

Social Indicators Research Series 52

Narelle Warren
Lenore Manderson *Editors*

Reframing Disability and Quality of Life

A Global Perspective

 Springer

Reframing Disability and Quality of Life

Social Indicators Research Series

Volume 52

General Editor:

ALEX C. MICHALOS

*Brandon University, Faculty of Arts Office
Brandon, Manitoba
Canada*

Editors:

ED DIENER

University of Illinois, Champaign, USA

WOLFGANG GLATZER

J.W. Goethe University, Frankfurt am Main, Germany

TORBJORN MOUM

University of Oslo, Norway

MIRJAM A.G. SPRANGERS

University of Amsterdam, The Netherlands

JOACHIM VOGEL

Central Bureau of Statistics, Stockholm, Sweden

RUUT VEENHOVEN

Erasmus University, Rotterdam, The Netherlands

This new series aims to provide a public forum for single treatises and collections of papers on social indicators research that are too long to be published in our journal *Social Indicators Research*. Like the journal, the book series deals with statistical assessments of the quality of life from a broad perspective. It welcomes the research on a wide variety of substantive areas, including health, crime, housing, education, family life, leisure activities, transportation, mobility, economics, work, religion and environmental issues. These areas of research will focus on the impact of key issues such as health on the overall quality of life and vice versa. An international review board, consisting of Ruut Veenhoven, Joachim Vogel, Ed Diener, Torbjorn Moum, Airjam A.G. Sprangers and Wolfgang Glatzer, will ensure the high quality of the series as a whole.

For further volumes:

<http://www.springer.com/series/6548>

Narelle Warren • Lenore Manderson
Editors

Reframing Disability and Quality of Life

A Global Perspective

 Springer

Editors

Narelle Warren
Social Science and Health Research Unit
School of Psychology and Psychiatry
Monash University
Caulfield East, Victoria, Australia

Lenore Manderson
Social Science and Health Research Unit
School of Psychology and Psychiatry
Monash University
Caulfield East, Victoria, Australia

ISBN 978-94-007-3017-5

ISBN 978-94-007-3018-2 (eBook)

DOI 10.1007/978-94-007-3018-2

Springer Dordrecht Heidelberg New York London

Library of Congress Control Number: 2013933238

© Springer Science+Business Media Dordrecht 2013

This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed. Exempted from this legal reservation are brief excerpts in connection with reviews or scholarly analysis or material supplied specifically for the purpose of being entered and executed on a computer system, for exclusive use by the purchaser of the work. Duplication of this publication or parts thereof is permitted only under the provisions of the Copyright Law of the Publisher's location, in its current version, and permission for use must always be obtained from Springer. Permissions for use may be obtained through RightsLink at the Copyright Clearance Center. Violations are liable to prosecution under the respective Copyright Law.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

While the advice and information in this book are believed to be true and accurate at the date of publication, neither the authors nor the editors nor the publisher can accept any legal responsibility for any errors or omissions that may be made. The publisher makes no warranty, express or implied, with respect to the material contained herein.

Printed on acid-free paper

Springer is part of Springer Science+Business Media (www.springer.com)

Foreword

A small but growing number of volumes, written primarily by anthropologists, describe the international conceptualization and experience of disability using the construction of quality of life as an organizing thread. Quality of life is a concept rooted particularly in health science fields, reflecting their desire to treat health in terms of well-being, not just the absence of disease. Medical anthropology has always recognized that well-being is culturally constructed, yet we know little of how this variation is interpreted in different settings, or the implications of this for people with variable bodies. This book makes a significant contribution to this literature, skillfully edited to appeal broadly to researchers in the health sciences as well as anthropology.

The book will also find an audience in disability studies, although this is not its stated purpose. Nussbaum's capability approach is debated in disability studies as a bridging model between disability studies and health sciences. Disability studies and the health sciences have an uneasy partnership. Disability studies scholars describe a 'medical model' of disability as a contrasting foil for various sociocultural, political, economic, environmental, and humanities-based models of disability. The essence of the medical model is its placement of the problem (a specific perceived health state, for instance) in the individual, albeit with growing recognition of all the contextual parameters. So too the medical model, as described by disability studies, places ameliorative strategies in the individual or in the immediate context of the individual. This is the practical reality of the clinical health sciences. The clash of perspectives between clinical and social justice approaches is common and may add vitality to both fields.

But it is only with the development of disability-related legislation and academic disability studies, and particularly disability policy studies, that medical anthropologists have started to tease out subtle differences between the concepts of illness and disease, suffering and well-being, of abled or capable, and disabled or functionally limited. The ethnographic literature, where this book belongs, has become increasingly sophisticated in its lack of assumptions: not only specific to disability but also that impairment, whatever its physiological signs, behave as cultural universals.

The most direct medical model foil for disability studies is rehabilitation science and occupational therapy. The community-based rehabilitation movement and occupational therapy without borders are perhaps the best practical attempts to bridge this gap in the delivery of direct services to individuals in local settings and context. The contributions by the authors in this book will further inform these immediate efforts. At the same time, they join others' work in gathering a critical mass of evidence that structural change on a population level is necessary to affect true disability social justice.

The creation of voluntary associations of and for people who experience disability, as described by Renne in Nigeria or Edwards in Guatemala, is another important contribution to the ethnography of how disability is structured in society. One legacy of colonialism is an assumption that there is no complex indigenous social structure pertaining to disability and that the role of offering support must be filled by some external NGO. This is one more example of how the complexity of disability is too often ignored. If this book does nothing but lead students to grasp the complexity of disability studies cross-culturally, it is well worth our promotional effort. Disability cannot be understood only by attempts to measure functional limitation, any better than quality of life can be understood by measures on Likert scales. The very concept of relating and rating experience on a bidirectional scale may not resonate in other cultures. As Renne illustrates, quality of life can be lost in translation into Hausa.

Analytical complexity also comes from the way disability impacts and is impacted by events in multiple domains of life. Tracking these interrelationships exposes when and how a critical mass of variant experience of impairment becomes disability, as it creates some indigenous sense of difference in self-identity and/or identification by others that researchers recognize as disability. The disability rights movement, at its core, is about assuming competence. Many make this a basic ethical tenet in research, for example, in research on autism, particularly with people who do not speak. Without this as a guide, any other ethical discussion – decisions to abort, to not treat, or to euthanize, for example – become even more controversial. Many of us, even those of us with long-term disability experience, have gone through periods of thinking “*Well, I'm glad I can see, hear, think, speak...*” or whatever other function/capability we most fear losing. Whether it is aphasia or locked-in syndrome, any suggestion that consciousness is not a basic need for any human quality of life is shocking. The human in the coma is not without value. But consciousness, the ability to love and to worship God, is a description of humanity in the Hebrew bible that permeates all the Abrahamic traditions. Stephen Hawking is the iconic figure of someone with huge value to society and to himself, where quality of life is completely merged with quality of thought. What constitutes a better quality of life, locked-in syndrome misdiagnosed as coma, or real coma? The literature from disability studies would be useful here. Arguments abound around genetics and selective abortion. In making sense of these quandaries, we need to ask: How are health professionals being trained?

Not all of these essays engage the disability studies literature on the topics covered. However, the book will receive a significant and appreciative disability studies

audience. Disability studies folks will read the international articles with great interest and will interpret the conclusions of the articles that come from a more health science perspective with a disability insider's eye. The medical literature is replete with a belief that quality of life is concrete and able to be quantified, but this approach is not unknown also in disability studies. This book helps critique the quality of life literature in a contextual and situational way that is useful to disability studies as it is to other fields concerned with health and well-being.

Constantinou's use of 'social disability' in this volume is interesting. In disability studies terms, it sounds almost an oxymoron, making it – to borrow from Mary Douglas – good to think. All disability is socially constructed; the emphasis in disability studies is usually on the effect not the cause, and in fact, the experience of social exclusion in part defines all experience of disability. The term 'social disability', in isolation, conjures an image of a diagnosis or impairment such as autism, wherein the primary symptoms are evident in social interaction. The phrase might also mark some extreme social exclusion not based on any distinct functional limitation, such as that experienced by twins in some African cultures or by people with severe facial disfigurement. Kidney failure is clearly a failure of the body, an experience of physical impairment. But rather than the physical cause, its impact on social functioning is what is marked. A physical impairment may result in deafness; the result is the experience of disability in the realm of communication, a communication disability. My own physical impairments, which are genetic, most people would describe as physical disability. I would more likely say, however, that my experience of disability, because of my real and perceived embodied differences, occurs mostly in the realms of mobility and speech. The impact on my life occurs in social realms as disparate as kinship and religion. The very essence of my social experience creates my self-identity as disabled. Perhaps, adding Wainer's ideas of the permeability of the body and of dignity would help here.

All of the essays in this volume dance around the definition of disability, and I do love to dance. This book provides plenty of rhythm.

Eureka, California
August 2012

Devva Kasnitz

Acknowledgements

For over 10 years, we have worked together on aspects of chronic illness and disability and have been surprised by the lack of anthropology relative to other methodological approaches. This has resulted in too few studies which foreground context and which illustrate how health status and the risks and consequences of illness are shaped by life circumstances and the broader local and global environment. Economics, politics, society, family, household structure, and cultural understandings of illness and well-being result in very different ways of preventing and managing injury and disease and in accommodating the lives of people who have been most affected by them.

Our frustration was marked as we explored the impact of ongoing conditions on quality of life. We were frustrated by the limits of the measurement tools available to assess this and the lack of qualitative research providing empirical support for the summary outcomes gained from psychometric measurement. One way to redress this was to invite medical anthropologists and other qualitative health researchers to reflect on and question the underlying precepts of quality of life and to consider the significance of context on such conditions – aphasia, locked-in syndrome, spinal cord injury, and so on. Intentionally, we have not differentiated between ‘disability’ and ‘chronic conditions’, nor between injury, noncommunicable and communicable diseases. Rather, our focus is on chronicity and its associated disablement, regardless of cause. The result of our invitation – the chapters in this volume – is a selection of richly nuanced studies that elucidate cultural and social influences that shape health choices and outcomes.

We thank the Australian Research Council, the National Health and Medical Research Council, The University of Melbourne, and Monash University for financial and institutional assistance. From the International Society for Quality of Life Studies (ISQOLS), we thank particularly Ralph Kober and Alex Michalos. We sincerely thank our authors for their commitment, and thank Myriam Poort and Miranda Dijkman from Springer for their recognition of the value of qualitative perspectives on quality of life.

Lenore thanks Pat Galvin for his continuing good humor and loving support. Narelle wishes to thank Brad and Hugo Wilkinson for their care and love and Silas for tracking the book through pregnancy, birth and infancy.

August 2012

Narelle Warren
Lenore Manderson

Contents

1 Reframing Disability and Quality of Life: Contextual Nuances	1
Narelle Warren and Lenore Manderson	
2 Uncertainty, Vulnerability, and Isolation: Factors Framing Quality of Life with Aphasia in a South African Township	17
Carol Legg and Claire Penn	
3 Disability and Well-Being in Northern Nigeria	39
Elisha P. Renne	
4 The Dignity of Children: How to Evaluate Bodies' (Im)Permeability	61
Rafael Wainer	
5 Who, How, and What? Quality of Life and Psychosocial Cancer Research	79
Helle Ploug Hansen and Tine Tjørnhøj-Thomsen	
6 Quality of Life and End-of-Life Decisions After Brain Injury	95
Athena Demertzi, Olivia Gosseries, Didier Ledoux, Steven Laureys, and Marie-Aurélie Bruno	
7 Transforming Social Disability into Normality: Medical Discourses on Kidney Transplantation in Cyprus	111
Costas S. Constantinou	
8 Spinal Cord Injury, Sport, and the Narrative Possibilities of Posttraumatic Growth	129
Andrew C. Sparkes and Brett Smith	
9 Narrating a Return to Work After Spinal Cord Injury	145
Carolyn Smith-Morris, Gilberto Lopez, Lisa Ottomanelli, and Lance Goetz	

10 Sports, Disability, and the Reframing of the Post-injury Soldier 163
Seth D. Messinger

**11 “Caring for” and “Caring About”: Embedded Interdependence
and Quality of Life 179**
Lenore Manderson and Narelle Warren

**12 Disability and Caregivers’ Inability Among Immigrant
Australians 195**
Victoria Team and Milica Markovic

**13 The Impact of Government on Quality of Life for People
with Disabilities in the United States and Guatemala 211**
Erica Skogebo McFadden

About the Authors..... 233

Index..... 239

List of Figures

Fig. 2.1	Map of Khayelitsha and surrounding townships.....	21
Fig. 2.2	A typical street scene in Khayelitsha	22
Fig. 2.3	New housing development	23
Fig. 3.1	Kungiyar Guragu Zazzau meeting in Zaria City, Sunday, 4 July 2009. Two of the older men are titled officers of the group; the man on the left is the Sarkin Kungiyar Guragu Zazzau, while the older man on the right is the Magajin Gari Dan Yaro. The young boy has just received an adapted tricycle (<i>keke guragu</i>) given to him by the group	44
Fig. 3.2	The Kaduna State Rehabilitation Centre Board workshop where <i>keke guragu</i> are constructed	52
Fig. 3.3	Lame-disabled students attending the secondary school, Al Huda Huda College in Zaria City, with Musa Muhammed (wearing cap), an alumnus of the college.....	54
Fig. 6.1	Various pathological modulations of consciousness defined by the correlation between wakefulness and awareness. The locked-in syndrome is not a disorder of consciousness, but is mentioned here as it can be misdiagnosed as one	97
Fig. 6.2	Short Form-36 (SF-36) self-rated quality of general health status in chronic locked-in patients as compared to healthy age-matched French controls	102
Fig. 6.3	Distribution of Anamnestic Comparative Self-Assessment ratings in locked-in syndrome.....	103

List of Tables

Table 6.1	Locked-in patients' memoirs and popular literature.....	96
Table 6.2	Quality of life studies with locked-in syndrome patients	100
Table 13.1	Consequences of the expert/charity models in contrast to the social model of disability	214

Chapter 1

Reframing Disability and Quality of Life: Contextual Nuances

Narelle Warren and Lenore Manderson

Nearly four decades ago, Mildred Blaxter observed that “disability, like sickness, is a relative concept which is difficult to define objectively” (1976: 207). Answers to questions about the degree of disablement, she argued, depended on a range of factors, including “perception, identification, cultural concepts of normality, social and family environment and individual factors of personality, as well as on clinical ‘facts’” (p. 207). These factors have significant implications in terms of examining quality of life in the context of disability and highlight the significance of social and cultural context.

Regardless of country setting, level of income, and industrialization, at national and international levels, we aspire for all people to enjoy good quality of life. At individual levels, we measure our own and others’ lives in terms of “quality”; understandings of what “quality” is vary between people. We associate good health with good quality of life; thus, poor health, disease, and disability are correlated with poor quality of life. Policy decisions are made on this basis, with resources allocated to support access to medications for pain relief, for example. Likewise, programs and services are developed to enhance people’s quality of life by maximizing their opportunities to participate fully in social, cultural, and economic life. We evaluate suffering in terms of poor quality of life, and decisions regarding the management of conditions that may negatively impact well-being are frequently couched in these terms.

Chronic and degenerative diseases, the long-term side effects of various diseases, and physical impairments are assumed to have adverse effects psychologically, socially, and economically, and accordingly, any “disability” is seen in a negative light. Some of the physical conditions included in this category – polio, cerebral palsy, impairments following measles infection – have declined in prevalence as a

N. Warren (✉) • L. Manderson
School of Psychology and Psychiatry, Monash University,
900 Dandenong Road, Caulfield East, VIC 3145, Australia
e-mail: Narelle.Warren@monash.edu; Lenore.Manderson@monash.edu

result of immunization programs, early successful interventions, prenatal diagnosis, and changes in pharmaceuticals, medical technology, and surgery. But many conditions have increased due to the same increased effectiveness of interventions and consequent greater longevity. Hence, quality of life has become an increasing concern, guiding decision making and practice in relation to clinical work, research, policy, and service provision for people whose health is compromised, who have physical or cognitive limitations, who are frail and aged, or who, for other reasons, require support in everyday living.

The chapters in this volume speak to the capabilities approach, as articulated, with variation, by Amartya Sen (1987) and Martha Nussbaum (2002, 2005; Clark 2006). Sen's work was aimed at the difficulty of making cross-cultural assessments of the quality of life, not through instrumentation to capture subjective evaluation, but by differentiating capability and function and by drawing out the rights of people to maximize capability. Quality of life is thus understood in terms of how people live their lives with the resources available to them. This extends beyond economic and financial resources and includes sociocultural, psychological, environmental, and interpersonal resources. For example, access to a wheelchair supports a person's ability to move around their community – and thus their social engagement and participation – only if there are suitable roads or paths; having a wheelchair when the community is built around the sandy tracks found in many rural settings, or clay soil that is readily muddy after rains, is unlikely to enhance quality of life in a significant way.

Nussbaum (2002, 2005) extends this argument while challenging any cultural relativist stance that might serve as an apology for restrictions on living and life choice for people who have functional impairment. Her work on social justice, as related to people living with mental disabilities, among others, addresses their as-yet-unrealized right to social equality (Nussbaum 2006). This speaks to the theoretical basis of quality of life: the conceptualization of quality of life influences how people perceive or experience it. Where quality of life is considered differently for different groups, there is a risk that “high” quality of life for people with disabilities is perceived as equates to the everyday existence, accompanied by neither high nor low perceived quality of life, for those without (Cummins 1997, 2005). Accordingly, quality of life and its assessment are ethical issues; the idea of “quality of life,” and the notion that this is tangible and measurable, shapes both the use of interventions to improve life and their use at the end of life.

Measurement and Quality of Life

Quality of life research undertaken with people living with a disability to date has relied heavily on quantitative instrumentation, whether intended to collect information of subjective aspects, such as personal perceptions of well-being and life satisfaction, or on objective dimensions (Cummins 2005). These are based on fundamental assumptions about shared aspects of human experience: in particular, that physical

functioning and capacity, as well as mental or emotional states, are experienced and valued in universally concrete ways, that such experiences are measurable, and that measurement has the same meanings and interpretations in all places (Herdman et al. 1997). In these instruments, functioning and disability are often positioned in opposition: the “positive” concept of functioning incorporates “functional and structural integrity” and “activities [and] participation” while the “negative” concept of disability is associated with “impairment... activity limitation [and] participation restriction” (World Health Organization 2001: 11). Thus, the instrumentation used to assess health, well-being, and quality of life as applied to people with disabilities of any kind primarily relates to physical functioning and capability, although many quality of life scales also consider mental or emotional dimensions of experience.

Quantitative instruments are undoubtedly important in gaining an understanding of the ways in which health conditions or disablement impact upon people’s well-being, physical functioning, mental and emotional health, and social participation, thereby foreshadowing how and in what ways governments and other social institutions can develop targeted strategies to improve people’s life circumstances. The assessments derived from these are helpful in identifying a person’s progress through self-management of a chronic condition or rehabilitation, the domains in which the limitations they may encounter occur, and the level of medical and social care required; the data collected assists in the long-term planning for individual patients, by identifying the needs to be fulfilled. Quality of life data also provides useful information for the longer-term measurement of how individuals are “travelling,” insofar as they include not only physical and mental functioning but also incorporate – to differing extents depending on the instrument used – social dimensions, such as social participation or isolation, access to support, and ability to mobilize resources. However, many commonly used quality of life instruments, such as the Medical Outcomes Study Short Form-36 (SF-36; Ware and Sherbourne 1992), EQ-5D (Nord 1991), and the Quality of Well-Being Scale (QWB-SA; Kaplan et al. 1998), do not measure quality of life, but, rather, measure various aspects of disease or condition impact or well-being (as discussed by World Health Organization 1996).

Quality of life instruments are constructed on the assumption that context plays a limited, if any, role in shaping people’s perceptions of quality of life and that people report on such measures in the same way, regardless of cultural setting or environment. The international application and validation of these measures alone is often a justification for the “goodness” of the instrumentation, and, as a result, these instruments are widely used across populations to plan services and environmental design (such as access to public transport depots), design health-care interventions, assess clinical outcomes, and shape policies related to the delivery of health care. As a result, notwithstanding significant contextual differences associated with infrastructure and health systems across countries, the instrumentation to assess quality of life is used internationally, and little attention is given to the relevance of context to peoples’ performance on such measures or on how this is influenced by the social, political, cultural, or economic environment in which they live.

However, given the influence that quality of life assessments have on people's lives, and the likelihood of contextual variance between settings, the World Health Organization in 1991 recognized the need for an internationally comparable, cross-culturally relevant quality of life instrument. This instrument, it was argued, needed to incorporate not only people's subjective satisfaction with their life and its circumstances but also to account for contextual and personal factors (World Health Organization 1996). After a series of consultations with international collaborators, quality of life was thus defined as "an individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization 1996: 5). The WHOQOL-100 and WHOQOL-BREF were subsequently developed, along with other instruments that attempt to capture the complexity of people's experiences. The Personal Well-Being Index, for example, is an 8-item scale that constructs well-being as related to satisfaction with domains of life: standard of living, health, achievements in life, relationships, personal safety, community connectedness, feelings of future security, and spirituality (International Wellbeing Group 2006).

Quality of life and disability are assessed to allow cross-country and societal comparisons, but often, the data collected through the instrumentation fail to capture the underlying inequalities that exist within and between countries (Bhui and Dinos 2008) or how the local cultural, economic, social, and political contexts profoundly shape people's lived experiences. By using a validated measure, it is possible to argue for similar quality of life outcomes for a person who has post-polio syndrome in, for instance, the Netherlands or Australia, and Rwanda or Ghana; yet, there is very little meaningful comparability between such lives. Allotey et al. (2003) and Reidpath et al. (2003) highlight that people may have conditions that rate similarly on objective, fixed measures of disablement (in their work, the DALY [Disability Adjusted Life Years]). But they point out that people in wealthy, well-resourced, and developed countries (Australia and the UK) experience conditions such as paraplegia as far less disabling than inexperienced by people in poorer, developing contexts (Cameroon and Niger), despite returning similar scores. Such research emphasizes the social production of disability and highlights the artificiality of categorizing quality of life outcomes by "types" of disability. We need a much better understanding of the material, structural, and attitudinal contexts in which disability occurs and people with disability live.

Questions about the nature of quality of life also remain in need of further elaboration: quality of life measures provide insights and indicate variance, but are unable to elucidate the "why" questions. For example, older residents of a Kenyan slum reported high quality of life scores, with participants' scores associated with sex, age, education, and marital status (Kyobutungi et al. 2010); however, the mechanisms through which this occurs are influenced by context, including gender relations, access to resources, and social status; these cannot be explored through instrumentation alone. Similarly, while the majority of Americans (five in six) ageing with disabilities reported high quality of life (Yorkston et al. 2010), in-depth exploration is needed to understand how and why they do so.

Thinking About Physical Disabilities and Quality of Life: Some Considerations

Researchers and policymakers both recognize enormous regional and international differences that make comparison problematic unless the criteria sit above such differences, hence the attraction of quality of life measures. Quality of life, after all, involves a personal judgment made by an individual about the life that they live: performance on measurement is tied to their experiences, evaluations, and expectations. When responding to the items, people's responses are shaped by their age, social and geographic location, socioeconomic status, and workforce participation and by the trajectory of their disability or disablement; they are also influenced by other health issues that impact on their everyday lives (e.g., the presence of clinical or subclinical mental illness) and discourses of disability (Phillips 1990). They are shaped too by respondents' own understandings of their comparative quality of life: how they feel on the day of questioning, for instance, compared with how they recall they felt a day earlier; how they assess their status compared with what they understand could be certain health problems, outcomes, and limits to function; and how they consider their health in contrast with other people with similar status (Clavarino 1999; Beadle et al. 2004). Hendry and McVittie (2004), for example, have argued that most instruments are unable to capture older people's understandings or conceptualizations of quality of life because they have lived with poor health for many years; such instruments are unable to reflect changes within their health, for example, when very poor health became worse and so fail to represent their experiences (see also Mallinson 2002, 1998; Warren et al. 2009).

People answer questions in terms that are meaningful for them. Yet the results are problematic when subjective assessments are reduced to a quantitative response without full consideration or further interpretation. In this book, we look behind and beyond quantitative responses about quality of life, to explore the sociocultural preconditions and mechanisms that shape people's experience of quality of life when they experience disablement, either as a result of injury or in the context of chronic illness.

Without thoughtful consideration of contexts – and in some cases, extensive and intense differences – the responses of participants to questionnaires on quality of life may appear puzzling or nonsensical. This has been the case in disability research, resulting in the emergence of the “disability paradox” (Albrecht and Devlieger 1999), where people with disabilities consistently report high quality of life, despite living a life that others perceive as characterized by hardships and, thus, as undesirable. Disablement is not always unexpected: older people or people with degenerative conditions often expect disablement as part of their life trajectory; they anticipate ill-health events would occur (Faircloth et al. 2004). Processes of adaptation and accommodation also cannot be discounted: as time elapses since a disability was “acquired,” it becomes mundane, practical hurdles are overcome, and everydayness increases (see Warren 2009). Clarke and Black (2005) highlight adaptability here. Disabling conditions often appear, in the immediate term, to disrupt the meanings

people give to their lives, their everyday existence, and how they imagine their future and so also reduce their quality of life. But as they adapt to their changed body and existence, quality of life improves (Manderson 2011). The mundaneness of living with a disability also may go some way to explaining why people with congenital disabilities experience high quality of life – for them, stasis includes their disability; it is a constant feature of their existence and so unlikely to profoundly impact their quality of life.

These ideas go some way to explaining why some people with disabilities may do well despite major physical limitations, while others with higher levels of physical functioning and capacity may do less well for a range of social, psychological, emotional, contextual, and other reasons. In a study with people who had had a lower limb amputation, for instance, we found that people who had recently had an amputation, within the previous 3 months, reported mental health scores equivalent to the wider Australian population and much higher than people with either depression or type 2 diabetes, despite almost all describing the emotional trauma they experienced as a result of the loss of their leg(s) (Warren et al. 2009).

As suggested above, people's evaluation of their quality of life, following the onset of a chronic or disabling condition, shifts as they adapt to their changed circumstances. One explanation for our findings is offered by Gill and Kurland (2003) who posit that disablement in older people is dynamic – they encounter condition-related disability, then recover or adapt; as time passes, they encounter other, new forms of disablement and the process continues. Following this, amputation was, for our participants, just another moment in a series of health disruptions and disablement. An alternative, albeit related, explanation is offered by Sprangers and Schwartz (1999) who argue that people have an “inherent” need to feel good about their lives, and so chronically ill or disabled people shift their values, standards, and conceptualizations of quality of life to maintain their perceived level of good quality of life.

Assessing Quality of Life: The Contribution of Ethnography

Ultimately, however, quality of life scores alone do not describe or account for all of the factors that may influence people's experience of quality of life in the context of disability, as the three following cases from our research with lower-limb amputees (Warren et al. 2009; Manderson and Warren 2010; Warren and Manderson 2008) illustrate. Qualitative research methods are designed to explore the factors that underlie responses on surveys, in the context of this volume, to elicit from respondents the reasons for their performance on different measures of quality of life or to gain insight into how people explain particular circumstances and find meaning in life circumstances. But because of the way in which the wider environment affects individual well-being, adaptation, and social engagement, we find ethnography especially, with its particular attention to “thick description” (Geertz 1973), to offer an epistemological and methodological approach to help unravel the complexities of

human behavior and everyday life. To illustrate how this shapes our understanding of people's experiences, we draw on our own research and three case studies which illustrate the way in which an ethnographic approach, and qualitative methods, enriches our understanding of disability and quality of life.

Our research on living with a lower limb amputated included ethnographic research, conducted primarily by Warren over a 2-year period at four rehabilitation centers (hospitals), during which time we met people who became study participants, met family members, and observed, interviewed, and occasionally worked with physiotherapists, nurses, rehabilitation consultants, and prosthetists. We also interviewed family members and peer support volunteers. These data provided us with rich contextual information in addition to 60 primary interviews conducted with men and women who had lost a lower limb, and of these, we followed ten participants on two or more occasions, 6–9 months after the first interview, to evaluate their accommodation to amputation over time. The three men, whose experiences we describe below, yielded similar scores on the SF-36; in this, a score of 50 is the population average or population norm. Our participants' physical component summary score, evaluating physical health based on the eight subscales that comprise the SF-36, ranged from 20.1 to 23.8, and their mental component summary scores, which took into account emotional and social functioning, as well as variables related to fatigue, vigor, and energy levels, ranged from 51.1 to 53. Given the temporal proximity (within past 3 months) of their amputation, their physical component scores, indicating that the amputation significantly impacted their quality of life, were not unexpected. Two of the men, who we call Max and Warwick, had nearly identical scores. Below, we present the stories of their amputations; in doing so, we demonstrate how, although their SF-36 scores provide a lens for understanding how amputation affected their quality of life, these scores are unable to account for the individual variations in circumstances that not only shaped how they experienced their amputation but also what factors would determine their recovery from amputation.

Max (aged 67 years), who experienced an above-knee amputation, had experienced multiple complex conditions that resulted from a history of smoking-related vascular (blood vessel) problems. His amputation was unexpected, however: after falling one night while turning out his kitchen light before bed, Max presented to his doctor, who became concerned about a swelling that appeared on his leg and would not heal. Surgeons discovered impaired blood flow to his right leg and attempted to save his leg by performing a bypass operation on one of his femoral arteries; this was unsuccessful and led to him developing compression sores which ultimately became gangrenous. He described how the smell of the infection "made you sick... [like] rotting flesh. Doesn't do much for your self-confidence." An amputation was therefore his only option. Max's amputation was complicated: 3 years previously, he had a stroke on the right hand of his body which left his hip permanently constricted, so that his leg bent at an angle of 30° to his body; he was unable to straighten his hip without considerable pain and effort. However, he explained that his right leg "had been useless for years," and he had long needed a walking stick.

Max's health significantly impacted upon his ability to move around, both inside his home and in the community. Following the stroke, he could still walk

(slowly) with his walking stick, but despite assurances pre-amputation that he would continue to be able to walk following the amputation, he was completely reliant on his wheelchair at the time of our interview, about a month after his surgery. He was also unable to drive after the amputation; while his car could have been modified to facilitate this, he did not have the financial resources to do so as he lived on a limited age pension provided by the Australian Government (\$AU459.00 per person per fortnight) compared with the average income of \$AU1288 (Australian Bureau of Statistics 2007). Regardless of his financial situation – and although it meant he was no longer actively involved in a war veterans association, which he had previously enjoyed – however, Max did not anticipate driving again: “It’s not important to me anymore.”

Max’s quality of life was further affected by his social circumstances. He lived in a small unit with his wife, Sylvia. His amputation left him extremely dependent on her: he was unable to leave his home without her assistance to carry him down the four steps to exit the premises. This was not an insignificant task: Sylvia was very petite. In consequence, although she maintained some social contact with family members and friends, Max’s social network consisted primarily of Sylvia. When questioned about what he did each day, Max replied “I mean it’s pretty much the same things I did before, like I have a bet on the phone, I read, I read the papers, I have a drink with dinner at night.” In talking about his daily life, he recognized that this was unlikely to change dramatically, and, as demonstrated by his participation in the veterans’ association, he would likely become more isolated as his health worsened. This suggested that while his physical situation was worsened by his amputation, the emotional, mental, and social aspects of his life were unaffected by his amputation; therefore, his SF-36 scores were unsurprising.

In contrast, Warwick (aged 72 years) underwent a below-knee amputation 6 years after his above-knee amputation. Despite having diabetes and impaired blood flow to his feet, which had led to his first amputation, Warwick was certain that he had been bitten by a white-tailed spider and that his amputation resulted from its medical mismanagement and poor hygiene practices (see Manderson and Warren 2012), which had resulted in a serious infection. As a result, he was extremely angry at his treating hospital and the medical and nursing staff, who he felt had not acted in his best interests. After recounting the story of his amputation, another reason for his anger emerged: Warwick was a wealthy, self-funded retiree who had made significant donations to the treating hospital, and he had funded the purchase of specific medical equipment. In light of this, he could not understand why his medical care had not been of higher quality.

Independence, the primary goal of rehabilitation, was very important to Warwick. Prior to his most recent amputation, he had used a computer-operated above-knee prosthesis (a C-leg™; see www.ottobockknees.com), which provided stability as well as mobility. Four days prior to our interview, he had received his below-knee prosthesis and had taken brief walks between rails in the amputee gym (see Warren and Manderson 2008); he also spent most of the remainder of his time doing strength-building exercising. In addition, while in the rehabilitation hospital, he

chose to manage his own self-care – particularly bathing and transferring between his bed and wheelchair – without the assistance of nursing staff:

I wheel myself in the bathroom, go to the toilet and I have me shower. Come out. I push myself up to the sink. I have my towel sitting there. I dry myself and put my PJs [pajamas] on before I come out of there, so I don't give them [nurses] a shock or they don't start chasing me for one thing or another., I am really supporting myself because I know when I go home I have got to do it. I haven't got any nurses or anything like that to do it for me.

His desire for independence and statement that he would be responsible for those tasks when he was discharged was interesting in light of his social circumstances: Warwick was married and lived with his adult data. In contrast to Max, who relied on his wife Sylvia to assist with his self-care tasks as well as the household tasks, Warwick's family largely left him alone: his wife and daughter went on vacation while he was in hospital, and they, with his son, each visited occasionally:

Well [my] son comes in and [wife and daughter] come in occasionally. I haven't seen the wife, Friday she was here and she hasn't been in [since]. The daughter had been in Sunday. She comes in sometimes only to go to the vending machine, buy a bottle of coke and a packet of chips, and come around here and eat it in front of me.

Through being able to afford technological innovations – such as the C-Leg – Warwick was able to imagine a future in which he saw a return to high levels of independent functioning, a necessity in his life given the nature of his familial relationships. While socioeconomic status, gender relations, and themes of dependence and independence were explored by Max and Warwick, Hugh described his emotional responses to the amputation and the experience of being an inpatient.

Hugh was a 79-year-old widower living in an aged care hostel when he was unexpectedly informed by his doctor that he needed to have his foot amputated due to diabetes complications; however, immediately prior to his amputation surgery, he learned it was to be below his knee. He described feeling deeply affected by this news: “That really shocked me... I was a little bit traumatized, but I knew I was, it had to be done.” Within 4 weeks of his surgery, he reported that he was feeling much better; some sadness about his lost leg remained however, and he became very upset during our interview. His emotional response to his amputation challenged his expectations about appropriate ways of responding to illness: “I wouldn't get... [it's] not the way a man behaves, I suppose.” While he found the amputation traumatic, Hugh described how the process of rehabilitation itself was a positive experience. Outside of the hospital, he had limited family support; however, a friend who had also had an amputation provided important outlet for his pre-amputation anxieties: “I spoke to a friend about [amputation], he couldn't help me through it, but [I could] at least confide in somebody. I'm on my own. I have a son and daughter, but I don't see much of them, um, they're both married. And ah, I did have Ruby [a close friend], you know.” While an inpatient, however, Hugh enjoyed the camaraderie with other recent amputees:

When I got out here [to the rehabilitation clinic], I found it different altogether because immediately rehab [rehabilitation] started and that was something to do every day... I'm a pretty outgoing person I think... Talking to everybody in there [the gym]... some you have

more conversations with, but they're a pretty good group. I often see the group [going into the hydrotherapy rehabilitation room, for another condition], they're not socializing... [At first], I was in a quiet room. I was on my own... I sat in [that] room, but I got out of the room [into a shared ward], I got out in the wheelchair and ah, now I wheel around the hospital after dinner. I couldn't do it for a few days because I was, just I was occupied by little bits of aches and things that were going on, what caused it, and talking on the phone to everybody... I wanted to be on my own at the start, because I didn't want to see people and ah, talk and things while I was in this condition.

Hugh described his process of accepting the amputation in relation to his engagement with others. This was an iterative process; he further explained how socializing with other inpatient amputees helped give him hope about what path his recovery would take and that he would regain full functioning (see Warren and Manderson 2008):

I do notice others who have a bit of trouble when they come here. Its different altogether actually, than what it is now [for me]... It's a hell of a thing to get used to. For a time, it is... [But] you have to adjust to it anyhow, so why not be positive, because you can't do anything about it... I hope within the next few months to be walking around pretty well. Well, I still have hope... There's one fellow in particular that walks around. You wouldn't think of him [as an amputee]. He's had one leg off... And he's marvelous. Um, he's had a few complications, but that's nothing to do with his leg. He's doing really well and when he walks, you wouldn't know it.

As these three cases illustrate, ideas such as family reciprocity, responsibility, gender roles, age, prior capacity, and personality are all difficult to capture quantitatively yet are relevant in shaping people's quality of life.

Conventional quality of life tools are unable or inadequate for measuring aspects of participation, engagement, identity, and well-being: their conceptualization of these factors may be outdated, they employ idioms that are often inappropriate or unclear, make generalizations without attention to the nuances of the individual's statements, and may be contextually inappropriate or insensitive. For example, the concept of "pep" included in the SF-36 is culturally bound – "pep" is not used widely in Australian English – and participants' comprehension of the term was further influenced by age. Younger participants, the bulk of our sample, were more familiar with the term than those aged over 40 due to their engagement with US popular culture (Warren et al. 2009). Other terms, too, included in instruments because they are idiomatic, date fairly rapidly unless the English is updated (consider "feeling blue," "down in the dumps," and so on). Notwithstanding care in translation, there are significant variations in the precision, transferability, use and understanding of terms and referents, and differences in the semantic, experiential, and conceptual translation of lexical items. This applies to physiology as well as emotional states, as documented with respect to various organs (Ibarretxe-Antuñano 2008). The cross-cultural use of general states of well-being, mood, and factors that impact on this (happy, dissatisfied, disabled, difficulty, etc.), and people's responses to questions about such items, is much harder (Bortfeld 2003; Guillemin et al. 1993; Kirmayer 2001; Kovecses 2010). Herdman and colleagues (1997) specifically investigated the equivalence – the finding and use of conceptually and psychometrically equal terms for cross-cultural translation (Stewart and Nápoles-Springer 2000) – of