Psychoprosthetics
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Editors

Psychoprosthetics
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_
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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 (16). 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