the Amputee Patient Care Program), individuals are able to develop and express a fuller understanding of their situation and those of their peers than are observers external to the setting. This is one of the advantages that interpretive social sciences have over more quantitatively driven ones in elucidating social experience, especially relatively understudied areas of it.

The anthropological approach to the study of the psychosocial life of prosthetics and people with amputations is distinguished by its holistic approach to both the prosthesis and the user. The strength of this approach is that it addresses the whole life not only of users but also of clinicians, as well as exploring the social and cultural meanings generated by prosthesis technology. Anthropological understandings of the psychosocial life of prosthetics users provide a new and important way to understand the clinical, rehabilitative, and day-to-day lives of prosthetics users. The study that I am currently involved in at the Walter Reed Army Medical Center addresses clinical questions of patient recovery and progress. Issues of recovery and progress are affiliated with a person's identification and sense of self. Medical services must include knowledge of patients' perspectives on recovery and progress for intervention to be successful. This has a significant impact on patient adherence. In an effort to more adequately understand the process of rehabilitation, attention must be paid to the knowledge produced by patients as they move through different phases of their recovery from injury. By focusing on the production of knowledge developed by clinicians about patients, and by patients about themselves and each other, this study will explore the complex activities and negotiations that occur on the trajectory from acute injury to the resumption of the life course beyond the gates of a military medical center. It is to be expected that the conclusions of this research will provide critical information to all rehabilitation providers that will ensure a positive resumption of a functional life course as well as directly address the important issue of patient compliance.

The research that I am currently involved with at Walter Reed Army Medical Center offers several possible specific contributions to clinicians working with military health beneficiaries. One contribution is my work on how patients learn to use their prosthesis. One of the insights of learning theory is that once individuals master a new skill, they "forget" the process of learning. If the process of learning how to use a myoelectric or body-powered arm or learning how to negotiate balance issues on prosthetic limbs can be better understood, it may contribute to developing new clinical practices in teaching people with amputations how to use prostheses. A second contribution is to understand why people with amputations prefer one prosthetic type over another. Kurzman (17) provided some idea of this based on how particular patients respond to a prosthetic device's weight. I will be building on this to explore how patients map out their day-to-day lives and make decisions about which prosthetic limb or terminal device is best suited to the majority of their tasks and goals. A third contribution that my study will make to clinicians is in developing understandings of the social and cultural context of prosthetic use and dis-use. People with amputations are embedded in rich cultural and social worlds. Some patients may prefer passive but cosmetic limbs to active but more robotic looking limbs. In other cases it may be the opposite. My study can also contribute to understanding differences in gendered responses to prosthetic technology and use. Lastly, my study will explore the use of prosthetics in patients' regular lives outside of their clinical encounters. This will enable me to comment on how people with amputations use their prosthetics in ways that they are trained to, but also in ways that they innovate on their own.

Summary of Key Points

Anthropology takes a holistic perspective on the lives of people with amputations and on their use of prosthetics. Anthropologists concern themselves with both the clinical and the public and private worlds patients inhabit. An example of this is my description of some of the significant research of the past few years, interpreted with attention to the three "bodies" that individuals inhabit: their individual body, the social body, and the broader cultural or body politic. My ongoing research is an example of this as I address the whole lives of patients in the military medical center by incorporating their clinical routines, their private lives, and their relationships to technology, and how that impacts on the self. In this chapter I have addressed two important issues. The first is that prosthetic limbs and prosthesis users cannot be seen in clinical or research isolation only. Instead a nuanced and contextualized perspective illuminates their position as clinical patients and research subjects, as participants in social interaction and social life, and as citizens or subjects of political regimes that structure their access to technology, health care, and social status. Second, anthropology is well positioned to participate in illuminating these aspects of the social and cultural lives of patients and prosthetics.

Further Reading

The following are a list of suggested readings for those interested in anthropology generally and medical anthropology in particular. This list is not exhaustive and is probably more representative of the author's predilections than the field in general. Interested readers should also see the references cited for this chapter.

Csordas T. Body/Meaning/Healing. New York: Palgrave, 2002.

Dumit J. Picturing Personhood: Brain Scans and Biomedical Identity. Princeton, NJ: Princeton University Press, 2003.

Geertz C. Interpretation of Cultures. New York: Basic Books, 2001.

Gerber D. Disabled Veterans in History. Ann Arbor, MI: University of Michigan Press, 2000.

Good B. Medicine, Rationality, and Experience: An Anthropological Perspective. New York: Cambridge University Press, 1994.

Kleinman A. Writing at the Margin: Discourse Between Anthropology and Medicine. Berkeley, CA: University of California Press, 1997.

Mead M. Sex and Temperament in Three Primitive Societies. New York: Harper Perennial, 2001.

Petryna A. Life Exposed: Biological Citizens After Chernobyl. Princeton, NJ: Princeton University Press, 2002

Serlin D. Replaceable You: Engineering the Body in Postwar America. Chicago: University of Chicago Press, 2004.

Sharp L. Bodies, Commodities, and Biotechnologies: Death, Mourning and Scientific Desire in the Realm of Human Organ Transfer. New York: Columbia University Press, 2007.

References

1. Gallagher P. Introduction to the special issue on psychosocial perspectives on amputation and prosthetics. Disabil Rehabil 2004;26:827–830.
2. Desmond D, MacLachlan M. Psychosocial issues in the field of prosthetics and orthotics. J Prosthet Orthot 2002;14:19–22.
3. Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation. Disabil Rehabil 2004;26:837–850.
4. Scheper-Hughes N, Lock M. The mindful body: a prolegomenon to future work in medical anthropology. Med Anthrop Q 1987;1:6–41.
5. Dillingham T, Pezzin L, Mackenzie E. Use and satisfaction with prosthetic devices among persons with trauma-related amputations: a long-term outcome study. Am J Phys Med Rehabil 2001;80:563–571.
6. Pezzin L, Dillingham T, Mackenzie E, Ephraim P, Rossbach P. Use and satisfaction with prosthetic limb devices and related services. Arch Phys Med Rehabil 2004;85:723–729.
7. Davidson J. A survey of the satisfaction of upper limb amputees with their prostheses, their lifestyles, and their abilities. J Hand Ther 2002;15:62–70.
8. Parkes C. Psycho-social transitions: comparison between reactions to loss of a limb and loss of a spouse. Br J Psychiatry 1975;127:204–210.
9. Rowlands A. Breaking my head in the prime of my life: acquired disability in young adulthood. In: Priestley M, ed. Disability and the Life Course: Global Perspectives. New York: Cambridge University Press, 2001:179–191.
10. Rybarczyk B, Nyenhuis D, Nichols J, Cash S, Kaiser J. Body image, perceived social stigma, and the prediction of psychosocial adjustment to leg amputation. Rehabil Psychol 1995;40:95–110.
11. Cacciapaglia H, Beauchamp K, Howells, G. Visibility of disability: effect on willingness to interact. Rehabil Psychol 2004;49:180–182.
12. French L. The political economy of injury and compassion: amputees on the Thai–Cambodian border. In: Csordas T. Embodiment and Experience: The Existential Ground of Culture and Self. New York: Cambridge University Press, 1994: 69–99.
13. Murray C. An interpretive phenomenological analysis of the embodiment of artificial limbs. Disabil Rehabil 2004;26:963–973.
14. Murray C. Social meaning of prosthetic uses. J Health Psychol 2005;10:425–441.
15. Behel J, Rybarczyk B, Elliott T, Nicholas J, Nyenhuis D. The role of perceived vulnerability in adjustment to lower extremity amputation: a preliminary investigation. Rehabil Psychol 2002;47: 92–105.
16. Frank, G. Venus on Wheels: Two Decades of Dialog on Disability, Biography and Being Female in America. Berkeley, CA: University of California Press, 2000.
17. Kurzman, S. "There's no language for this": communication and alignment in contemporary prosthetics. In: Ott K, Serlin D, Mihm S, eds. Artificial Parts, Practical Lives: Modern Histories of Prosthetics. New York: New York University Press, 2002.
18. Bourke J. Dismembering the Male: Men's Bodies, Britain, and the Great War. Chicago: University of Chicago Press, 1996.
19. Cohen D. The war Come Home: Disabled Veterans in Britain and Germany, 1914–1939. Berkeley, CA: University of California Press, 2001.
20. Gerber D. Disabled veterans, the state, and the experience of disability in western societies, 1914–1950. J Social History 2003;36:899–916.

21. Serlin D. Engineering masculinity: veterans and prosthetics after World War II. In: Ott K, Serlin D, Mihm S, eds. Artificial Parts, Practical Lives: Modern Histories of Prosthetics. New York: NYU Press, 2002.
22. Nelson D. Stumped identities: body image, body politic, and the Mujer Maya as prosthetic. Cultural Anthrop 2001;16:314–353.
23. Wright M. Desire and the prosthetics of supervision: a case of maquiladora flexibility. Cultural Anthrop 2001;16:354–373.
24. Jain S. The prosthetic imagination: enabling and disabling the prosthesis trope. Sci Technol Hum Values 1999;24:31–54.
25. Kurzman S. Presence and prosthesis: a response to nelson and wright. Cultural Anthrop 2001;16: 374–387.
26. Sobchak V. A leg to stand on: prosthetics, metaphor and materiality. In: Smith M, Morra J, eds. Prosthetic Impulse: From a Posthuman Present to a Biocultural Future. Cambridge, MA: MIT Press, 2006.
27. Serlin D. Disability, masculinity, and the prosthetics of war, 1945–2005. In: Smith M, Morra J, eds. Prosthetic Impulse: From a Posthuman Present to a Biocultural Future. Cambridge, MA: MIT Press, 2006.
28. Jackson J. "Camp Pain": Talking with Chronic Pain Patients. Philadelphia: University of Pennsylvania Press, 2000.
29. Cain C. Personal stories: identity acquisition and self understandings in alcoholics anonymous. Ethos 1991;19:210–253.
30. Herr H. Presented to the National Academies Keck Futures Initiative Conference on Smart Prosthetics. Irvine, CA: Beckman Center of the National Academies of Science, Engineering and the Institute of Medicine, 2006.
31. Merleau-Ponty M. Phenomenology of Perception. New York: Routledge, 2002 (1962).
32. Schutz A. Phenomenology of the Social World. Evanston, IL: Northwestern University Press, 1967.

9

Embodiment and Prosthetics

Craig D. Murray

Overview

Artificial, or prosthetic, limbs are considered a key element in the rehabilitation of people with acquired limb loss and those with congenital limb deformity (1). The rehabilitative process, whereby people with limb loss, absence, or deficiency are fitted with and trained to use a prosthesis, has formed a substantial area of research. These technological artifacts are often able to restore some of the functions, as well as offering some aesthetic approximation, of an anatomical limb. However, while prosthesis use is seen by many as necessary for the restoration of near normal appearance, for functional independence, as well as substantially repairing their damaged body image, the embodied experience of prosthesis use is little explored.

This chapter offers an overview of a largely neglected area of research: the embodied experience of prosthesis use. This includes a consideration of the concepts and theories of embodiment, along with an examination of how people's ideas about prosthetic limbs contribute to their experience of them. The chapter begins with an overview of research relating to the phenomenological experience of using an artificial limb, and then presents the personal, social, and cultural meanings that surround such use and impact on its embodied experience. This chapter argues that a consideration of these interrelated areas enables a deeper understanding of rehabilitation following limb loss or following congenital limb deficiency, and consequently for the use of artificial limbs in this process.

The Phenomenological Embodiment of Prosthesis Use

Phenomenological researchers have presented analyses of how certain technologies and artifacts can mediate both perceptual and motor skills and become incorporated into the phenomenal boundaries of the body. For instance, the experience of the blind person using a long cane has been discussed by a number of phenomenologists (2–5). Merleau-Ponty (4) argued that the cane is an extension of the realm of the senses, with touch being transferred from the hand to the end point of the cane; the cane becomes an intimate prosthetic device that withdraws into the sensorium of the body. This incorporation of the tool into the form and praxis of the body is what Leder (6) refers to as a phenomenological osmosis, whereby the body allows instruments to melt into it (7)

An analysis such as the above applied to prosthesis use would be useful for two broad reasons. First, the rehabilitation community working with prosthesis users often talks of the need to transform the prosthetic limb from an inert supplement or an extracorporeal structure into a corporeal one (8). Therefore, it would be informative to know if such an experience could be achieved by the prosthesis user. Second, if it is achievable, it could aid identification, for rehabilitative purposes, of the process and steps necessary to achieve this experience.

A number of researchers have proposed that an artificial limb may become "part of" the user. Fraser (9) observed and compared the movement patterns in a proficient user of an upper artificial limb with those of the other, anatomical limb. She argued that if an artificial limb were to become part of the user, then it might be expected that the movement patterns of the prosthetic and anatomical limb would be similar. Fraser, in fact, found evidence of this. However, Fraser's criterion for a prosthesis becoming part of a user was based on observable behavior and measurable performance, rather than the prosthesis user's own report of phenomenal experience. Additionally, one can question the assumption that it is necessary for a limb and prosthesis to have similar movement patterns in order for the latter to feel embodied. Indeed, the phenomenological work referred to earlier regarding tools and the blind person's long cane would suggest that artifacts that have different properties than the anatomy to which they are appended can nevertheless be embodied.

Anecdotal as well as empirical evidence of prosthesis adaptation, a process in which prosthesis users overestimate the length of their residual limb as the result of prosthesis use, has been reported by McDonnell et al. (10,11). These researchers proposed that long-term exposure to discordant forms of sensory information (the visual, proprioceptive, and tactile aspects of this prosthesis use) result in this phenomenon. Inasmuch as prosthesis use leads to the overestimation of the length of residual limbs, it may be argued that the prosthesis has become part of the user's body image.

Recent research (12) has centered on the phenomenological boundaries of prosthesis user's bodies. Artificial limb users are predominantly people who have had a limb amputated (in contrast to being born with a missing limb). One pervasive aspect of such users' experience is a phantom limb, whereby they feel as if the anatomical limb is still present in its usual place. This experience has been found often to play a large part in enabling the incorporation of a prosthetic into the phenomenal body of participants, such as when the prosthetic limb is experienced as part of the phenomenal body, with the phantom and the prosthetic interlacing into a phenomenal corporeal structure:

> "It is certainly nice to still feel the [phantom] foot. Primarily, it facilitates the use of the prosthesis because I don't feel as anything is really missing.
> So my prosthesis is 'natural"' (12, p. 969).

In the above example the prosthetic and phantom limb phenomena entwine their different properties (the "legness" of the phantom, the solidity and reality of the prosthetic limb), which anchors (a "connectedness-to-the ground") people with amputations to their habitual world. However, it is important to note that for some people the phantom limb does not have a close correspondence to their amputated limb. It may only be experienced in part (e.g., a phantom hand with no forearm); it may be experienced as lighter and more hollow; it may be contorted into an anatomically impossible position; and it may also be experienced as much shorter than their amputated limb.

While prosthesis users may report that the limb feels "part of" them, a phantom limb is not always necessary for such an experience. Murray (12) found people with congenital limb absence gave similar accounts. One female interviewee with congenital absence of her right forearm, stated:

> "It's [the prosthesis] a part of me now, that's the only way I can describe it. To me it's as if, though I've not got my lower arm, it's as though I've got it and it's a part of me now. It's as though I've got two hands, two arms" (12, p. 970).

Such reports reflect the possibility that under certain circumstances a prosthesis can be transformed from an extracorporeal structure into a corporeal one (8). Just as McDonnell and colleagues (10,11) report that users overestimate the length of their residual limb as the result of prosthesis use, prosthesis users themselves often provide accounts of how their prosthesis is incorporated into phenomenal body structures.

Churcher (13) has discussed the process of learning a new task, with special attention to the use of prostheses. He provides the example of learning to use a pencil, whereby new physical and informational properties of the hand need to be internalized to adequately use a pencil as an extension of the body. The phenomenon experienced by some artificial limb users, whereby they are able to lose a focal awareness of their prosthesis and use it as a replacement of their anatomical limb, is demonstrative of the process described by Churcher: the new physical and informational properties that accompany prosthesis use are incorporated and allow the prosthesis to be used as a practical extension of the body.

The incorporation of an artificial limb into the phenomenal boundaries of the body enable some users to achieve corporeal knowledge, that is, a form of phenomenological understanding that is usually achieved with an anatomical limb. For instance, Murray (12) reports how one woman with congenital limb deficiency recounted an attempt earlier in her life to learn how to play the piano. On one particular week she had forgotten to take her left prosthetic hand with her, and her tutor asked her to "just do the right hand, but think where the left hand would be." As she explains, "I could not think left handed."

> "And when I had to think left hand, and play the piano right hand on my lesson, I gave up. Because the man didn't understand, I couldn't think about the left hand, because it's not there. I've never had it and I can't think about the left hand. I've no experience. And there's an old Chinese proverb, 'I do and I understand, I don't do and I don't understand.'" (12, p. 969).

She then explained a more recent occasion when she had had similar difficulties:

> "We were doing exercises in the pool. … You were having to put your right hand to your left knee, and your left hand to you right knee. I was sort of going like this [flails arms], for ages, almost disoriented by limb. There's one limb not there, I can't even think left hand." (12, p. 969).

However, it became evident that the prosthetic hand was able to provide her with knowledge that is usually corporeal:

> "With the prosthesis, the bit I do understand is holding the hymn book, that [the prosthesis] can hold a hymn book, now I know what it feels like to hold a hymn book in the left hand. Can you understand that?" (12, p. 969).

In this manner, a prosthetic limb is able to imbue a form of corporeal knowledge to users. Using a prosthetic becomes a form of knowing—an understanding that is achieved practically and corporeally. The above participant at once describes the limits and potentiality of a prosthetic hand. While she is unable to perform complex motor acts with the prosthesis, relatively simple activities, such as holding a hymnbook, are made "knowable" to her by virtue of the prosthesis.

While the above form of experience was recounted by a number of Murray's (12) participants, it is all the more interesting that this was often the experience of participants who had congenital limb absence, and could describe the experience of not only having an artificial limb redesign the natural topography of their body, but that it could also imbue the implicit knowledge, which is usually embodied corporeally.

Not all prosthesis users experience the types of bodily incorporation of an artificial limb described above. Some describe their prostheses merely as practical aids (12). Many people with amputations, for instance, do not have the physical strength (particularly if they are elderly) or a residual limb that affords such an outcome. However, the recent identification that the experience of a prosthesis as part of the phenomenal body is a common occurrence raises the possibility that many people who could benefit from prosthesis use simply do not persevere to the point where these benefits could be realized.

The accounts of prosthesis users suggest that the training of persons to use artificial limbs should emphasize the long-term process involved, for instance, in gaining effective balance and walking gait with the aid of a prosthesis. The accounts of Murray's (12) successful prosthesis users demonstrate that the use of an artificial limb is not intuitive to begin with, nor does such use initially feel natural. However, prosthesis users stress the process of adjustment to using a prosthesis, in which there was a natural switch and subconscious compensation to changes in weight distribution and body balance following amputation and subsequent prosthesis use. One implication of such experience is that, whereas previous research has found that the increased physical effort associated with prosthesis use (14) as well as discomfort experienced when wearing a prosthesis (15) often leads to rejection of artificial limbs, the accounts of successful prosthesis users suggest that these experiences may be overcome with perseverance. That is, the often-cited reasons for the rejection of prostheses are frequently part of the initial experiences of successful prosthesis users also who, unlike those who reject their prosthesis, persist with using their artificial limbs to find that these negative experiences give way to a more natural pre-reflective use of their artificial limbs.

While the personal accounts of the perceptual experience of prosthesis use provided by people with amputation and congenital limb absence provide important insights into the manner in which prosthesis use may become embodied, it is also important to stress that such experience does not take place in a social vacuum. Rather, the physical and technological metamorphosis of prosthesis users takes place within social and historical contexts, where meanings of such prosthesis use are made and remade within both social interaction and the dominant views of wider society (16). These meanings can be expected to impact upon the experience of prosthesis use, and upon the likelihood that such use will be continued. Therefore, it must be borne in mind that prosthesis use cannot be fully understood without a consideration of the cultural milieu in which such experiences are embedded.

A clue to the understandings and meanings that using a prosthetic limb has for the person concerned can be found in a reflection of the centrality of the body in personal experience (16). Dise-Lewis (17) notes that, in Western cultures, the loss of a right hand means that people are no longer able to shake hands in the socially accepted manner, whereas the loss of the left hand prevents them from wearing their wedding ring on the correct hand. A prosthetic limb, then, may be able to restore some of these rudimentary customs in which the body is routinely and socially deployed (Fig. 9.1).

The meaning of the social body (18) in relation to prosthesis use has been examined by Murray (16). Such meanings can be illustrated by the comments made by one female interviewee regarding the use of her prosthetic hand. This participant discussed how her prosthesis integrated her into an important social ritual, one of adolescent courtship. What is important here is not that the prosthesis facilitated romantic or sexual relationships—indeed the respondent remarks she "usually had three boyfriends at a time"—but, rather that it enabled participation in a social ritual, one in which the conventional use of the body was of central importance.

FIGURE 9.1. An image of a cosmetic glove wearing a wedding ring and watch as used in promotional material by Realistic Prosthetics Limited. (From Realistic Prosthetics Limited, with permission.)

> "The reason I wanted it [the prosthesis] when I was sixteen—remember I was a teenager, very popular, I usually had three boyfriends at a time [laughs]. 'Sweet sixteen and never been kissed,' I'd been kissing boys since I was thirteen. To me kissing was absolutely lovely. I always had lots of boyfriends. But when I was dancing it was nice to have a hand to put on their shoulders. It was a cosmetic reason really, but I was pleased to have it." (16, p. 431).

The social normalizing role of prostheses is found to be important for many users, both people with congenital limb absence and people who had experienced amputation. As can be seen from the above extract, a prosthetic hand not only enabled participation in an important social ritual (one of adolescent courtship), but, more specifically, the dancing that accompanied this activity required conventional uses of the body, for example the hand on the shoulder, which would be impossible to achieve without the prosthesis.

The above example also indicates a gendered context within which prosthesis use takes place. The topic of gender in relation to prosthesis use has been largely overlooked in the research literature. The limited research on the issue of gender, amputation, and prosthesis use has examined depression following amputation. (Kashani et al. (19) found women were more likely than men to be depressed following an amputation, while several studies have found gender does not predict levels of psychosocial adjustment (20–22)).

It is important to recognize that culture and gender may have an influence in the experience of embodiment for prostheses users. Murray (23) has found that for male participants, the issue of gender and prosthesis use is located in discussions of gendered roles, such as the male breadwinner, and in descriptions of strength (24). Here males viewed prosthesis use as important in allowing them to continue providing financially for their family, and prostheses were valued for allowing or enabling strenuous activities. Such views are evident in, and typified by, the following interview extract:

> "For me it was important that I could get back to work and sort the finances of the family. My wife had taken on a job that she had had before our son was born, and I wanted to have things back to normal as soon as possible. The [prosthetic] leg allowed me to do this, and I was soon back repairing the house (back on ladders), and putting in 12 hours per day of physically demanding work." (23, p. 149).

In contrast to a male focus on the utilitarian functions provided by their prosthesis, many women indicated that their prostheses were central to maintaining their feminine identity, such as being able to continue wearing high heels, to go dancing, and so forth. However, other women emphasized the "ugliness" of their prostheses, and how they interfered with the establishment of sexual relationships [23,24]. While masculinity is implicated in prosthesis use, as described above, for female prosthesis users, in particular, the gendered nature of prosthesis use was of personal significance. Female prosthesis users have been found to speak of the frustration they encounter in obtaining prosthetic limbs that are appropriately gendered [16]. On occasion, some female prosthesis users have artificial limbs provided to them that are designed for male users. The affront to a person's sense of femininity on such occasions had profound personal significance:

> "I probably would not have retained some anger at a prosthetist who put men's feet on my limbs if he had told me that only men's feet were available at any point in time!" (23, p. 149).

However, such a distinction between male and female artificial limbs is not always clear or appropriate. Rather, for some female participants a prosthesis designed for use by males was sometimes more appropriate for their needs. As the following interview excerpt demonstrates, the prosthesis that had been designed for use by females was too small for the participant, who then had to use an alternative which was originally designed for a male:

> Participant: This is a man's hand. I used to have really long nails and everything beforehand, but you can't really have long nails with that.
> Interviewer: Why have you got a man's hand?
> Participant: Because the ladies hand, I looked at it and said it's a tiddly that. It is, it's too small. I mean, I've always done quite hefty work in my jobs, so I suppose it's given me quite muscular type hands. And this to me was more like my hand than what the other tiddly things were, you know." (23, p. 150).

Some females perceive prosthesis use, particularly upper-limb prostheses, as not suitable for females. A lack of cosmesis and the view that women have more of a problem with wearing prostheses have been cited as reasons for nonuse:

> "I know that having another [prosthetic] arm would make life much easier in many respects, but my reason for not using them has been largely cosmetic. It seems that women have more of a problem with wearing a hook than men (blame it on Peter Pan, if you will!) and I admit, I am one of them." (23, p. 159).

Clothes emerge as important in female prosthesis users' sense of femininity and self-identity. Clothes worn prior to limb loss and prosthesis use are therefore often still worn, even when this makes prosthesis use more difficult and threatens one's health. This is evident in the following interview excerpt, where a participant talks of her determination to continue wearing high heels:

> "I know when I first got my limb I was determined to lead quite a normal life. And before I ever had my leg amputated I used to wear high heels. And I wanted to be able to carry on wearing high heels, because it felt as though I was still being me. And there were lots of arguments at the time. These are 3½-inch heels. You won't see anyone else with them. But that was me and that is what I wanted. There was lots of arguments, erm, as regards me getting that, because of pressure on my other leg. And with it being circulation problems, vascular disease, I also have a lot of problems with the other leg. But, even though I put strain on the other leg by wearing the heels, it makes me feel better." (23, p. 151).

The gendered nature of prosthesis use then is generally more prominent for females. This is perhaps reflective of (Western) societies' more pronounced emphasis on the appearance of females [25], which artificial limbs disrupt. For females, the ability to wear items of clothing that can be seen as quintessentially feminine is found to be important for their sense of self-identity.

The emphasis here on feminine clothing differs from the use of clothing as discussed by Kaiser and colleagues [26,27] in the management of appearances by persons with physical disabilities. Whereas Kaiser et al.'s research found that

FIGURE 9.2. An image of a man with a left arm amputation seated in a car and using the Boston Digital Arm System as used in promotional material by Liberating Technologies, Ltd. (From Liberating Technologies, Ltd., with permission.)

disabled persons attempted to appear as normal as possible through their clothing choices, using a variety of techniques to conceal or deflect attention away from their disabilities, here female prosthesis users often wanted to wear clothes that were important for their sense of identity, but did not necessary make it any easier to conceal a prosthesis. Male concerns about prosthesis use appeared more concerned with purely utilitarian functions provided by their prostheses, such as being able to continue driving a car. Interestingly, prosthesis company advertisements often depict male prosthesis users in cars, emphasizing the culturally valued link between men and driving (Figs. 9.2 and 9.3) (28). Thus, the cultural context of feminine attractiveness contrasts with masculine functionality, both of which play a part in a cultural and gendered embodiment of prostheses. The preceding discussion of gender and embodiment indicates that gendered identities are important in the embodied experience of prosthesis use, and that the use of artificial limbs is more likely when such use is able to support such gendered identities.

The affective responses that prosthesis users have to their bodies are in part constituted by the values, opinions, and behaviors of other people and wider society, and which are exerted within social interaction. Erving Goffman's (29) seminal work on stigma positions the body as a repository of meaning (discourses of body and embodiment), and highlights its role in social encounters as well as stressing the importance of management (bodily performance) in social competence.

The management of bodily performance in social interaction tends to proceed, for most people, most of the time, in an unproblematic manner. However, Goffman argues that problems can occur when people's self-identity (how they view themselves) does not accord with their actual social identity (how other people see them). A

FIGURE 9.3. A prosthetic company advertisement featuring a couple in a car, as used in promotional material by Endolite/Chas A. Blatchford & Sons, Ltd. (From Endolite/Chas A. Blatchford & Sons, Ltd., with permission.)

person's self-identity is often premised on a wish to be seen as normal. In this regard, the problems of the disabled feature prominently in Goffman's work. For people with stigmas, such as amputations, problems can arise in social interactions with able-bodied persons that have particular and lasting damage for their self-identity.

As one example of the importance of culture and social reactions to prosthesis use, and amputation in particular, we can consider a study of a Cambodian population with a high number of people with amputations due to land-mine injuries (30). Amputation, French (30) argues, so alters the integrity of the body that both the person with amputation and the people he or she comes into contact with are affected. For example, the embodiment of able-bodied people simultaneously equips them with a sympathetic identification with the person with amputation, and a fearful repulsion that they too could become like them.

Of particular importance to French was the impact of so many amputations on one Cambodian population. This included questions of the effect that these amputations and people with amputations had on the wider population, how the population experienced the bodies of people with amputations, and how these bodies were "read." Therefore, the social experience and understanding of amputation in the population as a whole was the research focus.

Responses to these questions were found to be understood only with reference to the political, economic, historical, and religious milieu of the people and region. Initially, French had supposed that people with amputations would be seen as a reminder of the war that had raged there for so many years, but that they would receive a compassionate Buddhist response. What French found was that people with amputations did not provoke a general anxiety about the war, but rather a more specific anxiety about personal safety. Young males with amputations in particular had a reputation for violence and theft, and were avoided. They were looked down upon and were rarely treated compassionately. Individuals with amputations themselves felt abandoned and degraded by their families and society in general.

French described her study as phenomenological in that it was concerned with lived experience and its meanings. However, these meanings were located within the intersubjective domain of social relations and cultural signs. The social nature of the life-world means that, while we experience as individuals, the "what" of experience is constituted through complex interwoven subjectivities.

Representations of prosthesis use in cultural vehicles, such as the media and advertising, provide further insights into how the meaning of prosthetic embodiment is socially and culturally constituted. The analysis by Lisa Herschbach (31) of prosthesis company advertisements for artificial limbs following the American Civil War identified a narrative pattern in this historical material, which sustained a "persistent dream of bodily revitalization" and in which text and images were used to emphasize prosthesis users as "embracing the robust pleasures and pursuits of civilian life, absolved of their injuries" (p. 31). While a similar systematic analysis of modern prosthetic literature is lacking, as noted earlier such advertisements often feature artificial limb users in culturally valued activities appropriate, for example, for their gender (28).

While the social world around us, along with the culture, can be seen to play a part in molding embodied experience for people with and without disabilities, it is important not to invest these with a determining role. For example, in a series of papers, Frank (32–34) has examined the culturally and socially embedded experience of embodiment for people with congenital limb deficiency. In contrast to Goffman's (29) theory that suggests that rejection by normals forces people with disabilities to conceal, and therefore minimize the negative impact of their physical difference, Frank's (34) informants used self-display as a method of self-empowerment. She argued that stigma was a factor in her participants' lives to which they had to adapt. However, Frank argued that not only does stigma not remain static over time, but that there is no final state of adjustment. Rather, Frank's participants adopted and developed a variety of strategies for dealing with stigma that were not all about concealing their disability. Importantly, Frank's informants emphasized that managing stigma was not the focal point of their lives.

Frank (32) provided a life history of Diane DeVries, a woman born without legs and with above-elbow stumps, in which she emphasized the normalcy of her participant's body for her.

Frank described this work as a collaborative effort between informant and researcher, with the aim of producing a holistic, qualitative account that would relate to theoretical issues, but that would also convey a sense of the personal experience of congenital disability. Within this paper Frank emphasized themes of cultural normalcy and orientation to independent living: these themes conveyed the normal cultural development of Diane's life in relation to her age, gender, and social background, which included initiation into sex, falling in love, and living with a partner. DeVries judged the prosthetics forced upon her at an early age as more stigmatizing than her unencumbered body. With her prostheses she felt she looked like "a little Frankie" (a Frankenstein monster), and felt more natural without them. The same informant formed the basis of a later paper by Frank (33), in which she wrote of how DeVries articulated intactness in her descriptions of her body. Although trained at an early age, and for a prolonged period (age 4 to 18), to use prostheses, DeVries always liked her "body to be completely free" (p. 208).

In a later paper, Frank (34) emphasizes themes of public visibility and personal display in the life stories of her informants, born with multiple limb deficiencies. These participants, Frank argued, demonstrate an attitude of activity against stigma, more than a reacting toward it. In this manner, Frank emphasizes the self-accepting attitudes that her informants had about their bodies despite their limb deficiencies. The rejection of prostheses by people born without limbs, Frank argued, can be seen as an adjustment to their embodied condition, where bodily competencies are better deployed without prostheses.

The body of work reviewed here highlights important aspects of the embodied experience of prosthesis use, and how the social and cultural worlds in which we live contribute to this experience. It is only with a full consideration of the phenomenology of using an artificial limb, and the personal, social, and cultural meanings that surround this practice, that the embodied experience of a prosthesis can be understood and fully inform the rehabilitative process. However, to achieve this, more work is needed to understand the diverse variety of meanings and experiences that surround prosthesis use, both by the person with congenital limb absence or acquired limb loss and those able-bodied members of society who encounter prosthesis users.

Future Developments

While the work referred to above emphasizes the need to consider personal and social meanings in order to understand the embodied experience of prosthesis use, such considerations need to be appropriately informed. For instance, the issue of gender was discussed earlier as an underexplored area with important implications for the individual's identity and experience of using an artificial limb. Another significant example of the relationship between identity and embodied experience is that of race and ethnicity. Gendered, racial, and ethnic identities are fashioned out of social relationships and culture, within which such identities are also situated. A full consideration of the embodied experience of prosthesis use requires attention to these issues.

The research on race and ethnicity in relation to amputation and prosthesis use tends to focus on the elevated risk to amputation found in ethnic minority groups. For instance, research in the U.S. has generally found that African Americans have a much higher risk of major lower extremity amputation than white patients (35). Similarly, Young et al. (36) have found that compared with diabetic patients without amputations, diabetic people with amputations were more likely to belong to a minority ethnic group. Dolezal et al. (37) have found nonuse of artificial limbs to be associated with being of African-American race. However, there is a paucity of research specifically on the experience of prosthesis use among racial and ethnic groups, or on the attitudes of able-bodied members of these groups toward prosthesis use. Vernon (38) argues that when researching and writing about disability "academics have either ignored or tagged on the experience of disabled Black and minority ethnic people" (p. 385). This tendency to subsume the experiences of ethnic minorities in research conducted with predominantly white sample groups may overlook important familial, religious, social, and cultural parameters of ethnic identity, which in turn modify the experience of disability.

As with gender, race can be expected to be an integral issue in prosthetic embodiment (23). For example, prosthetic cosmetic covers, which surround the working mechanisms of an artificial limb, need to be visually redolent of the color of the user's skin. While issues surrounding race do not currently appear in existing research material, there are companies that specialize in providing these cosmetic covers, which therefore indicates that race is an important consideration. Indeed, recently in the United Kingdom the national press reported on a black woman about to undergo amputation who was offered a pink rather than a black foot, and the distress which the offer caused (39). Until issues of race and ethnicity have been explored with respect to prosthesis use, it is not possible to explicate their role further here, aside from highlighting these issues as important areas of future research.

Summary of Key Points

- People with amputations and congenital limb absence vary in the degree to which they feel their artificial limb is "part of" them. However, it is a recent recognition that many prosthesis users can achieve this experience with practiced use.
- The personal meanings that current and potential users of prostheses have toward artificial limbs influence their experience of prosthesis use.
- The social roles or identities that people have are important aspects of their embodied experience.
- The society and culture within which prosthesis use takes place influences able-bodied persons' perception and meanings of this activity, which impacts on the embodied experience of the prosthesis user.
- Further work is needed to examine gendered, racial, and ethnic identities and their relationship to the embodied experience of prosthesis use.

Glossary

Corporeal: Relating to, or being characteristic of, the body or a part of the body.

Culture: An enduring way of life for a group of people, which incorporates acceptable and valued patterns of behaviors, beliefs, values, and symbols, and which is transmitted from one generation to the next via a variety of social practices.

Embodiment: The way in which people experience their own body.

Ethnicity: The shared and distinct characteristics of a group of people, such as linguistic, national, racial, religious, or cultural heritage, but especially when such people belong to a national group by heritage or culture and reside outside its national boundaries.

Gender: Referring to activities, appearance, attributes, behaviors, and social roles that society considers acceptable or appropriate for men and women.

Phenomenology: The study of phenomena or things as they are perceived, to uncover the essential features of experiences and the essence of what is experienced.

Race: The shared genetically transmitted physical characteristics that distinguish a local geographic or global human population as a more or less distinct group, such as skin color.

Stigma: An attribute that is socially unacceptable and imbued with a sense of shame or disgrace.

Further Reading

Frank G. (2000) Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America. Berkeley, CA: University of California Press, 2000.

Ihde D. Technology and the Lifeworld: From Garden to Earth. Bloomington, IN: Indiana University Press, 1990.

Leder D. The Absent Body. London: University of Chicago Press, 1990.

MacLachlan M. Embodiment: Clinical, Critical & Cultural Perspectives on Health and Illness. Milton Keynes, UK: Open University Press, 2004.

Murray CD. An interpretative phenomenological analysis of the embodiment of artificial limbs. Disabil Rehabil 2004;26(16):963–973.

Murray CD. The social meanings of prosthesis use. J Health Psychol 2005;10(3):425-441.

References

1. Cutson TM, Bongiorni DR. Rehabilitation of the older lower limb amputee: a brief review. J Am Geriatr Soc 1996;44(11):1388–1393.

2. Heidegger M. Being and Time. New York: Harper and Row, 1962. [Translated by J. Macquarrie and E. Robinson].
3. Ihde D. Technology and the Lifeworld: From Garden to Earth. Bloomington, IN: Indiana University, 1990.
4. Merleau-Ponty M. The Phenomenology of Perception. London: Routledge and Kegan Paul, 1970. [Translated by C. Smith].
5. Schilder P. The Image and Appearance of the Human Body. New York: International Press, 1935/1950.
6. Leder D. The Absent Body. London: University of Chicago Press, 1990.
7. Kujundzic N, Buschert W. Instruments and the Body: Sartre and Merleau-Ponty. Res Phenomenol 1994;24:206–215.
8. Scarry E. The merging of bodies and artifacts in the social contract. In: Bender G, Druckery T, eds. Culture on the Brink: Ideologies of Technology. Seattle: Bay Press, 1994:85–97.
9. Fraser C. Does an artificial limb become part of the user? Br J Occup Ther 1984;47(2):43–45.
10. McDonnell PM. Developmental response to limb deficiency and limb replacement. Can J Psychol 1988;42(2):120–143.
11. McDonnell PM, Scott R, Dickerson J, Theriault R, Wood B. Do artificial limbs become part of the user? New evidence. J Rehabil Res Dev 1989;26(2):17–24.
12. Murray CD. An interpretative phenomenological analysis of the embodiment of artificial limbs. Disabil Rehabil 2004;26(16):963–973.
13. Churcher J. Implications and applications of Piaget's sensorimotor concepts. In: Selfridge OG, Rissland EL, Arbib MA, eds. Adaptive Control of Ill-Defined Systems. New York and London: Plenum Press, 1984:289–304.
14. Waters R, Perry J, Antonelli D, Hislop H. Energy cost of walking of amputees: the influence of level of amputation. J Bone Joint Surg 1976; 58A(pt 1):42–46.
15. Millstein SG, Heger H, Hunter GA. Prosthetic use in adult and upper limb amputees: a comparison of the body powered and electrically powered prostheses. Prosthet Orthot Int 1986;10: 27–34.
16. Murray CD. The social meanings of prosthesis use. J Health Psychol 2005;10(3):425–441.
17. Dise-Lewis JE. Psychological adaptation to limb loss. In: Atkins DJ, Meyer RH, eds. Comprehensive Management of the Upper-Limb Amputee. New York: Springer-Verlag, 1989:165–172.
18. Synnott A. The Body Social: Symbolism, Self and Society. London: Routledge, 1993.
19. Kashani JH, Frank RG, Kashani SR, Wonderlich SA. Depression among amputees. J Clin Psychiatry 1983;44:256–258.
20. Bradway JK, Malone JM, Racy J, Leal JM, Pool J. Psychological adaptation to amputation: an overview. Orthot Prosthet 1984;38(3):46–50.
21. Rybarczyk BD, Nyenhuis DL, Nicholas JJ, Schulz R, Alioto RJ, Blair C. Social discomfort and depression in a sample of adults with leg amputations. Arch Phys Med Rehabil 1992;73(12):1169–1173.
22. Dunn DS. Well-being following amputation: salutary effects of positive meaning, optimism and control. Rehabil Psychol 1996;41(4):285.
23. Murray CD. Technologising the body: embodiment and phenomenologies of prosthesis use. Unpublished PhD thesis, Manchester Metropolitan University, 2003.
24. Murray CD, Sixsmith J. The corporeal body in virtual reality. Ethos 1999;27(3):315–343.
25. Young I. Throwing Like a Girl and Other Essays in Feminist Philosophy and Social Theory. Indiana: Indiana University Press, 1990.
26. Kaiser SB, Freeman CM, Wingate SB. Stigmata and negotiated outcomes: management of appearance by persons with physical disabilities. Deviant Behav 1985;6(2):205–224.
27. Kaiser SB, Wingate SB, Freeman CM, Chandler JL. Acceptance of physical disability and attitudes toward personal appearance. Rehabil Psychol 1987;32(1):51–58.
28. Kurzman SL. Cultural attitudes towards prostheses: an anthropological approach. Capabilities: Communicating the Science of Prosthetics and Orthotics 1997;6(4):3–5, 8.
29. Goffman E. Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, NJ: Prentice-Hall, 1963.
30. French L. The political economy of injury and compassion: Amputees on the Thai-Cambodia border. In: Csordas TJ, ed. Embodiment and Experience: The Existential Ground of Culture and Self. Cambridge: Cambridge University Press, 1994:69–99.
31. 31. Herschbach L. Prosthetic reconstructions: making the industry, re-making the body, modelling the nation. History Workshop J 1997;44:23–57.
32. Frank G. Life history model of adaptation to disability: the case of a "congenital amputee." Soc Sci Med 1984;19(6):639–645.
33. Frank G. On embodiment: a case of congenital limb deficiency in American culture. Culture Med Psychiatry 1986;10:189–219.
34. Frank G. Beyond stigma: visibility and self-empowerment of persons with congenital limb deficiencies. J Social Issues 1988;44(1):95–115.

35. Feinglass J, Rucker-Whitaker C, Lindquist L, McCarthy WJ, Pearce WH. Racial differences in primary and repeat lower extremity amputation: results from a multihospital study. J Vasc Surg 2005;41(5):823–829.
36. Young BA, Maynard C, Reiber G, Boyko EG. Effects of ethnicity and nephropathy on lower-extremity amputation risk among diabetic veterans. Diabetes Care 2003;26(2):495–501.
37. Dolezal JM, Vernick SH, Khan N, Lutz D, Tyndall C. Factors associated with use and nonuse of an AK prosthesis in a rural, southern, geriatric population. Int J Rehabil Health 1998;4(4):245–251.
38. Vernon A. The dialectics of multiple identities and the disabled people's movement. Disabil Soc 1999;14(3):385–398. 39.
39. Brough G, Miller I. Black amputee told: we only do feet in pink. Daily Mirror August 25, 2003

10

Osseoperception and Osseointegrated Prosthetic Limbs

Kerstin Hagberg, Eva Häggström, Stewe Jönsson,
Björn Rydevik, and Rickard Brånemark

Overview

The Method of Osseointegration

During the last decade, bone anchorage of prosthetic limbs has become a realistic alternative to socket prostheses for patients with amputations due to causes other than severe peripheral vascular disease. The theoretical advantages that could be assumed to exist with an artificial limb attached to the bone as an extension of the residual skeleton, were first described more than 20 years ago (1) and could be summarized as follows: a stable attachment of the prosthetic device with elimination of any movements of a socket, better proprioception due to the stable attachment directly to the bone; elimination of skin and pain problems related to a prosthetic socket; and a better potential to control the prosthetic limb. However, it is through recent clinical research that these advantages have become a reality for patients.

The first successful clinical applications of patients treated with bone-anchored amputation prostheses was by the use of the method of osseointegration (2). The discovery that implants made of commercially pure titanium could provide a stable anchorage for an implant in bone tissue was made by the Swedish Professor Per-Ingvar Brånemark, during the 1950s. This phenomenon was later named osseointegration (3). Since 1965 the method of osseointegration has been in successful clinical practice for dental applications (4,5) and to date there have been more than two million patients who have been treated with dental implants due to edentulousness worldwide. Currently the same method is, for example, also used for treatment with bone-anchored hearing aids, for anchorage of prostheses due to other defects in the head and neck area (6), for finger joint prostheses (7,8), and for thumb amputation prostheses (9).

Treatment with an osseointegrated (OI) transfemoral amputation prosthesis was performed for the very first time in 1990 in Sweden (2). Since then, the treatment has continued to be performed in Sweden and more recently also in the United Kingdom (10,11). Until today, most patients treated have had a transfemoral amputation, but individuals with amputations on the upper extremity, that is, transhumeral, transradial, and thumb amputations, have also been treated with OI prostheses. To date, more than 120 patients have been treated with OI prostheses worldwide, with most patients treated at the Sahlgrenska University Hospital in Gothenburg, Sweden.

The treatment includes two surgical sessions. At the first surgery (S1), a titanium implant (fixture) is inserted in the residual bone and left unloaded for 3 to 6 months. At the second surgery (S2), a titanium rod (abutment) is inserted into the distal end of the fixture and then penetrates out of the skin on the residual limb (Fig. 10.1). Prosthetic suspension is obtained by connecting the OI prosthesis to the abutment with a specific attachment device (Figs. 10.2 and 10.3). After the second surgery, the patient undergoes a period of rehabilitation. For

FIGURE 10.1. Photograph of the titanium abutment penetrating the skin of the residual limb. The patient has a transfemoral amputation and the photo is taken 10 weeks after the stage 2 surgery.

FIGURE 10.2. Photograph showing donning of a transfemoral osseointegrated (OI) prosthesis with an Allen key.

patients treated on the transfemoral or transhumeral amputation level, the period of rehabilitation is 4 to 6 months with gradually increased weight bearing and prosthetic activity (12). Thus, for those patients a total treatment period of approximately 12 months is normal. For patients with a transradial or thumb amputation the treatment period is shorter.

For most patients treated with OI prostheses several years have passed since the amputation and most have been supplied with several socket prostheses prior to the treatment. This means that most patients have a relatively established situation in relation to their disability when the treatment is performed. Moreover, most patients live far away from the hospital, in different parts of Sweden or other parts of Europe. This means that the treatment includes traveling to the Sahlgrenska University Hospital on several occasions during the treatment period. Except for the two surgery sessions, none of the visits lasts longer than a few days. During the rehabilitation, instructions for the training is given at outpatient visits, but the daily training is performed back home by the patient and, in some cases, with assistance by a therapist closer to home. In the same way, the OI prosthesis is supplied at the Department of Prosthetics and Orthotics at the Sahlgrenska University Hospital, but, in the long term, repairs and minor changes

FIGURE 10.3. Example of an OI prosthesis used by a patient with a transhumeral amputation level. The prosthesis has an attachment device and a myoelectric controlled hand in combination with a body-powered elbow, a so-called hybrid prosthetic type.

to it could be handled by a prosthetic workshop closer to home.

For patients provided with a bone-anchored prosthesis, there are some immediate and evident advantages compared with socket prostheses. These include easy and fast donning and doffing of the artificial limb, an artificial limb that fits properly every day, and no socket that is restricting the range of motion in the joint above the level of amputation. Patients treated with OI prostheses have also reported various kinds of new sensations in relation to their artificial limb and phantom limb. Several patients have reported a better feeling of control of their artificial limb and that they can now better identify what type of surface they stand or walk on, for example, asphalt, gravel, or grass. Another frequent comment is that the OI prosthesis feels more like a natural part of the body than did the socket prosthesis. Furthermore, new sensations related to the phantom limb have been reported. For instance, one woman with more than 30 years' experience of a socket prosthesis reported after 3 years of use of the OI prosthesis that she felt her phantom limb starting to slowly "grow" toward its normal length.

Osseoperception

We know today that patients with osseointegrated implants can identify tactile thresholds transmitted through the implant. The phenomenon is called osseoperception (3,13). Recently, a consensus statement defined the term *osseoperception* as "the mechanosensibility associated with osseointegrated implant rehabilitation," which was further defined as follows (14):

> (i) the sensation arising from mechanical stimulation of a bone-anchored prosthesis, transduced by mechanoreceptors that may include those located in muscle, joint, mucosal, cutaneous and periosteal tissues; together with (ii) a change in central neural processing in maintaining sensorimotor function.

The phenomenon of osseoperception was first identified with the benefit of improved sensory feedback for bite force and oral function for patients with osseointegrated implants in the edentulous jaw (15,16). Later work has further established the importance of osseoperception in dental sciences and recognized the pathways through which this mechanoreception occurs in the absence of a functional periodontal mechanoreceptive input (17,18). In the case of bone-anchored implants, there are histological, neurophysiological, and psychophysical evidence that it is likely that a proper peripheral feedback pathway can be restored by loading osseointegrated implants (19). Still, the underlying mechanism of the phenomenon of osseoperception is a matter of debate. Sensitive periodontal ligaments are lost after extraction of teeth, still the patients seem to function very well and can experience sensory perception, and patients with bone anchored amputation prostheses report that the prosthesis feels more like their own limb. Ysander et al. (20) have found an increase of neuropeptides around osseointegrated implants, for instance calcitonin gene-related peptide (CGRP). The physiological integration of implants appears to be of great importance for the patients in order to provide a more natural function. Osseoperception is vital for both improved prosthetic function as well as for reducing the feeling of being disabled for individuals treated with OI prostheses.

Review of the Evidence

Osseointegrated Prostheses and Health-Related Quality of Life: Results from a Prospective Study

Any evaluation of a new treatment should include evidence of its impact on health and quality of life. The concept of health-related quality of life (HRQoL) refers to those aspects of quality of life that could be supposed to be affected directly by a health condition and reflects patients' perceptions of their degree of physical, psychological, and social well-being. It is considered especially important to study the HRQoL in groups of patients with chronic conditions. Limb loss is a chronic condition and the OI prosthesis is a new treatment, which means that evaluation of HRQoL in this group of patients is very important.

In 1999, a prospective clinical investigation named OPRA (Osseointegrated Prosthesis for the Rehabilitation of Amputees), was started at the Sahlgrenska University Hospital in Gothenburg, Sweden, on patients treated with transfemoral OI prostheses. Inclusion criteria for the study are as follows: the patient has a transfemoral amputation, is experiencing problems using a socket prosthesis, has complete maturation of the skeleton and normal skeletal anatomy, is younger than 70 years of age, and qualifies for the surgery based on the medical and physical examination. Exclusion criteria are as follows: the patient has severe peripheral vascular disease with or without diabetes mellitus, is undergoing treatment with specific drugs (e.g., chemotherapy, corticosteroids), is overweight (about >100 kg), or is pregnant. The decision on patient selection is made by a team of professionals, including orthopedic surgeons, physiotherapists, and prosthetists. The OPRA protocol includes a wide range of assessments performed prior to S1 and at defined time points after S2 until the 2-year follow-up. The protocol includes objective measures such as radiography, registration of complications, hip range of motion, energy cost while walking, computerized gait analyses, and vibrametric analyses, as well as the subjective assessment of HRQoL.

The preferred format for assessment of HRQoL is a self-report questionnaire. There are two main types of HRQoL measures described in the literature: general measures and disease- or condition-specific measures (21). The general tool gives a broader perspective of the HRQoL and could be used on healthy persons as well as on persons with different kinds of health problem and it can be used for comparisons of different categories of patients. The condition-specific tool is designed for a targeted group of patients or conditions and gives a more detailed perspective of HRQoL for that specific group. One common piece of advice is to use both kinds of measure in order to best capture the overall situation and change in health due to an intervention. The assessment of the HRQoL within the OPRA study is with two self-report questionnaires: the general HRQoL is assessed with the Short-Form 36 Health Survey (SF-36) (22), and the condition-specific HRQoL is assessed with the Questionnaire for Persons with a Transfemoral Amputation (Q-TFA) (23).

The SF-36 is commonly used worldwide and has documented validity and reliability (22, 24). It gives results in eight separate scales and two summary component scores (physical component score and mental component score). The eight scales each represent a specific dimension of the HRQoL; physical functioning (PF), role functioning from a physical perspective (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role functioning from an emotional perspective (RE), and mental health (MH). The scores range from 0 to 100. A higher score represents better health.

The Q-TFA is a condition-specific outcome measure designed to reflect current prosthetic use, mobility, problems, and global health (23). It was designed for nonelderly persons using transfemoral prostheses and for studying the outcome when changing from socket prostheses to OI prostheses. Initial validity and reliability of the Q-TFA have been established on 156 individuals using socket prostheses (67% male, 33% female; mean age 51 years, range 20 to 70 years; mean years since amputation, 25 years, range 2 to 56 years). The results are presented in four scores: prosthetic use score, prosthetic mobility score, problem score, and global score, all with a range from 0–100. For individuals not using any prosthesis, the only score that could be presented is the prosthetic use score

TABLE 10.1. Details of the first 18 patients included in the OPRA study

Gender:	8 male, 10 female
Mean age at inclusion:	45 years (22 to 62)
Mean time since the amputation:	15 years (10 months to 33 years)
Amputation level:	Transfemoral:16 unilateral and 2 bilateral
Amputation cause:	12 trauma 5 tumor 1 arterial embolus
Prosthetic users at inclusion:	15/18

together with some single items, which could be reported even if no prosthesis is used at all (e.g., back pain, phantom limb pain, perception of the overall situation).

The study's initial results on HRQoL and prosthetic function have been analyzed for the first 18 consecutive patients treated (25). The characteristics of these 18 patients are listed in Table 10.1. At the 2-year follow-up, 17 of the 18 patients used the OI prosthesis with unrestricted weight bearing. One patient did not use it due to pain and later loosening of the implant. The results of the HRQoL showed improvements in the general physical HRQoL with statistically significant improvements in the SF-36 scales measuring PF, RP, BP, and the physical component score. There were no statistically significant differences in the other scales of the SF-36. The condition-specific HRQoL, as measured with the Q-TFA, was improved in all four scores with increased prosthetic use, better prosthetic mobility, fewer problems, and a better global situation reported after treatment (25). Some details of the results from the Q-TFA with regard to the amount of prosthetic use and reported problems preoperatively and at the 2-year follow-up are listed in Tables 10.2 and 10.3. These tables also list results for the 156 nonelderly patients with socket prostheses, taken from the study reporting on the measurement properties of the Q-TFA (23,26). The prospective comparison of the problem score (Table 10.3) is presented for the 14 cases that used a prosthesis at both occasions. A lower problem score indicates fewer problems. It is interesting to note the increase in prosthetic use and the decrease in socket-related problems reported, such as heat and perspiration, sores and skin irritation on the residual limb, and discomfort when sitting, among patients treated with OI prostheses (Tables 10.2 and 10.3).

Regarding problems not directly related to the prosthetic socket, such as back pain and phantom limb pain, the preliminary results do not indicate any clear improvement at 2-year follow-up. Our clinical experience is that for most patients the phantom limb pain is not affected by this treatment. Regarding low back pain, there are several aspects that we believe have the potential to reduce the pain problems in the long term, such as more

TABLE 10.2. Details of prosthetic use among 156 nonelderly individuals with a unilateral transfemoral amputation using socket prostheses, and the first 18 patients included in the OPRA study preoperative and at the 2-year follow-up

		OPRA study: preoperative	OPRA study: 2-year follow-up
Prosthetic use score	*n* = 156*	*n* = 18	*n* = 18
Mean (SD)	79 (25)	51 (42)	83 (27)
MD (min-max)	90 (2–100)	52 (0–100)	100 (0–100)
Of the users: % (*n*)**	*n* = 156	*n* = 15	*n* = 17
>15 h/day	31% (49)	27% (4)	53% (9)
13–15 h/day	35% (54)	20% (3)	18% (3)
10–12 h/day	11% (17)	6% (1)	18% (3)
<10 h/day	12% (19)	27% (4)	5.5% (1)
Not daily	11% (17)	20% (3)	5.5% (1)

∗ Prosthetic use was a criterion for inclusion.

∗∗ Details of prosthetic use for the number using prostheses.

Source: Hagberg et al. (25).

Table 10.3. Details of the problem score on the Questionnaire for Persons with a Transfemoral Amputation (Q-TFA), and the percentage of individuals reporting a selection of common problems related to the prosthesis and amputation among 156 nonelderly individuals with a unilateral transfemoral amputation using socket prostheses, and the first 18 patients included in the OPRA study preoperative and at the 2-year follow-up

		OPRA study: preoperative	OPRA study: 2-year follow-up
Problem score *	*n* = 156	*n* = 14	*n* = 14
Mean (SD)	34 (20)	39 (18)	18 (11)
MD (min-max)	30 (1–84)	41 (5–63)	18 (4–39)
Number with problems**: Heat/perspiration[a]	82%	87% (13/15)	18% (3/17)
Sores/skin irritation[a]	71%	53% (8/15)	6% (1/17)
Back pain	55%	44% (8/18)	39% (7/18)
Phantom limb pain	57%	44% (8/18)	44% (8/18)
Discomfort when sitting[a]	55%	80% (12/15)	12% (2/17)

* The problem score is reported for the 14 patients in the OPRA study who used a prosthesis both preoperatively and at follow-up. A lower score indicates fewer problems.

** Number reporting having had at least a moderate problem during the last 4 weeks. Heat and perspiration problems relate to last summer.

[a] Items requiring prosthetic use to be reported. Three patients did not use a prosthesis preoperatively, and one patient did not use a prosthesis at follow-up.

Source: Hagberg et al. (25).

equal limb length, free hip range of motion, increased physical activity, and a more normal sitting.

Results of Vibrametric Analyses

To analyze the osseoperception, vibratory stimuli transmitted through the osseointegrated implant are studied and such assessments are now part of the OPRA protocol. A vibratory test using a Békésy audiometer has previously been modified and evaluated on patients with carpal tunnel syndrome (27). Today the same method is also used for evaluations of various types of neuropathy (28).

The first experimental study, analyzing the osseoperception in orthopedic applications, to determine if passive stimuli applied to the implant could be detected or not, was performed on a small group of individuals with upper and lower limb amputations with comparisons with the intact limbs (29). Those initial tests suggested that the stable anchorage of the prosthesis by the implant improves the perception. When the mechanical stimulus was applied directly to the abutment, without wearing the prosthetic limb, the results showed even better sensations of vibration than when applied to the normal hand or to the OI prosthesis.

In a continuing study (30), the psychophysical detection threshold levels for mechanical stimulation of 32 individuals wearing prosthetic limbs on the upper and lower extremity (OI prosthesis, *n* = 17; socket prosthesis, *n* = 15) regarding pressure and vibratory stimulation applied to the prostheses were investigated. Again, the normal limb on the contralateral side was used as control. The same apparatus as in the experimental test was used and it could be described as being similar to a hearing test. At the assessment the individual places the foot or hand (or prosthetic foot or hand) on a box with a vibrating pin placed against it (Fig. 10.4). At first, the pin is vibrating with low amplitude and then the amplitude continuously rises. Patients are asked to press and hold a button as soon as they start to feel the vibration. When holding onto the button, the amplitude falls again,

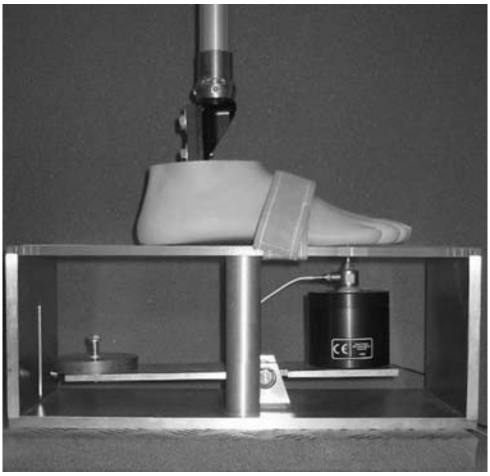

FIGURE 10.4. Illustration of the vibrametric test setup performed on a prosthetic foot.

and patients are asked to stop pressing the button when they can no longer detect any vibration. The vibration will in this way occur in different cycles and different frequencies.

The relative threshold levels for vibrotactile and pressure stimulation were expressed as the proportion to the threshold level of the control limb. The control limb was set at 1 (score = 1) and higher levels indicated an increased threshold level by scores greater than 1. The results showed that the detection of vibrotactile threshold was increased with an average of 20% for socket prostheses, but for patients treated with OI prostheses the threshold was close to the values of the control limb (score: 0.9–1.1). Analyses of pressure stimulation showed that the threshold was increased, with about 60% for socket prostheses and 40% for OI prostheses compared to the control limbs. While the OI prostheses yielded statistically significant lower threshold levels for the vibratory stimulation than the socket prostheses, there was no statistically significant difference between the groups in relation to the pressure stimulation (30). The results were similar for individuals with upper and lower limb amputations. This study showed that the detection thresholds for pressure and especially vibratory stimulation of prosthetic limbs generally are higher than for the control limbs, and that OI prostheses yielded better perception than did socket prostheses.

Discussion

Ongoing Research

The initial report (25) on the HRQoL improvements at 2-year follow-up indicates the great potential for treatment with OI prostheses for patients with transfemoral amputations. However, one must bear in mind that the results presented are still on a limited number of patients, and the outcome might be different when analyzing a larger group. Moreover, the 156 individuals with socket prostheses presented in Tables 10.2 and 10.3 have not been matched to be compared with the first 18 patients in the OPRA study. The OPRA study is still ongoing and the entire study and more detailed results will be reported in the coming years. Thus far, 43 patients with 47 implants (four treated bilaterally) have been included in the study. It will be interesting to analyze in greater detail the outcome on the larger number of patients in terms of the general and specific HRQoL, but also in terms of gait analyses, energy cost, and the important matter of complications associated with the treatment.

A study to investigate if there are any changes in the vibrotactile detection thresholds over time in patients with bone-anchored transfemoral prostheses compared to the contralateral limb and a control group is also ongoing. The assessments in the OI group are performed preoperatively and at 1-year and 2-year follow-up after the S2 surgery. The control group consists of patients with conventional socket prostheses, and they have been assessed at one point in time. The analysis was conducted with the same type of apparatus as the study by Jacobs et al. (30) placing the prosthetic or sound foot on the vibrating pin against the first metatarsal head. Differences in detection of thresholds are compared in the groups. A preliminary evaluation of the data indicates an increase in detection of ability of vibration by subjects with OI prosthesis compared to the preoperative data. The study also indicates that detection threshold for vibratory stimulation of OI prostheses improve over time.

Osseoperception and Improved Prosthetic Feedback

The phenomenon of osseoperception provides a natural feedback mechanism in itself. The sensorimotor interaction is an opportunity for physiological integration, and it might lead to greater acceptance of the prosthesis (19). Recent research from Lundborg et al. (31) has shown that tactile stimuli applied to an osseointegrated thumb prosthesis activated the somatosensory cortex of the brain, and the authors conclude that their findings suggest that osseoperception is based on an activation of the central nervous system. The method to measure sensibility of the hand based on cortical audiotactile interaction in this way had been tested earlier (32,33). The perception of vibrations can be utilized, for instance, for the creation of some kind of artificial sensory function of the prosthetic component. For example, upper limb prostheses can have thermal sensors built into the prosthetic fingers, and such sensors could be designed to generate vibration of different frequencies depending on the temperature. This is just an example of how it might be possible in the future to use osseoperception to create artificial sensation. A somewhat similar approach has been made by Lundborg et al. (32) to help patients with sensory defect in the hand to “feel” with “hearing” gloves.

Conclusion

The method of osseointegration is likely to become an important platform for new prosthetic technology, due to the stable fixation of the artificial limb. Ongoing research and development by different groups around the world can be expected to result in new technology platforms, and the phenomenon of osseoperception could make those platforms more usable. Already today osseointegration and osseoperception seem to improve quality of life (26), prosthetic control, and body image (31), probably due to activation of the somatosensory cortex in the central nervous system.

Summary of Key Points

Osseointegrated amputation prostheses can lead to the following:

- Improved health-related quality of life
- Improved prosthetic feedback
- Improvement of body image

Glossary

HRQoL: Health-related quality of life: The perception of an individual of his or her degree of physical, psychological, and social well-being, and the effects that illness and treatment have on daily life.

Osseointegration: “Direct anchorage of an implant by the formation of bony tissue around it without growth of fibrous tissue at the bone–implant interface” (3).

Osseoperception "(i) The sensation arising from mechanical stimulation of a bone-anchored prosthesis, transduced by mechanoreceptors that may include those located in muscle, joint, mucosal, cutaneous and periosteal tissues; together with (ii) a change in central neural processing in maintaining sensorimotor function” (14).

Vibrametric analysis: A diagnostic tool for sensory testing.

Further Reading

Additional information on the treatment with OI prostheses can be found at these Web sites:

www.sahlgrenska.se/su/osseointegration

www.integrum.se

Additional information on the SF-36 can be found at www.sf-36.org

The thesis by Hagberg (2006) can be found at http://hdl.handle.net/2077/726

References

1. Hall CW. A future prosthetic limb device. J Rehabil Res Dev 1985;22(3):99–102.
2. Branemark R, Branemark PI, Rydevik B, Myers RR. Osseointegration in skeletal reconstruction and rehabilitation: a review. J Rehabil Res Dev 2001;38(2):175–181.
3. Dorland WAN, Anderson DM. Dorland’s Illustrated Medical Dictionary, 30th ed. Philadelphia: Saunders; 2003.
4. Brånemark P-I, Hansson BO, Adell R, et al. Osseointegrated implants in the treatment of the edentulous jaw. Experience from a 10-year period. Stockholm: Almqvist & Wiksell International; 1977.

5. Brånemark P-I, ed. The Osseointegration Book: From Calvarium to Calcaneus. Berlin, Chicago: Quintessence; 2005.
6. Tjellström A. Osseointegrated systems and their applications in the head and neck. Adv Otolaryngol Head Neck Surg 1989(3):39–70.
7. Lundborg G, Branemark PI, Carlsson I. Metacarpophalangeal joint arthroplasty based on the osseointegration concept. J Hand Surg [Br] 1993;18(6): 693–703.
8. Moller K, Geijer M, Sollerman C, Lundborg G. Radiographic evaluation of osseointegration and loosening of titanium implants in the MCP and PIP joints. J Hand Surg [Am] 2004;29(1):32–38.
9. Lundborg G, Brånemark P-I, Rose´n B. Osseointegrated thumb prostheses: a concept for fixation of digit prosthetic devices. J Hand Surg 1996;21A:216–221.
10. Sullivan J, Uden M, Robinson KP, Sooriakumaran S. Rehabilitation of the transfemoral amputee with an osseointegrated prosthesis: the United Kingdom experience. Prosthet Orthot Int 2003;27: 114–120.
11. Robinson KP, Brånemark R, Ward D. Future developments: osseointegration in transfemoral amputees. In: Smith DG, Michael JW, Bowker JH, eds. Atlas of Amputations and Limb Deficiencies: Surgical, Prosthetic and Rehabilitation principles, 3rd ed. Rosemont, IL: American Academy of Orthopaedic Surgeons; 2004:673–681.
12. Hagberg K. Physiotherapy for patients having a trans-femoral amputation. In: Brånemark P-I, ed. The Osseointegration Book: From Calvarium to Calcaneus. Berlin, Chicago: Quintessence; 2005:477–487.
13. Rydevik B, Shubayev V, Myers R. Osseoperception. In: Brånmark P-I, ed. The Osseointegration Book: From Calvarium to Calcaneus. Berlin, Chicago: Quintessence; 2005:149–155.
14. Klineberg I, Calford MB, Dreher B, et al. A consensus statement on osseoperception. Clin Exp Pharmacol Physiol 2005;32(1–2):145–146.
15. Haraldson T, Carlsson GE. Bite force and oral function in patients with osseointegrated oral implants. Scand J Dent Res 1977;85(3):200–208.
16. Haraldson T, Carlsson GE, Ingervall B. Functional state, bite force and postural muscle activity in patients with osseointegrated oral implant bridges. Acta Odontol Scand 1979;37(4):195–206.
17. Klineberg I, Murray G. Osseoperception: sensory function and proprioception. Adv Dent Res 1999;13:120–129.
18. van Steenberghe D. From osseointegration to osseoperception. J Dent Res 2000;79(11):1833–1837.
19. Jacobs R, Van Steenberghe D. From osseoperception to implant-mediated sensory-motor interactions and related clinical implications. J Oral Rehabil 2006;33(4):282–292.
20. Ysander M, Branemark R, Olmarker K, Myers RR. Intramedullary osseointegration: development of a rodent model and study of histology and neuropeptide changes around titanium implants. J Rehabil Res Dev 2001;38(2):183–190.
21. Fayers PM, David M. Quality of Life: Assessment, Analysis and Interpretation. Chichester: Wiley; 2000.
22. Ware JE Jr, Sherbourne CD. The MOS 36–item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992;30(6):473–483.
23. Hagberg K, Brånemark R, Hägg O. Questionnaire for Persons with a Transfemoral Amputation (Q-TFA): initial validity and reliability of a new outcome measure. J Rehabil Res Dev 2004; 41(5):695–706.
24. Ware JE Jr, Kosinski M, Bayliss MS, McHorney CA, Rogers WH, Raczek A. Comparison of methods for the scoring and statistical analysis of SF-36 health profile and summary measures: summary of results from the Medical Outcomes Study. Med Care 1995;33(4 suppl):AS264–279.
25. Hagberg K, Brånemark R, Gunterberg B, Rydevik B. Osseointegrated trans-femoral amputation prostheses: Prospective results of general and condition-specific quality of life in 18 patients at 2-year follow-up. Prosthet Orthot Int. Accepted 2007.
26. Hagberg K. Transfemoral Amputation, Quality of Life and Prosthetic Function. Studies focusing on individuals with amputation due to reasons other than peripheral vascular disease, with socket and osseointegrated prostheses. Göteborg, Sweden: Göteborg University; 2006.
27. Lundborg G, Lie-Stenstrom AK, Sollerman C, Stromberg T, Pyykko I. Digital vibrogram: a new diagnostic tool for sensory testing in compression neuropathy. J Hand Surg [Am] 1986;11(5): 693–699.
28. Lundborg G, Dahlin LB, Lundstrom R, Necking LE, Stromberg T. Vibrotactile function of the hand in compression and vibration-induced neuropathy. Sensibility index—a new measure. Scand J Plast Reconstr Surg Hand Surg 1992;26(3):275–279.
29. Rydevik B. Amputation prostheses and osseoperception in the lower and upper extremity. In: Brånemark P-I, Rydevik B, Skalak R, eds. Osseointegration in Skeletal Reconstruction and Joint Replacement. Berlin, Chicago: Quintessence; 1994: 175–182.

30. Jacobs R, Branemark R, Olmarker K, Rydevik B, Van Steenberghe D, Branemark PI. Evaluation of the psychophysical detection threshold level for vibrotactile and pressure stimulation of prosthetic limbs using bone anchorage or soft tissue support. Prosthet Orthot Int 2000;24(2): 133–142.
31. Lundborg G, Waites A, Bjorkman A, Rosen B, Larsson EM. Functional magnetic resonance imaging shows cortical activation on sensory stimulation of an osseointegrated prosthetic thumb. Scand J Plast Reconstr Surg Hand Surg 2006;40(4):234–239.
32. Lundborg G, Bjorkman A, Hansson T, Nylander L, Nyman T, Rosen B. Artificial sensibility of the hand based on cortical audiotactile interaction: a study using functional magnetic resonance imaging. Scand J Plast Reconstr Surg Hand Surg 2005;39(6):370–372.
33. Hansson T, Brismar T. Tactile stimulation of the hand causes bilateral cortical activation: a functional magnetic resonance study in humans. Neurosci Lett 1999;271(1): 29–32.

11

Virtual and Augmented Reality, Phantom Experience, and Prosthetics

Jonathan Cole

Overview

After losing a limb, persistence of sensation of the limb, so-called phantom limb sensation, is normal. This can be a background awareness of that limb or more focused sensations of position, shape, and movement of the limb and of pins and needles, or warmth or cold. The feelings are embodied, owned, and so vivid that occasionally people try to walk on their phantom leg (1,2), or find the phantom arm gesturing.

Unfortunately, it is also normal to have phantom limb pain (PLP). Since its earliest descriptions (3,4) and its naming by Weir Mitchell (5,6), epidemiological studies have suggested that this pain occurs in 50% to 80% of people with amputations (7). The pain is chronic and intractable, and shows little evidence of improvement with time, although, fortunately, its low frequency and the short duration of attacks mean that it is not a severe problem for most individuals. However, such pain is felt by 66% of people with amputations at least 8 years after the amputation (8), and in a large survey phantoms were painful 25 years post-amputation, in 70% of people (9).

Descriptions of the pain are varied, from an unpleasant itching (which can, in extremis, be as unpleasant as pain itself), to severe burning, or clenching. Some say it is like their fingers are being squeezed in a vice, or a nail is being hammered through their hand or foot. The pain is felt most vividly in the feet, buttocks, and hands/fingers, with fewer reports of the thigh or forearm being involved. Therefore, it follows the known sensory representation of the extremities within the brain, with more brain area receiving input from the hands and fingers than from the arm itself. The pain can be continuous and unrelenting or come intermittently and severely.

Though this phantom limb pain has received much attention, it is really a form of a generic pain, which follows loss of a body part or functional disconnection of that body part with the brain. Thus this deafferentation pain is also experienced, as severely and as frequently as PLP, after spinal cord injury, where the body is obviously present but cannot be felt (10) and, say, brachial plexus lesions and thalamic stroke, where the arm remains but its nerves or central connections have been damaged.

This chapter considers theories regarding the role of visual and sensorimotor interactions and neuroplasticity in the genesis of this pain and the work such approaches have stimulated on a novel analgesic technique, involving virtual reality (VR) and augmented reality (AR). These new ideas have, in turn, allowed new ways of looking at the neural and cognitive mechanisms of pain and of perception in general. They may also allow for more effective management of phantom limb pain in the future, though claims for this treatment should be treated with caution.

The Pathogenesis of Phantom Limb Pain

The mechanism of pain following amputation remains largely unknown, but is likely to involve effects at many different levels of the nervous system (3,7). In addition to peripheral and central nervous system changes, changes occur in the brainstem, thalamus, and cortex, and there is also evidence for larger plastic changes in the representation of the amputated limb in sensory areas of the brain (11). Flor and colleagues (12) have evidence, moreover, that these plastic changes correlate with the emergence of phantom limb pain. Subjects with arm or hand amputations have a shift in sensory representation of the mouth areas into sensory cortex hand areas, and the larger this shift, the greater the phantom limb pain. Thus it is suggested that pain may develop as a result of maladaptive central nervous system plasticity (12). However, one must be cautious; it is by no means certain that PLP is a phenomenon confined solely to the sensory cortex, and there may be other plastic changes higher in the analysis pathways for pain. Nonetheless, this work has helped give an important impetus to work to reverse such plastic change.

Ramanchandran's Reflection

In the 1990s another influential idea in relation to PLP was published by Ramachandran et al. (13): "Despite a vast clinical literature on phantom limbs, there have been no experimental studies on the effect of vision on phantom sensations. We used a mirror to resurrect the phantom visually to explore intersensory effects." Their aim, therefore, may have been in relation to cross-sensory perception and theories of synesthesia rather than for a purely therapeutic role. "A tall mirror was placed vertically on the table, perpendicular to the patient's chest, so that he could see the mirror reflection of his normal hand 'superimposed' on the phantom. As the normal hand was moved the phantom hand was seen moving and was also felt to move with 'vivid kinaesthetic sensation.'"

This was in a sample of nine patients; six patients also had this sensation if they saw the experimenter's hand moving instead. Patients in the sample had not previously tried to move their phantoms themselves. Five patients also had painful involuntary spasms, which were "remarkably" relieved immediately on looking into the mirror and opening both hands, by which I presume the subjects had to make an effort to move both arms in some way, rather than merely watch passively. The authors explained their findings thus; "When motor commands are sent from the premotor and motor cortex to clench the hand, they are normally damped by error feedback from proprioception. In a phantom such damping is not possible, so the motor output is amplified further, and this outflow itself may be experienced as a painful spasm."

They authors did caution that double-blind experiments would be needed to confirm whether the effect is a specific consequence of visual feedback. The patients with an analgesic effect were all seen relatively soon after amputation, within 2 to 7 months, whereas others, who were seen longer since amputation, did not have the effect. Interestingly the authors found that touching the normal hand led to sensation of touch being felt in the phantom, but cold, pain, and heat could not be so referred.

In a more formal paper Ramachandran and Rogers-Ramachandran (14) further described the mechanisms for the effect they observed. They also showed their mirror box rather than a simple mirror alone (Fig. 11.1) and described how some patients experience vivid passive, involuntary movements of their phantom (fending off a blow for instance), while others cannot move their phantom at all, with it being frozen in one position. The latter may occur if the real arm was immobile for any time before amputation. They also described how patients can often move their phantoms immediately after amputation but that with time this ability fades. When the phantom is painful, they suggest that attempts to generate movements can actually increase the pain.

The authors' explanation was that motor cortex commands continue even without the arm, that these commands are monitored within the parietal lobes, and that, without sensory return from the limb, the motor commands become perceived as movements and pain. Learned paralysis occurs when motor commands are sent but the paralyzed

FIGURE 11.1. The mirror box illusion. (Courtesy of the Dublin Psychoprosthetics Group.)

arm remains still, with visual feedback of paralysis, so that the brain learns that the arm is fixed.

By asking patients to make mirror symmetrical movements, that is, move both existing and phantom arms with (mirror box) visual feedback of movement in the phantom, the authors suggested they had found a way of overcoming this learned paralysis. Ramachandran's work introduced a new way of looking at the pathogenesis and treatment of PLP, with visual replacement of the lost limb and with attempts to reduce pain by asking patients to move their phantom themselves. This was an audacious idea, which still, over 10 years later, both interests and challenges fellow neuroscientists.

Distraction and Virtual Reality

This original account had used mirrors in a simple box. But a more elegant method of presenting an absent limb to a subject might be to use a virtual one in VR. The use of VR for the treatment of pain has been pioneered by, among others, Hoffman's group in Seattle. They have employed VR for distraction in a number of situations including during burn wound care in adults and adolescents (15) and dental pain (16). They suggest that the stronger the illusion of entering the virtual world, the greater the analgesic effect (17). The virtual worlds were of a predetermined path through an icy three-dimensional (3D) virtual canyon, with subjects able to shoot virtual snowballs at snowmen, igloos, robots, and penguins.

Hoffman and colleagues suggest that the effect works through an attentional mechanism; humans have a limited amount of conscious attention and if it is diverted, for example to snowballing penguins, it is less able to focus on pain. They note that pain is a very "grabby" percept, and why VR immersion can overcome it remains to be determined. The reductions in pain found were around three to four points on a 10-point scale. These findings are important because Flor (3) has also suggested that similar reductions in pain, of 30% or so, can be explained on the basis of distraction alone. Such effects can be useful clinically, but also mean that any VR-induced effect must be greater than this to be due to more than distraction.

Manipulating Around the Phantom

Independently of mirror effects, the idea that plastic changes within the brain may be causally linked to the development of PLP has led a number of groups to attempt to manipulate sensation and movement of and around the phantom. Peripheral anesthesia has been shown to temporarily reduce PLP (18), though this is not a long-term treatment, and one must be careful to distinguish pain originating from the stump from central PLP.

If PLP has a relation to the loss of agency toward the missing limb, then one way to reduce or reverse this might be through a myoelectric prosthesis that patients move themselves via electromyography (EMG) signals picked up from muscles on the remaining stump. This was investigated by Flor's group (19) in 14 subjects with upper limb amputations. They found that there was a significant reduction in pain on a visual analogue scale (VAS) from 3.5–6 down to 0–4 (and to 0.7 in the last subject), if subjects were using the prosthesis up to 16 hours per day. Set against these findings, some pain reduction also occurred in those using it for far less time (or even, in one patient, not using it at all). With pain reduction cortical sensory plastic changes were also reduced. Clearly, further work is required. One should also be aware of how heavy and cumbersome such prostheses are, making them, as yet, impractical for some people.

Flor et al. (20) also used sensory discrimination tasks to see if enhancing sensory inputs from the stump penumbra can reduce plastic change consequent on deafferentation and reduce pain. They used a series of small electrodes to stimulate the stump skin for 90 minutes per day over 10 days. Progressive improvements in the sensory discrimination task (of which electrode was being stimulated and how intense) were correlated with reduced PLP. They concluded that alteration of the cortical reorganization by behavioral sensory manipulation might be possible.

Rather than enhancing sensory inputs, Giraux and Sirigu (21), ingeniously, gave their subjects illusory movements of the phantom limb. Three patients were asked to match movements of their phantom limb with various moving images of a limb, shown in a homologous position to their normal limb, displayed on a screen in front of them. After 8 weeks' training with three sessions per week and each involving 100 movements, two subjects reported significant reductions in pain, which was accompanied by increased activity in contralateral premotor cortex. Interestingly PLP increased when the displayed arm moved faster than the subjects could keep up with (matching it with illusory movement of their phantoms arms). The authors suggest that this visuomotor training might restore a coherent body image in motor cortex and so affect phantom pain.

Distraction via VR immersion can reduce pain, while either enhanced sensory input or illusory motor output can reduce PLP temporarily. After Ramachandran's demonstration that the mirror box has an effect during a bimanual task, several groups independently suggested that the use of virtual or augmented reality might reduce pain even more effectively.

Virtual and Augmented Reality Effects on Phantom Limb Pain

While some patients in Ramachandran's study found an analgesic effect from illusory movement when they viewed the moving mirror-reversed arm of a control subject passively, most required imagining their way into "moving" both arms. The sense of active, intentional, initiation of action is often called the sense of agency. The mirror box seemed to require this sense of agency.[1] Another, more technically complex but aesthetically purer, approach presented itself. Instead of using a mirror box, the examiner could present the arm to subjects in a VR environment, with the use of either a computer screen or a head-mounted display (HMD). The several groups that have begun this work have all taken slightly different approaches.

MacLachlan and the Dublin Psychoprosthetics Group made the point that a patient's phantom limb does not appear to them like a normal limb; it frequently is irregularly shaped and may have a thin forearm and a larger, more elaborated hand and fingers (22,23). The authors, therefore, developed an AR environment that simulates the mirror box. They represent the arm on a flat screen in 3D and then control it via a wireless data glove worn on the intact arm. As the intact arm moves, so the avatar follows with realistic finger and hand movements. This allows representation of various shapes of phantom limbs and enables the arms to move in the same direction rather than only mirror symmetrically, as in the mirror box. Nearly 90% of control subjects using the system felt a clear phantom sensation; 44% found the AR system preferable to the mirror box, which was in turn preferred by 28%.

Murray and Pettifer's group (24,25) from the University of Manchester has a slightly different approach. They have transposed movements made by subjects' remaining anatomical limb into movements of a virtual limb, which is presented in the phenomenal space of their phantom limb. Evidence from three subjects suggests that the system may be useful for phantom pain relief, though further work is required. The authors state:

> VR offers an opportunity to provide a visual representation of the amputee's whole body, including their phantom limb. Unlike the mirror box, which confines participants' limbs to a narrow spatial dimension, VR enables complex hand-eye coordination, and both fine and gross motor movements of the fingers, hand and arm, and toes, feet and legs. Users of such virtual limbs

---

[1] Interestingly, in a trial of hypnosis for PLP, Oakley et al. (46) found an analgesic effect during motor image tasks (move and take control of the phantom) and ipsative tasks (represent and then modify the presentation of pain to oneself), which may be a way to reduce general passivity toward the pain.

can engage in tasks made impossible by the mirror box, such as pegboard tasks, racket games, ball games, etc. It is hoped that such virtual environments will prove to be a therapeutic treatment for phantom limb pain, as well as aiding successful prosthesis use.

Our approach in Bournemouth has been along slightly different lines. When we were at the Johnson Space Center some years ago, we used the National Aeronautics and Space Administration (NASA's) DART (Dexterous Anthropomorphic Robotic Testbed) robot (26), which has robotic arms and hands so that when one is rigged up in position-sensitive gloves and position sensors, one follows one's own movements. Visual information about the robot's movements was fed back via a HMD from two cameras in a robotic head, which looked down on the robot arms from an appropriate viewpoint. One soon learned to move the robotic arms, fingers, and hands, slowly and accurately, seeing them in the HMD rather than seeing one's own arms. Within a minute or so one was hardly aware of doing this, and then imperceptibly, but remarkably, one felt embodied in the robot. One person thought that if he were to drop a mole wrench he was moving from (robot) hand to (robot) hand, it would land on his own real leg. What we see and what we move we inhabit and become embodied in. This led us to be less concerned about the appearance of a virtual arm, whatever the perceived phantom felt like (27).

We were also concerned that other VR systems, and the mirror box, required movement of the intact limb, but agency for both limbs; one was moved, but two were seen moving, and subjects had to imagine their way into moving both. Instead we have worked on a system in which the motion of the virtual arm was performed by the correct side of the subject's body, using a motion capture device placed on the subject's remaining body part, with the stump or most proximal remaining area (Fig. 11.2). We then made and presented a virtual arm to subjects that moved forward as the motion capture device signaled movement of their stump (Fig. 11.3).

A VR system allowed the user to perform a preset task, an animation of a virtual hand and arm picking up an apple from a table. The grasp animation had two parts, the reach toward the apple, and the grasp of the apple. After the grasp, the apple was held by the hand, and could be transported away from the table. When the arm was moved toward the table once more, the apple was released. The display was horizontally flipped to match the handedness of the user.

FIGURE 11.2. The Bournemouth phantom. A motion capture device is placed on the subject's right shoulder, which drives the movement of the virtual arm.

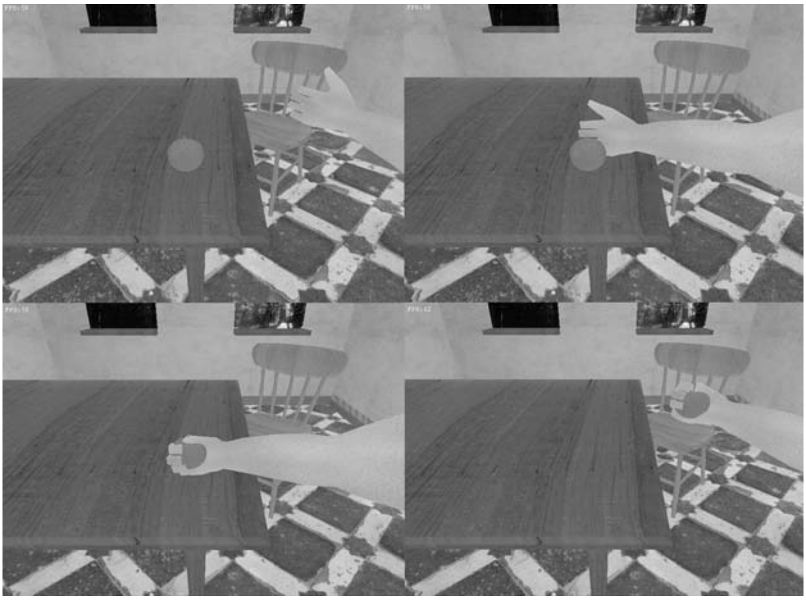

FIGURE 11.3. The Bournemouth phantom. Four positions of the virtual arm are shown as it moves to pick up the apple.

The virtual reach forward occurred as subjects moved their stump or shoulder forward and as the sensor moved closer to the transmitter, and vice versa. Motion of the virtual arm mimicked real motion of an arm to grasp an object. The VR animation had a similar speed to subjects' own movement and stopped if they stopped, thereby giving them a feeling of control.

Thus far we have tried this in preliminary studies on six patients with forelimb or forequarter amputations (28,29). Four of the six patients gained a sense of agency for the virtual arm, usually within half an hour. They commented on the difference between just seeing the avatar move and intending its movement, in terms of both the mental effort involved and the subsequent perception: "It is much heavier and needs more effort to move the virtual arm than just to move the avatar from the shoulder alone." This return of intention and execution of action often did not involve the whole arm at once. One patient who could move his arm but not all his fingers remarked, "When trying to move the hand, the fingers are stiff and seem to resist movement." With time, minutes to an hour or so, most patients "picked up" more parts of their arm and hand.

With this sense of agency also came distinct perceptions. One man, with severe PLP in the third ot fifth fingers and the elbow, described a new buzzing feeling in his first two fingers as he controlled the avatar when he made a grasp movement. Another could feel touch sensation when he picked up the apple. The sensations felt, therefore, were not only in relation to movement but also of exteroceptive touch, seeing the hand grasp an object.

With the sense of virtual agency and sensation, pain was reduced. One patient remarked, "Now, when I move the fingers, there is still pressure but there is no pain, they are not being ripped off or squashed." Another suggested, "When I move and feel the arm, it does not tingle; pain disappears into the background and merges into the movement sensation." The maximum reductions in pain during trials of virtual agency, on a visual analogue scale, were from 8–9 to 2 in three participants and from 4 to 0 in another. More results are required before the statistical significance of this finding can be ascertained. One patient's subjective report of experiencing virtual agency and analgesia is given as a timeline in Table 11.1. The capturing of the virtual arm's movement into the subject's own—the creation, or reemergence, of a sense of agency—required conscious effort and concentration.

TABLE 11.1. Timeline of one patient's experience of the virtual agency system: patient 5—agency and analgesia

Pain VAS	Time (min)	Phenomenology
4		Most of time before
4	0	
	10	"Novel feeling of moving the arm, hand still clenched"
0	20	"Can feel and move phantom arm and pain disappears into background"
	0	
0	15	"Can feel and move arm, can feel hand, joints and knuckles and skin in hand when grasping, elbow less. It moves quickly when I do"
0	30	"When trying to move, the fingers are stiff. I can feel the elbow coming from the stump and the hand on the end of it, but the two do not match up"
0	50	"The arm is now a gentle presence"

Virtual agency is tiring. Typically during a day's trial patients would develop agency within 30 minutes or so and then have several hours with pain reduction. The subject with the most rapid return of agency and embodiment had the shortest time since operation. The subject with the worst pain had periods of pain reduction during the procedure but, as he tired and found it difficult to concentrate on producing virtual agency, so his pain returned. There seemed to be a balance between pain and virtual embodiment, which depended, at least in part, on his ability to focus on motor agency. No carryover effects were described on stopping the trial.

Two subjects had no sense of agency, embodiment, or pain relief. One had not moved the limb for 5 years before it was amputated, the second had not moved her arm for 18 years before her amputation. This suggests a decay in intention with time, first described by Ramachandran (29) as "learned paralysis." Interestingly, one of these patients felt her phantom arm move in a mirror box, and being touched by her other one in the mirror. Her phantom also moved, from lap to mirror. But this movement remained passive; she did not develop a sense of agency either in the mirror or from our virtual system. If reproducible, this suggests that there may be different mechanisms for passive and active movement with agency with independent effects on analgesia.

Intriguing work in relation to this phantom paralysis has been done recently by Sirigu's group (30,31) in Lyon. The group began from the observation that phantom limb sensations persist despite plasticity within the sensory cortex, which leads to reduction in the sensory area represented by the bent arm. They found that using transcranial magnetic stimulation (TMS) over the sensory cortex led to conscious perception of the phantom and in some cases to perceptions of movement, even when the subject themselves was unable to move their phantom voluntarily. They concluded that the movements may remain embedded with their access reduced or denied.

They also showed that a different pattern of EMG activation at the stump occurred when subjects tried to move their stump or imagined moving their phantom. Therapies to reawaken agency toward the phantom might include TMS and that, if movement of the phantom does improve PLP, then such awakenings might allow for a reemergence of agency and analgesia.

Are New Theories for Sensorimotor Integration and Pain Required?

These observations in relation to PLP, though based on small numbers of patients, do require consideration of the underlying mechanisms of pain after deafferentation and of sensation associated with movement.

As we have seen, plastic changes in sensory areas of cortex do seem to be associated with the emergence of pain, and reductions in PLP, albeit temporarily, can occur with restoration of more normal cortical sensory maps. Even though it is not entirely clear that remapping in sensory cortex, per se, is the necessary condition for deafferentation pain, these results do allow us to think that there is a potential way to reverse this chronic pain.

The insight of Ramachandran, followed by others' observations with VR and AR systems, has allowed us to consider whether pain is purely a sensory deafferentation phenomenon. Rather, it seems, it involves a balance between efferent and afferent and motor and sensory systems. As Wall (32) suggested, perhaps pain is not simply a sensation but a need state, like thirst or hunger. Perhaps the need, in part, is for action.

And yet there are intriguing differences between the various new techniques. In Ramachandran's original studies, it appears that passive observation of movement by others might be effective in pain relief, so that movement of the intact arm at least might not be essential. The effects of use of a myoelectric prosthesis, sensory discrimination, and insertion of one's own agency within a moving, filmed arm all took several weeks of training, whereas an analgesic effect following virtually induced agency and use of the mirror box was seen within minutes. This suggests that either these two sorts of effects have different mechanisms, or that the more immersive methods are far more effective and fast inducers, possibly of agency and analgesia (presuming these two to be causally linked).

At the heart of these new observations are several new phenomena. First, visual feedback seems sufficient to allow pickup and movement of previous unmoved phantom limbs, in other words for the reemergence of agency. Not only do subjects see their limbs move as they intend them to, they can also feel the limbs move and feel touch in their seen, moved, virtual induced, arm.[2]

Some years ago Frith and colleagues (33) introduced an influential theory that found similarities between some phenomena in schizophrenia and others in motor control. They suggested that though much of what occurs in the motor system occurs without awareness, we are aware of some aspects of it. They also gave evidence that we can make and prepare movements in our imagination. Mental representations of actual and possible states of the motor system, they suggest, have two origins: sensory signals from the skin and muscles, and an awareness of motor commands sent to the effector organ by the brain. They suggest that abnormalities of the motor system can lead to abnormalities of action but also of awareness of action.

They explain how the brain has internal models of motor control. Two types of model are the predictors and controllers. Whenever a motor command is made, the predictor estimates the sensory consequences of that movement. The controller intervenes between the desired movement state, forward in time, and the motor command required to bring it about. It follows that three states are held within the system: the current one, the desired one, and the state predicted to get there. The predictors are forward models capturing the relationship between action and outcome. Each time a motor command is produced, an efferent copy of it is produced, which is used to estimate the sensory consequences of a movement that is used to anticipate and compensate for the sensory effects of movement, and it can filter predicted sensory information. There is some evidence that what we are aware of during some simple predictable movements is dependent more on motor outflow than on sensory inflow (34,35).

Frith and colleagues (33) suggest that there are several clinical syndromes dependent on abnormalities of function in these systems. In anarchic hand syndrome, the hand moves "of its own accord," say, to pick up a pencil. Here, with visual feedback of movement, but without conscious intention or agency, the patient interprets the hand as moving on its own.

To return to the phenomenon of phantom limb sensation (though not, for the moment, PLP), the authors consider the case of when patients are able to move their phantom and feel it move.[3] They

---

[2] I am being careful about the use of "virtual" in relation to these effects. One may see a virtual arm in an HMD or on a screen. But when one is in the immersed condition and feels that arm move and touch, say, an apple, then it may be virtually induced, but it seems to have become assimilated into the body image and so to be felt as though real. Similarly it makes little sense to talk about agency, the sense of intention and initiation of movement, in these experiments as being virtual; rather, it may be the fact that agency can only be real and embodied that produces the effect.

[3] It seems obvious that they need both to make an intentional action with the phantom and have the perception of this movement, but we do move our limbs without being aware of so doing, for example during gesture

suggest that in this situation the estimated position of the limb is based on incoming sensory information and on the stream of motor commands sent to the limb. With these commands the predictor can estimate a new limb position before sensory feedback and, since the sensory experience of a limb can be determined by this predicted state, it follows that during imagined movement there can arise a sensation of the limb. To explain the progressive loss of the ability to move the phantom with time after amputation, Frith et al. suggest that since there is no actual sensory input, the predictors will be modified to reduce discrepancies between intention and sensory experience, and the stream of motor commands themselves will reduce.

While intriguing, such theories do not quite explain the continuing experience of phantom limb sensation without movement, or the phenomenological reports that patients only very rarely say—that they are intentionally moving their phantoms. But the theories do allow an explanation of the return of voluntary movement shown by Ramachandran and others in the mirror box or during virtual agency. By providing visual feedback of a moving limb corresponding to the phantom, the subject has a strong illusion of the missing limb. This visual feedback from a limb, in the correct position, may allow updating of the predictors and so allow efferent copies of movement to be mapped onto what is seen in the mirror as the arm is moved. It seems that seeing movement allows the subsequent capture of intention for this movement. This theoretical account may be the beginning of an understanding of the phenomenon, but it is unlikely to be sufficient. Missing is the fact that this process does not seem to occur without attention toward it, that is, that it is a top-down phenomenon requiring effort and that it is tiring.

Implicit in such theories is that sensory perception is based on internal feed-forward, predicted, movement commands that require, at least in the acute experiments thus far, constant visual updating. Indeed, it is the constant visual return that seems necessary for the motor commands to map onto and so allow a sense of agency and intention and sensation (of both movement and of touch, suggesting a visual/tactile cross-modal interaction (36)). Such accounts do not explain why agency and motor commands toward a phantom limb can lead to analgesia, either.

Gallagher (37) has differentiated between a sense of agency, intending and executing an action, and a sense of ownership, the sense that one's own body experiences a certain sensation, either externally or self-generated through internal fed-forward commands. Following this work, Tsakiris and Haggard (38) have discussed the acting self, based on motor efferent processes, and a sensory self, based on passive afferent information from the periphery. Their concerns, which are slightly different from Frith et al.'s, are to provide evidence of how the acting self can modulate the sensory self's input. In an earlier experiment, for example, they showed that perception of a given movement was less intense when it was produced by a voluntary action than by an artificially induced movement, induced by TMS (39).

They have developed a model of an embodied agent showing, based on empirical data, interactions between motor efference and sensory, visual, and proprioceptive return, and the forward model and visual reafference. Perhaps visual feedback of movement allows the generation of intention and agency toward the visually induced limb, which, in turn, allows a re-emergence of proprioceptive and external cutaneous sensation in the phantom. In some way, unclear as yet, this also leads to reduction in the internally generated phantom limb pain.

Harris (40) suggested that the genesis of PLP was homologous to the way in which incongruent signals from vision and vestibular sensation lead to motion sickness. He suggests that incongruence or mismatch between intention, proprioception, and vision leads to pain. Pain or discomfort has also been reported in controls under conditions of sensorimotor and visual mismatch (41). But there are some concerns in such theories. It is not established that mismatch rather than overload in one sensory system underpins all motion sickness (J. Lackner, personal communication), and that incongruity is necessary for pain to emerge (42). Intention does not seem essential for the genesis of PLP, since it can occur in paralyzed phantoms. Also, all pains and all pain mechanisms may not be similar (43).

---

and walking. Occasionally, subjects say they feel their phantom move during gesture when that gesture was not consciously initiated.

These complex cognitive models seek to explain how motor commands may lead to perception, how sensory input can be modified by efferent motor output, and how mismatch between motor command and sensory feedback may lead to pain. They do not provide completely satisfactory answers to all the phenomena observed in PLP, but may provide a framework toward such an understanding and to the mechanism of effectiveness of virtual and mirror analgesia. Why PLP (assuming it is a single mechanism) arises remains unclear, at least to this author, while the precise mechanisms by which the newer virtual techniques may work (assuming they do in larger trials) are also unclear, whether they be a return of action to assuage pain as a need state (according to Wall), or a return of functional coherence (according to Sirigu), or an abolition of a mismatch between motor intention and sensory return, with pain a consequence of internal forward models unrestrained by peripheral feedback (according to Ramachandran). These models also approach PLP at a cognitive high level, rather than focusing on synaptic, cellular levels.

Conclusion

Ramachandran's initial results were both a breakthrough in the conceptual analysis of chronic deafferentation pain and an amazing piece of lateral thinking. It is disappointing, however, that controlled trials and long-term follow-up has not, as yet, been published in patients with forelimb amputations. This may be because patients with forelimb amputations and PLP appear quite difficult to enroll into such trials.

Far commoner are patients with amputations of the foot and leg (due to diabetes or ischemic vessel disease). One single case-controlled study has suggested that mirror box therapy can be useful in this situation (44), but one of the largest studies of mirror box therapy, a controlled trial with patients with leg amputations, did not find an effect in 80 patients (45). This should temper too great enthusiasm for this technique, although the leg may be less "grabby" than the arm, that is, less able to be focused on intentionally, thus contributing to these null results.

If agency toward and vision of the virtual limb leads to sensation of limb movement and even touch, then this might lead one to expect similar sensations during use of a prosthesis. That this is not widely reported may be because most prostheses are heavy and difficult to use, so that they are not incorporated into the subject's body image. It is fascinating that a prosthetic leg, for instance, which is far lighter than a real one, still feels heavy when put on, whereas we are never aware of the weight of our own leg normally. With better, lighter prostheses that are used without thought, one would expect the emergence of such sensations. One consequence of this work is that health care workers might encourage patients after amputation to try to continue to move their phantom as a way of avoiding the development of PLP. In contrast, some patients after amputation of the leg who feel able to move their missing limb find this can increase rather than decrease their pain.

There is an old adage that any device or equipment for rehabilitation should only be assessed outside the hospital or laboratory; it is only by seeing how much patients actually use something in everyday living can we truly know how useful it is to them. So there is an urgent need for assessment of whether patients use these new VR and AR systems at home in the long term. Ramachandran and Rogers-Ramachandran did describe one patient who had a carryover effect and who, over weeks, could generate voluntary movements in his phantom even without using the box, despite being 9 years since amputation. How common this is must be determined.

It is usually the case that new and experimental treatments are used on the most affected patients in whom other treatments have failed. In this case it means that clinicians may refer for mirror box or VR therapy when all other drug treatments have failed. But it seems to be those patients seen soon after amputation who find it easiest to pick up agency for their phantom limb and who achieve pain relief most easily. These treatments might be suited to people soon after amputation. It also suggests that trials might be undertaken prophylactically, before the onset of PLP in the first place. If agency can so be preserved despite loss of the limb, then maybe PLP would be less common or severe. Then there might also be greater carryover effect on pain when not in the system, and patients might find it easier to maintain agency without continuing visual feedback.

It is also unclear how long per day a patient might need immersion in such a system, and how the balance between analgesia and effort toward agency and pain and its return might be tipped. Similarly, in Ramachandran's original work he mentioned that cramping pain was relieved but that burning pain was not. Further studies are needed to see if there are differential effects on differing pains.

But the greatest need is for more studies on larger numbers of patients over longer periods of time. It is of concern that despite the enthusiasm of an increasing number of groups, numbers within published papers remain small. This chapter has provided some evidence for the effectiveness of these methods, temporarily, though reproducibly, in laboratory settings. Before such techniques can claim any efficacy larger, controlled longer duration trials are needed. The treatment of chronic pain has a long and not entirely honorable history, with many overblown claims for new treatments along the way. To avoid raising false hopes in patients, we need more rigorous trials on more patients over longer periods.

Glossary

Brachial plexus: Collection of sensory and movement nerves in the upper chest wall/shoulder area that supply and control this area and the arm, and connect between these areas and the spinal cord.

Brainstem: Part of the central nervous system between the spinal cord and the brain.

Deafferentation: Loss of sensory nerve input to the brain.

Kinesthesia: Perception of limb or body movement.

Myoelectric prosthesis: A motorized arm or leg with movements that are controlled by movements of the muscles of the stump.

Plasticity, neuro-: Slow changes in the brain seen after injury or learning; can be an advantage or the opposite, maladaptive.

Premotor: The brain has areas in the motor cortex that have connections through the spinal cord to muscles and that control movement. The premotor cortex lies in the brain just in front of the motor cortex and is involved in the planning and generation of motor commands and actions at a higher level, between intention and brain output.

Prophylactic: Treatment used before the onset of a medical problem to prevent its emergence.

Proprioception: The perception of movement or position of the limbs or body.

Sensorimotor: A term that by joining sensation and motor or movement reflects the way in which these two are closely related normally.

Synesthesia: Condition in which sensations are experiences in more than one sensory modality, so that tastes are perceived as spatial shapes, or words have colors.

Thalamus: Relay nucleus just under the cerebral cortex in the brain.

Transcranial magnetic stimulation (TMS): A noninvasive and easily tolerated method that uses magnetic fields to alter brain activity.

Acknowledgements

The author gratefully acknowledges the support of this work by a Wellcome Trust Showcase award.

Further Reading

The following Web sites report on research into VR and pain. The Washington site is concerned with work using VR as distraction; the other sites have information or links to VR and phantom limb pain.

www.hitl.washington.edu/projects/vrpain/
www.psych-sci.manchester.ac.uk/
www.tcd.ie/Psychoprosthetics/pages/publications.html
www.som.soton.ac.uk/research/neuro/CNS%20WEB/dr_jonathan_cole.htm

References

1. Hunter JP, Katz J, Davis KD. The effect of tactile and visual sensory inputs in phantom limb awareness. Brain 2003;126;579–589.
2. Kooijman CM. Djikstra PU, Geertzen JHB, Elzinga A and Van der Schans CP. Phantom pain and phantom sensation in upper limb amputees: an epidemiological study. Pain 2000;87;33–41.

3. Flor H. Phantom limb pain: characteristics, causes and treatment. Lancet 2002;1;182–189.
4. Halligan PW. Phantom limbs: the body in mind. Cogn Neuropsychol 2002;7;251–268.
5. Mitchell SW. Injuries of Nerves and Their Consequences. Philadelphia: Lippincott; 1872.
6. Mitchell SW. The Autobiography of a Quack: The Case of George Dedlow. New York: Century; 1900 (originally published in 1866).
7. Jensen TS, Rasmussen P. Phantom pain and other phenomena after amputation. In: Wall PD, Melzack R, eds. Textbook of Pain, 4th ed. Edinburgh and London: Churchill Livingstone; 1994;799–814.
8. Gallagher P, MacLachlan M. Amputation: a qualitative perspective. J Health Psychol 2001;6;85–100.
9. Sherman RA, Sherman CJ, and Parker L. Chronic phantom and stump pain amongst American veterans: results of a survey. Pain 1984;18;83–95.
10. Rose M, Robinson J, Ells J, Cole JD. Pain following spinal cord injury: results from a postal survey. Pain 1988;34;101–102.
11. Karl A, Birbaumer N, Lutzenberger W, Cohen LG and Flor H. Reorganisation of motor and somatosensory cortex un upper extremity amputees with phantom limb pain. J Neurosci 2001;21;3609–3618.
12. Flor H, Elbert T, Knecht S. Phantom limb pain as a perceptual correlate of cortical reorganisation following arm amputation. Nature 1995;357; 482–484.
13. Ramachandran VS, Ramachandran-Rogers D, Cobb S. Touching the phantom limb. Nature 1995;377;498–490.
14. Ramachandran VS, Rogers-Ramachandran D. Synaesthesia in phantom limbs induced with mirrors. Proc R Soc B 1996;263;377–386.
15. Hoffman HG, Doctor JN, Patterson DR, Carrougher GJ, Furness TA III. Virtual reality as an adjunct pain control during burn wound care in adolescent patients. Pain 2000;85;305–309.
16. Hoffman HG, Garcia-Palacios A, Patterson DR, Jensen M, Furness T 3rd, Ammons WF Jr. The effectiveness of virtual reality for dental pain control: a case control study. Cyberpsychol Behav 2001;4;527–535.
17. Hoffman HG, Sharar SR, Coda B, Everett JJ, Ciol M, Richards T, Patterson DR. Manipulating presence influences the magnitude of virtual reality analgesia. Pain 2004;111;162–168.
18. Birbaumer N, Lutzenburger W, Montoya P, et al. Effects of regional anaesthesia on phantom limb pain are mirrored in changes in cortical reorganisation. J Neurosci 1997;17;5503–5508.
19. Lotze M, Grodd W, Birbaumer N, Erb M, Huse E, Flor H. Does use of a myoelectric prosthesis prevent cortical reorganisation and phantom limb pain? Nature Neurosci 1999;2;501–5002.
20. Flor H, Denke C, Schaefer M, Grusser S. Effect of sensory discrimination training on cortical reorganisation and phantom limb pain. Lancet 2001;1; 1763–1764.
21. Giraux P, Sirigu A. Illusory movements of the paralysed limb restore motor cortex activity. NeuroImage 2003;20;S107–111.
22. Desmond DM, O'Neill, De Paor A, McDarby G, MacLachlan M. Augmenting the reality of phantom limbs: case studies of induced movement and constraint in the 'augmented mirror box' procedure. J Prosthet Orthot 2006;18(3):74–79.
23. Wright A, Halligan P, Kew J. Wellcome Sciart project, 1997.
24. Murray CD, Patchick EL, Caillette F, Howard T. Pettifer S. Can immersive virtual reality reduce phantom limb pain? Stud Health Technol Inform 2006;119;407–412.
25. Murray CD, Patchick E, Pettifer S, Caillette F, Howard T. Immersive virtual reality as a rehabilitative technology for phantom limb experience: a protocol. Cyberpsychol Behav 2006;9(2);167–170.
26. Cole J, Sacks O, Waterman I. On the immunity principle: a view from a robot. Trends Cogn Sci 2000;4(5):167.
27. Cole J, Austwick G, Dawson C, Zhang Z, Wynne R. Virtual agency and analgesia in phantom limb pain. Clin Neurophysiol 2006;117;S50.
28. Cole J, Austwick G, Dawson C, Zhang Z, Wynne R. Virtual agency, embodiment and analgesia in phantom limb pain. J Physiol Proc Phys Soc 2006;1;C20.
29. Ramachandran VS. Phantom limb, neglect syndromes, repressed memories and Freudian psychology. Int Rev Neurobiol 1994;37;291–333.
30. Reilly KT, Mercier C, Schieber MH, Sirigu A. Persistent hand motor commands in the amputees' brain. Brain 2006;129;8;2211–2223.
31. Mercier C, Reilly KT, Vargas CD, Aballea A, Sirigu A. Mapping phantom movement representations in the motor cortex of amputees. Brain 2006;129(8):2202–2210.
32. Wall P. Pain, The Science of Suffering. London: Weidenfeld and Nicholson, 1999.
33. Frith CD, Blakemore S-J, Wolpert D. Abnormalities in the awareness and control of action. Philos Trans R Soc Lond B 2000;355;1771–1788.
34. Fourneret P, Jeannerod M. Limited conscious monitoring of motor performance in normal subjects. Neuropsychologica 1998;36:1133–1140.

35. Blakemore S-J, Wolpert DM, Frith, CD. Central cancellation of self-produced tickle sensation. Nature Neurosci 1998;1:635–640.
36. Spence C, Driver J. Crossmodal Space and Crossmodal Attention. Oxford: Oxford University Press; 2004.
37. Gallagher S. Philosophical concepts of the self: implications for cognitive science. Trends Cogn Sci 2000;4;14–21.
38. Tsakiris M, Haggard P. Experimenting with the acting self. Cogn Neuropsychol 2005;22:;387–407.
39. Tsakiris M, Haggard P. Awareness of somatic events following a voluntary action. Exp Brain Res 2003;149;439–446.
40. Harris AJ. Cortical origin of pathological pain. Lancet 1999;354;1464–1466.
41. McCabe CS, Haigh RC, Halligan PW, Blake DR. Simulating sensory-motor incongruence in healthy volunteers: implications for a cortical model of pain. Rheumatology 2005;44(9):1083–1085.
42. Moseley GL, Gandevia SC. Sensory–motor incongruence and reports of ‘pain.’ Rheumatology 2005;44(9):1083–1085.
43. Apkarian AV. Functional magnetic resonance imaging of pain consciousness: cortical networks of pain critically depend on what is implied by “pain.” Curr Rev Pain 1999;3(4):;308–315.
44. MacLachlan M, McDonald D, Waloch J. Mirror treatment of lower limb phantom pain: a case study. Disabil Rehabil 2004;26(14–15): 901–904.
45. Brodie EE, Whyte A, Niven CA. Analgesia through the looking glass? A randomised controlled trial investigating the effect of viewing a ‘virtual’ limb upon phantom limb pain, sensation and movement. Eur J Pain 2007;11(4):428–436.
46. Oakley DA, Whitman LG, Halligan PW. Hypnotic imagery as a treatment for phantom limb pain: two case reports and a review. Clin Rehabil 2002;16;368–377.

12

Psychological Fit of a Prosthetic Arm: An Illustrative Case Study Using Repertory Grid Analysis with a User of a High-Tech Upper Limb Prosthesis

Sinéad Ní Mhurchadha, Elisabeth Schaffalitzky, Pamela Gallagher,
and Malcolm MacLachlan

Overview

Recently it has become clear that if rehabilitation professionals are to ensure the best possible match of prosthesis and user, it is imperative that they consider the person's psychosocial comfort with the prosthesis. For example, the loss of ability to relate psychologically, socially, sexually, and vocationally after amputation may have more impact on quality of life than the loss of the limb itself (1). Furthermore, Rybarczyk et al. (2) have noted that the physical aspects of a disability are much less important to the process of adaptation to disability than the psychological, developmental, and social environment, as well as the resources of the individual with the disability (see Chapter 3). Individuals may express dissatisfaction with their prosthesis as a form of denial or as an excuse for an inability to cope with the prosthesis and their impairment (3). Some 57% of those who admit to not using their prescribed prosthesis are "not at all" adapted to their prosthetic limb (4). Difficulties in adjustment and acceptance of an amputation are typically associated with reports of depression, low self-esteem, feelings of hopelessness, anxiety, fatigue, and in the extreme, suicidal ideation (5). Overall, although psychological acceptance of an amputation and its myriad of consequences is essential for the well-being of the person (6), it remains uncertain why some individuals adjust and grow psychosocially following amputation, whereas others do not (7,8).

Prosthetic technology is becoming increasingly sophisticated. For example, the development of energy-storing feet, electronic control hydraulic knees, ankle rotators, and shock absorbers have made an important impact in the field of prosthetics (9), along with prosthetic fitting techniques such as osseoimplantation (see Chapter 10). There have also been significant developments in upper limb prostheses, referring to the myoelectric and externally powered prostheses. The next important stage of development of the externally powered arm is incorporating the prosthesis into the nervous system. This will replace the need for microswitches, or pressure pads being operated through movements of the remaining musculature, and instead control could be achieved through directly wiring the prostheses into the nervous system (10). However, for innovative technology to be effectively incorporated into efforts to improve quality of life, it is imperative that the technology user's perspective is explored (11). Furthermore, as the costs of producing such technology are considerable, this poses a dilemma about whom to prescribe such technology to and who will benefit most from such technology?

In order for prosthetic users to be able to get the greatest benefit from their prosthetic limbs, it is important to understand how the use of such technology affects self-perception and perceptions of how the self relates to the broader social world (3,10,12). The "social meanings" of prosthetic use are the experiences and feelings, in relation to social occasions and relationships, of the person who is using the prosthetic and are concerned with the prosthetically enhanced body (13). In his qualitative research into the social meaning that upper and lower limb prosthesis users attach to their prosthetic devices, Murray (13) found that the negative responses of others to their prosthesis or their limb loss were of great social significance to individuals with amputations (see Chapter 9). These negative responses included intrusive as well as offensive behaviors and led many of them to avoid social contact, which Williamson et al. (14) have found to be associated with higher levels of depression. Similarly, Williamson (15) examined the withdrawal of elderly people from social life following amputation by measuring their restriction of normal activities (e.g., self-care, household chores, and visiting friends). Restriction of normal activities was found to be independently related to both above-knee amputation, which would be obvious due to the more restrictive nature of this amputation, and more interestingly, high public self-consciousness. These both predicted higher levels of vulnerability and feelings of being unable to defend oneself, which in turn predicted increased levels of activity restriction. This shows that prosthetic users may restrict their normal activities due to their fears about how society views them and reacts to them, which would in turn have an effect on their mobility and quality of life. In effect, then, psychological evaluations may mediate between physical impairments and psychological, social, and physical disability (16).

Participants in Murray's (13) study found that becoming skilled in impression management, such as using their prosthesis as well as clothing to hide their disability, helped them to avoid social stigma, and thus lessen social withdrawal. This suggests the ability of the prosthesis to conceal limb loss and prevent disability, which decreases stigmatization, enables social integration, and reduces the emotional problems that are associated with amputation. In fact, Murray found that the social role of the prosthesis played a greater role than the functional and cosmetic roles of the prosthesis in its use, with users choosing to wear their prosthesis even when they were not functional or cosmetic, or even comfortable.

Clearly, the social role of the prosthesis, and the psychosocial meanings attached to it, have an effect on the use of the prosthetic limb. But how do we identify and measure meanings? In particular, due to the expense of this technology, it is important to understand how the experience of using a high-tech prosthesis affects the perception of self within an individual and social context, and also how the prosthesis is viewed in relation to alternative prosthetic options.

Psychoprosthetics is both a research area and an important focus for clinical practice and so we now present, in summary form, a simple methodology for trying to understand better an individual's explicit and implicit values and how these interact with their prosthetic use. The methodology is highly collaborative and has the advantage of engaging the private knowledge of the participant and bringing this to their awareness, in a nonthreatening way.

Repertory Grid

A full description of repertory grid methodology and analysis is beyond the scope of this illustrative case study, and we recommend further reading at the end of this chapter for those who want more detail on it. The repertory grid technique was devised by George Kelly (17) as an assessment technique that elicits important constructs that individuals use to construe, evaluate, and anticipate events in their lives. The repertory grid is an idiographic measure and therefore is not concerned with comparing people with others or gathering information about large numbers of people; rather, it is concerned with identifying and exploring the distinctive qualities of a single person and identifying patterns in how he or she constructs meaning in relation to specific aspects of one's life. This technique can highlight a range of personal constructs, but it also allows a researcher to distinguish between more relevant core constructs and relatively superficial subordinate ones (18). The repertory grid, therefore, is a technique that allows its users to explore a system of personal constructs that reveal the way they organize their social world (19).

We are constantly construing and solving problems in our social world. How we make sense of our world depends on the kinds and range of constructs available to us. These personal constructs in turn create expectations about how we should behave in relation to others (20). Personal constructs are elicited directly from and are specific to the person studied. Kelly (17) argued that in order to understand people, we must do so in their own terms, which means identifying their personal constructs; otherwise, we run the risk of simply projecting our own thinking onto them (21). Repertory grids are thus often used to go beyond the obvious and provide a deeper insight to what someone understands in a given situation.

Methods

There are various ways in which constructs can be elicited. In this illustrative case study, constructs were elicited through the "difference method," in which the participant is given the names of three elements at a time (for example, the "ideal self," the "self as I am now," and the "self as others see me") and asked to identify "any way in which any two of these are alike in some way, yet different from the third." An element is a focus of the person's thoughts and each one relates to different but related aspects of the theme being explored. The way in which two of the elements are viewed as similar forms one pole of the construct, whereas the way in which the third one differs forms the contrast pole. A second set of three elements is then chosen and the procedure repeated, yielding a second construct dimension. This is continued until a full set of personal constructs, relating to the focus of the study, is elicited. Following completion of the construct elicitation phase, the participant is instructed to rate each of the elements, along each of the constructs, in a stepwise fashion (22). In the illustrative case study below, we used an 11-point rating scale (0 to 10) to indicate an element's ratings along the construct dimension.

Analyses

The analysis of a repertory grid can be undertaken in a number of ways. For example, it is possible to carry out correlation analyses between different elements and different constructs, to rank the elements and constructs, to provide a graphical representation using multidimensional scaling, or to eyeball the data. The latter, used in this illustrative case study, is particularly appropriate with individual case studies (23), as the grid is then explored and interpreted using the participant's own terms and language (24). This involves simply looking at the data and interpreting it without statistical analysis. This avoids wrongly interpreting the data by including subtle nuances that may be justified mathematically but are in fact not relevant in the context of the grid and the individual (25).

Illustrative Case Study

B.D. had his left arm amputated at the shoulder over 20 years ago. His first prosthetic was a myo-hand, which operated by means of a body-powered cable-operated elbow. B.D.'s high-tech prosthetic arm utilizes microchips, position-control circuits, miniature motors, gears, and pulleys. It rotates at the shoulder, bends at the elbow, rotates and twists at the wrist, and can grip using artificial fingers.

Repertory Grid for B.D.

Eleven elements were selected, by the interviewer (M.M.), in discussion with B.D., and these are reproduced in the first column of Table 12.1. The nine constructs that were elicited are reproduced in the first row of Table 12.1. Lower scores (on the 0 to 10 scale) reflect relatively stronger endorsement of the constructs in the first row, and relatively weaker endorsement of their polar opposites.

When looking at the repertory grid, we can see from a quick glance at the numbers what B.D. feels about his electric high tech prosthetic arm. While he believes that the arm is not greatly functional and is most definitely not living, he is fairly resigned to it, and believes that it is close to

TABLE 12.1. Repertory grid

	Best I can be	Morally OK	High acceptability	Contentment	Functional	Living	Ideal	Resignation	As good as it gets
My ideal self	0	0	0	0	0	0	0	0	0
Self as Iam now	0	0	3	2	5	4	8	1	0
Self as others see me	2	1	2	1	3	1	4	2	1
Electric arm	3	2	4	3	6	8	4	3	2
Intact arm	0	0	0	0	0	0	0	0	0
Own body	2	1	2	3	2	1	6	3	2
Mannequins	10	10	10	10	10	10	10	10	10
Cosmesis	10	10	10	10	10	10	10	10	10
Transplanted arm	9	7	8	9	2	0	7	7	10
Self before amputation	0	0	0	0	0	0	0	0	0
Self after first prosthesis	2	1	4	6	4	0	4	2	3

having what is "as good as it gets" in the prosthetic world. The "self as I am now" element also quickly offers some interesting insights. He sees himself as nowhere near the "ideal," but he is still resigned to the fact and accepts it. Furthermore, he displays a realistic outlook by rating himself as being the best that he can be right now and as good as it gets with a score of 0 in these particular constructs. This may be because, at the time of the interview, he was using some of the most sophisticated prosthetic technology available. His impression of how others see him is also quite informative. For example, he believes that others think he has more functionality than he thinks he does (which may arise from the fact that the arm looks very technical) and that they think the prosthesis he uses makes him closer to the ideal than he thinks it does. Thus it seems that other people tend to overestimate the functionality of the electric arm, at least compared to his experience of it.

Greater understanding of B.D.'s world can be achieved by comparing different elements for a slightly more in-depth and implicit analysis. For instance, the similarity of the mannequin and the cosmesis elements, being scored by BD the most negatively across all constructs, suggests that for BD the thought of wearing a cosmetic arm evokes the same emotional response as the thought of a shop mannequin—something completely without life or function. Such a response contrasts with those of others who see a cosmesis as allowing them to enter into a more valued social life, with diminished stigma and greater self-confidence. The issue is not, of course, which perspective is correct, but rather to appreciate how the prosthesis is interpreted by the user.

Another similarity that appears in the grid is that of the "ideal self" (which as would be expected has the strongest possible endorsement across each construct) and both of the "intact arm" and "self before amputation" elements, which also have the strongest endorsement for each construct. This indicates that the participant equates his self with an intact arm before the amputation with his perfect self, and this may be an unrealistic view of the self before the amputation. However, it also indicates that even with strenuous rehabilitative efforts, a return to his perceived preamputation "perfection" is virtually impossible, thus predisposing him to possible frustration.

The "intact arm" element, with scores indicative of the strongest endorsement on each construct, is in contrast with the electric arm element. This demonstrates how different the self with the prosthetic is now—no matter how good the prosthetic and what it offers—to the ideal self, before the amputation with an intact arm. It appears that no matter what kind of technology is provided, there will always be a discernible psychosocial difference between it and the ideal.

One comparison that is relevant for prosthetic technology is that the "self after first prosthesis" element can be compared with the "self as I am now" to show how the new prosthesis has retrospectively improved the participant's life. Certainly, he was less content with the first prosthesis, and feels that he is better off now than he was with the first prosthesis. He also believes that his current prosthesis is more advanced than the one he used to have, and this may explain why he's more resigned to it than to the first one. However, he sees his first prosthesis as more "living" than his current one, and even more of an ideal than the current arm. Most surprisingly, he rates his electric arm, and his self now, as less functional than with his first prosthesis, although this is only by 2 points and 1 point, respectively. This is interesting, as it appears that even though the electric arm is deemed less functional, he still believes it to have improved his life more than the first prosthesis did. Perhaps the promised heightened functionality of the arm or the fringe benefits of receiving cutting-edge technology such as the perceived status, attention, or additional opportunities are enough to find it more life improving.

It could be assumed that the prosthesis selected by this participant was chosen for functional reasons, as it is perhaps not as aesthetically pleasing as other cosmetic options, and this opinion is certainly reflected in the repertory grid. Yet interestingly, of the options that may be presented after amputation, B.D. sees the transplanted arm as being the most functional, yet he still sees it as being the worst type of replacement arm he could have, as denoted by his score on the "as good as it gets" construct. This shows that functionality is not the only salient issue, as he believes he would be hugely discontented with a transplanted arm, perhaps due to concerns about its morality. The inclusion of "unacceptability" and "morality" here are two constructs that appear to be related to society and show the influence of the social meanings attached to the transplanted arm. However, B.D. believes that having an arm transplant is still more acceptable than having a cosmesis, and also more morally sound than a cosmesis. This again highlights his disregard for cosmetic prostheses and what they achieve in comparison to functionality. This fits into how B.D. lives his life as he has no fear in showing his amputation, or his prostheses, which would potentially indicate that he has accepted his amputation well and does not appear to worry about the social acceptance and stigma that might arise from the amputation itself. This acceptance is also reflected in his high resignation to his self as it is now, as represented in the grid.

Similar to his rejection of the cosmesis, it can be noted that there are no aesthetic-related constructs. Considering that constructs reflect the way that a person views the world, his lack of aesthetics may reflect his lack of need for a prosthetic that is aesthetically pleasing, or even a lack of interest. However, this is a tentative assumption, as his constructs would be limited by the elements that were chosen to be put together for triadic elicitation.

The overall pattern of the repertory grid serves to indicate that while B.D. perceives improvements with the electric arm over other prostheses, and he is happy with using this prosthesis, there are some areas in which the electric arm cannot compete with an intact arm. Furthermore, overall satisfaction does not translate into satisfaction in each and every area. Finally, it seems likely that B.D.'s choice of an optimal prosthesis may not be a matter purely of functionality or appearance, or physical elements of the prosthesis, but that he is also aware of how he and others will react socially and psychologically toward the prosthesis. This highlights the importance of the psychosocial meanings that are attached to a particular prosthesis and how they can affect a prosthetic user's choice, and even use, of a prosthesis.

Conclusion and Future Directions

This chapter has sought to illustrate how a particular interview methodology can provide valuable insight into how people construct a view of themselves and their world, in relation to prosthetic use. Repertory grid methods, which can be used by a wide range of practitioners and researchers, provide a sort of psychological x-ray of the person–prosthetic fit. To realize the potential of prosthetic technologies and to prescribe prostheses that are appropriate to meet individual's needs, we must build on the physical science of prosthetic fitting, by developing an equally sophisticated psychological science of prosthetic fitting.

Summary of Key Points

- Prosthetic choice is not solely driven by the physical aspects of a prosthetic option, but also by the social meaning that an individual ascribes to it.
- Due to the expense of recently advanced prosthetic technology, it is important to understand how the experience of using a high-tech prosthesis affects the perception of self within an individual and social context, and also how the prosthesis is viewed in relation to alternative prosthetic options.
- The repertory grid is a simple methodology for trying to understand better an individual's explicit and implicit values and how these interact with their prosthetic use and choice.
- The repertory grid is highly collaborative and provides the participant, and the interviewer, with the opportunity to explore conscious and unconscious thoughts and feelings in a nonthreatening way and without the interviewers imposing their preconceived ideas on the interviewee. This methodology can provide valuable insight into how a person constructs a view of him- or herself and his or her world in relation to prosthetic use.
- We can improve the quality of life provided by the physical side of prosthetic fitting by taking into account the psychological and social factors that can be heavily influential on both prosthetic choice and prosthetic use.

Glossary

Construct: The quality attributed to the thought that discriminates it from other thoughts (e.g., angry-calm, encouraging-irritating).

Elements: An element is the object of a person's thoughts (e.g., a book, a shoe, a person).

Repertory grid: An assessment technique that elicits important constructs that individuals use to construe, evaluate, and anticipate events in their lives.

Social meaning: A shared understanding of an event or phenomenon, that reflects others aspects of people's shared values; in the present context, how people understand what the use of a prosthesis means about the person using it.

Triadic elicitation: Asking an individual to form a construct based on three elements.

Acknowledgements

We are most grateful to B.D. for his willingness to participate and the very constructive way in which he approached the interview. B.D.'s enthusiasm for and insights regarding prosthetic research and development have been a major impetus to our research group. {The letters B.D. are not his real initials.)

Further Reading

Gow D, MacLachlan M, Aird C. Reaching with electricity: externally powered prosthetics and embodiment. In: MacLachlan M, Gallagher P, eds. Enabling Technologies: Body Image and Body Function. Edinburgh: Churchill Livingstone; 2004.

Jankowicz D. The Easy Guide to Repertory Grids. London: John Wiley; 2004.

Kelly GA. The Psychology of Personal Constructs (vols. 1 and 2). New York: Norton; 1955.

MacLachlan M. Embodiment: Clinical, Critical and Cultural Perspectives on Health and Illness. Milton Keynes: Open University Press, 2004.

Murray C. The social meanings of prosthesis use. J Health Psychol 2005;10(3):425–441.

Neimeyer GJ, Bowman JZ, Saferstein J. The effects of elicitation techniques on repertory grid outcomes: differences, opposite and contrast methods. J Constructivist Psychol 2005;18:237–252.

References

1. Fitzpatrick M. The psychological assessment and psychosocial recovery of the patient with an amputation. Clin Orthop Rel Res 1999;361:98–107.
2. Rybarczyk B, Edwards R, Behal J. Diversity in adjustment to limb amputations: Case illustrations of common themes. Disabil Rehabil 2004;26: 944–953.
3. Gallagher P, MacLachlan M. Psychological adjustment and coping in adults with prosthetic limbs. Behav Med 1999;25:117–124.
4. Gauthier-Gagnon C, Grise M-C, Potvin D. Predisposing factors related to prosthetic use by people with a transtibial and transfemoral amputation. J Prosthet Orthot 1998;10:99–109.

5. Desmond D, MacLachlan M. Psychosocial issues in the field of prosthetics and orthotics. J Prosthet Orthot 2002;14:19–22.
6. Jacobsen JM. Nursing's role with amputee support groups. J Vasc Nurs 1998;16:31–34.
7. Oaksford K, Frude N, Cuddihy R. Positive coping and stress-related psychological growth following lower-limb amputation. Rehabil Psychol 2005;50:266–277.
8. MacLachlan M. Embodiment: Clinical, Critical and Cultural Perspectives on Health and Illness. Milton Keynes: Open University Press; 2004.
9. Esquenazi A. Amputation rehabilitation and prosthetic restoration. From surgery to community reintegration. Disabil Rehabil 2004;26(14/15): 831–836.
10. Gow D, MacLachlan M, Aird C. Reaching with electricity: externally powered prosthetics and embodiment. In: MacLachlan M, Gallagher P, eds. Enabling Technologies: Body Image and Body Function. Edinburgh: Churchill Livingstone; 2004.
11. Gallagher P, MacLachlan M. Thinking through enabling technologies: guidelines for development and implementation. In: MacLachlan M, Gallagher P, eds. Enabling Technologies: Body Image and Body Function. Edinburgh: Churchill Livingstone; 2004.
12. Gallagher P. Introduction to the special issue on psychosocial perspectives on amputation and prosthetics. Disabil Rehabil 2004;26(14/15): 827–830.
13. Murray CD. The social meanings of prosthesis use. J Health Psychol 2005;10(3):425–441.
14. Williamson GM, Schulz R, Bridges MW, Behan AM. Social and psychological factors in adjustment to limb amputation. J Social Behav Person 1994;9:249–268.
15. Williamson GM. Restrictions of normal activities among older adult amputees: the role of public self-consciousness. J Clin Geropsychol 1995;1: 229–242.
16. MacLachlan M, De Silva M, Devane D, et al. Psychosocial interventions for the prevention of disability following traumatic physical injury (Protocol). Cochrane Database Syst Rev 2007;1:CD006422.
17. Kelly GA. The psychology of personal constructs New York: Norton; 1955.
18. Hayes N. Doing Psychological Research: Gathering and Analysing Data. Buckingham: Open University Press; 2000.
19. Giles DC. Advanced Research Methods in Psychology. Sussex: Routledge; 2002.
20. Koch E. Personal constructs and psychodynamic psychotherapy: a case study. Psychoanal Psychol 2006;23(3):554–578.
21. Jankowicz D. The Easy Guide to Repertory Grids. London: John Wiley; 2004.
22. Neimeyer GJ, Bowman JZ, Saferstein J. The effects of elicitation techniques on repertory grid outcomes: differences, opposite and contrast methods. J Constructivist Psychol 2005;18:237–252.
23. Beaumont D. Exploring parental reactions to the diagnosis of cleft lip and palate. Paediatr Nurs 2006;18(3):14–29.
24. Melrose S, Shapiro B. Students' perceptions of their psychiatric mental health clinical nursing experience: a personal construct theory exploration. J Adv Nurs 1999;30(6):1451–1458.
25. Burr V, Butt T. Invitation to Personal Construct Psychology. London: Whurr; 1992.

Index