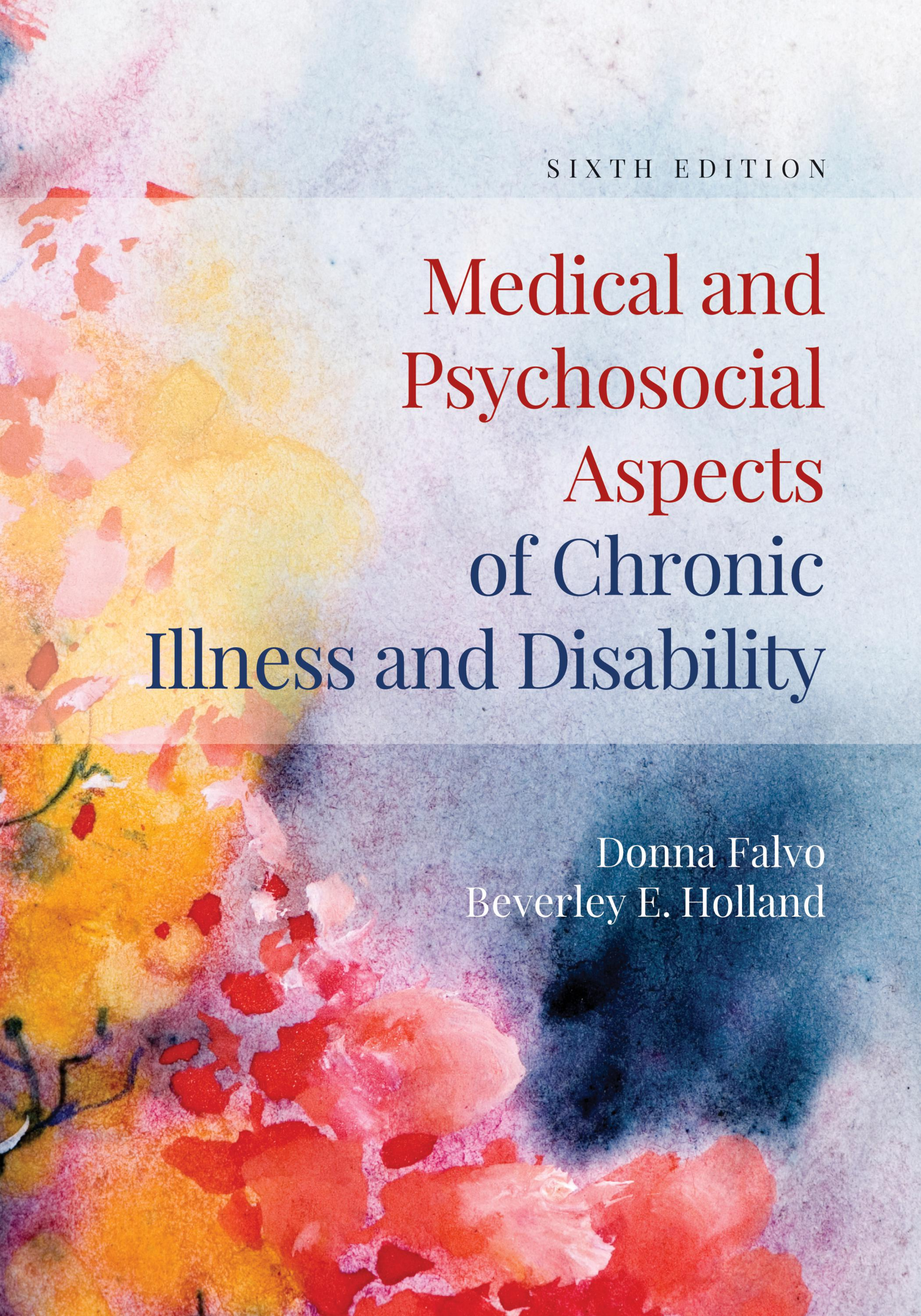
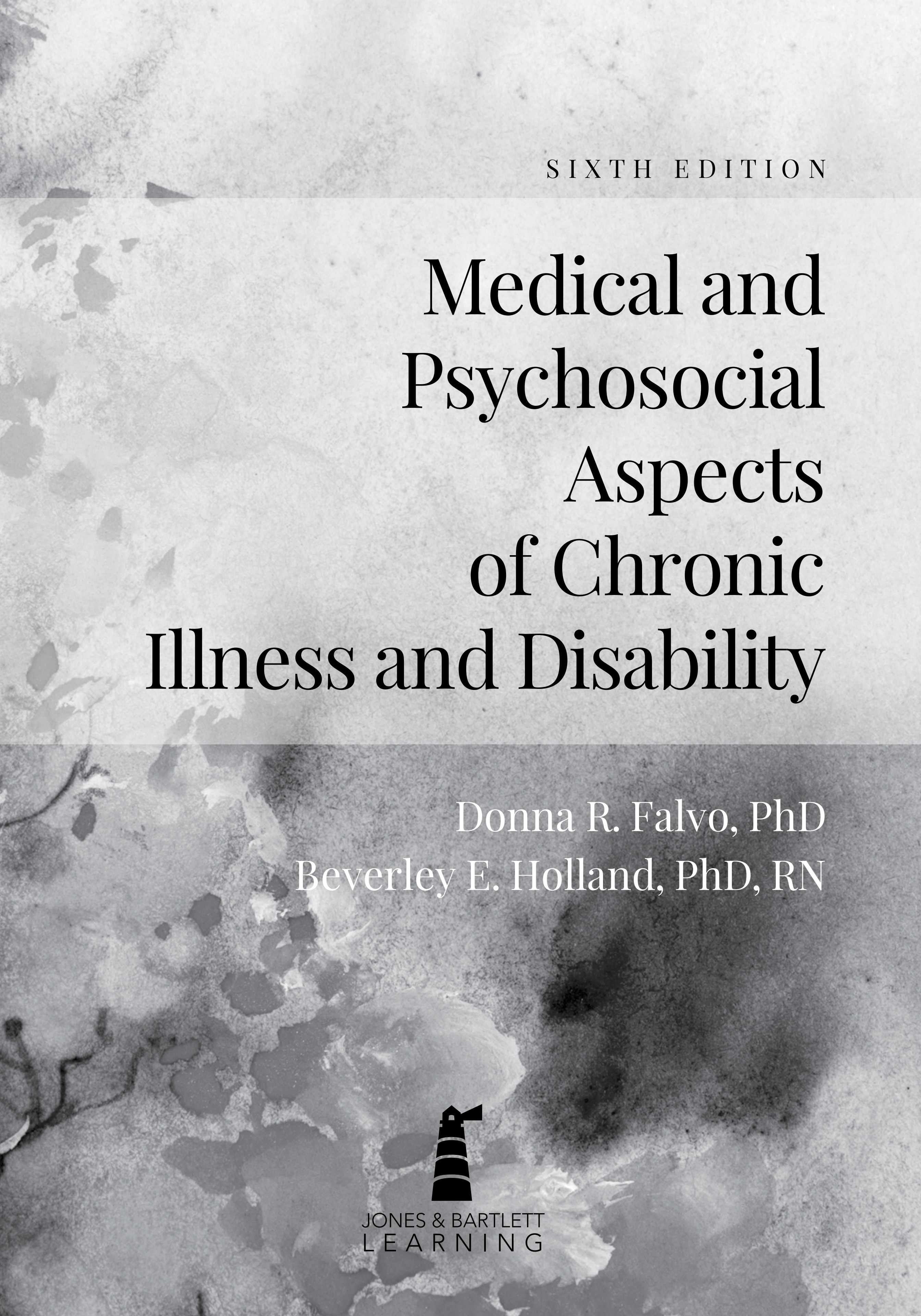


SIXTH EDITION

Medical and Psychosocial Aspects of Chronic Illness and Disability

Donna Falvo
Beverley E. Holland



SIXTH EDITION

Medical and Psychosocial Aspects of Chronic Illness and Disability

Donna R. Falvo, PhD
Beverley E. Holland, PhD, RN

JONES & BARTLETT
LEARNING

World Headquarters
Jones & Bartlett Learning
5 Wall Street
Burlington, MA 01803
978-443-5000
info@jblearning.com
www.jblearning.com

Jones & Bartlett Learning books and products are available through most bookstores and online booksellers. To contact Jones & Bartlett Learning directly, call 800-832-0034, fax 978-443-8000, or visit our website, www.jblearning.com.

Substantial discounts on bulk quantities of Jones & Bartlett Learning publications are available to corporations, professional associations, and other qualified organizations. For details and specific discount information, contact the special sales department at Jones & Bartlett Learning via the above contact information or send an email to specialsales@jblearning.com.

The content, statements, views, and opinions herein are the sole expression of the respective authors and not that of Jones & Bartlett Learning, LLC. Reference herein to any specific commercial product, process, or service by trade name, trademark, manufacturer, or otherwise does not constitute or imply its endorsement or recommendation by Jones & Bartlett Learning, LLC and such reference shall not be used for advertising or product endorsement purposes. All trademarks displayed are the trademarks of the parties noted herein. *Medical and Psychosocial Aspects of Chronic Illness and Disability, Sixth Edition* is an independent publication and has not been authorized, sponsored, or otherwise approved by the owners of the trademarks or service marks referenced in this product.

There may be images in this book that feature models; these models do not necessarily endorse, represent, or participate in the activities represented in the images. Any screenshots in this product are for educational and instructive purposes only. Any individuals and scenarios featured in the case studies throughout this product may be real or fictitious, but are used for instructional purposes only.

The author, editor, and publisher have made every effort to provide accurate information. However, they are not responsible for errors, omissions, or for any outcomes related to the use of the contents of this book and take no responsibility for the use of the products and procedures described. Treatments and side effects described in this book may not be applicable to all people; likewise, some people may require a dose or experience a side effect that is not described herein. Drugs and medical devices are discussed that may have limited availability controlled by the Food and Drug Administration (FDA) for use only in a research study or clinical trial. Research, clinical practice, and government regulations often change the accepted standard in this field. When consideration is being given to use of any drug in the clinical setting, the health care provider or reader is responsible for determining FDA status of the drug, reading the package insert, and reviewing prescribing information for the most up-to-date recommendations on dose, precautions, and contraindications, and determining the appropriate usage for the product. This is especially important in the case of drugs that are new or seldom used.

Production Credits
VP, Executive Publisher: David D. Cella
Executive Editor: Amanda Martin
Associate Acquisitions Editor: Rebecca Stephenson
Vendor Manager: Sara Kelly
Senior Marketing Manager: Jennifer Scherzay
Product Fulfillment Manager: Wendy Kilborn
Composition and Project Management: S4Carlisle Publishing Services
Cover Design:
Rights & Media Specialist: Wes DeShano
Media Development Editor: Troy Liston
Cover Image: ©
Printing and Binding: Edwards Brothers Malloy
Cover Printing: Edwards Brothers Malloy

Library of Congress Cataloging-in-Publication Data
Names: Falvo, Donna R., author. | Holland, Beverley, author.
Title: Medical and psychosocial aspects of chronic illness and disability / Donna Falvo and Beverley Holland.
Description: Sixth edition. | Burlington, MA : Jones & Bartlett Learning, [2018] | Includes bibliographical references and index.
Identifiers: LCCN 2016040476 | ISBN 9781284105407 (casebound)
Subjects: | MESH: Chronic Disease | Disabled Persons--psychology | Disabled Persons--rehabilitation | Social Adjustment
Classification: LCC RC108 | NLM WT 500 | DDC 616/.044--dc23 LC record available at https://lccn.loc.gov/2016040476

6048

Printed in the United States of America
20 19 18 17 16 10 9 8 7 6 5 4 3 2 1

Dedication

This book is dedicated to the memory of

Judy Mayer Irick, RN
1945–2015
Dedicated nurse, loving mother, loyal, and trusted friend.

Contents

Preface

Each person is unique. Consequently, chronic health conditions are not experienced in exactly the same ways by all individuals. The effects of chronic illness and disability are individual, and encompass not only physical function but also psychological, social, and work function. The extent to which individuals are able to function in their environment is, however, not always a direct result of their chronic health condition but rather may reflect misconceptions, lack of understanding, erroneous attitudes, and prejudice on the part of those persons encountered in the individual's environment or other environmental barriers that impede function. An understanding of chronic illness and disability, their functional implications, and the environmental constraints that may be present can contribute to removal of these barriers and support increased functional capacity.

This text, like the four previous editions, is designed as a reference for nonmedical professionals and as a text for students who have little prior medical knowledge but who work with individuals with chronic illness and disability. Moreover, this edition, like the previous edition, reflects the approach and philosophical underpinnings of the International Classification of Functioning, Disability and Health (ICF), which conceptualizes health as a continuum.

This edition has been revised and updated and, like previous editions, attempt to acquaint the reader with little or no medical background with concepts and medical terminology. In addition to basic information regarding physical aspects of each chronic health condition, the text addresses psychosocial aspects as well as the potential functional impact on activities and participation at home, work, and employment. Focusing on functional capacity in the context of personal goals and individual environment rather than focusing solely on physical effects of chronic health conditions can enable individuals to achieve not only optimal functional capacity but also increased quality of life.

Donna R. Falvo
Beverley E. Holland

About the Authors

Donna R. Falvo, PhD. has more than 35 years of experience as a registered nurse, licensed clinical psychologist, and certified rehabilitation counselor. At Southern Illinois University at Carbondale School of Medicine, she was Director of Behavioral Science in the Department of Family and Community Medicine and later directed the Rehabilitation Counseling Program at the Rehabilitation Institute at SIU. Most recently, she was clinical professor in the Rehabilitation Counseling and Psychology Program at the University of North Carolina at Chapel Hill School of Medicine. Dr. Falvo is past president of the American Rehabilitation Counseling Association and a former Mary Switzer Scholar. She served as Dimension Expert with the National Research Corporation/Picker Institute, Lincoln, Nebraska, from 2005 to 2008.

Beverley Holland, PhD, RN, is a registered nurse and an Adult Nurse Practitioner. She received her Ph.D. in Rehabilitation from the Rehabilitation Institute, Southern Illinois University at Carbondale. She is an associate professor of Nursing at the School of Nursing, Western Kentucky University in Bowling Green, Kentucky. In addition to teaching graduate students in nursing, she maintains a practice, which includes community wellness visits and working with the geriatric population.

Contributors

Thanks and appreciation to the following people who are responsible for major revisions of selected chapters. Their dedication, expertise, and professionalism are greatly appreciated.

Elizabeth Moran Fitzgerald, EdD, RN, CNS-BC, LMFT, LPCC. Dr. Fitzgerald is an associate professor of Clinical Nursing at Ohio State University. In addition to clinical teaching she practices as a Child & Adolescent Psychiatric Mental Health Clinical Nurse Specialist.

Kathy K. Hager, DNP, RN, is a family nurse practitioner and diabetes nurse educator and associate professor at Bellarmine University Lansing School of Nursing and Health Sciences, Louisville, KY. She practices at the university clinic and in the community with individuals with diabetes.

Kelly A. Kazukauskas, PhD, LCPC, CRC, CVE is a clinical assistant professor, clinical coordinator, and admissions coordinator with the Division of Counseling and Rehabilitation Science, Lewis College of Human Sciences at the Illinois Institute of Technology, Chicago, IL.

David B. Peterson, PhD, CRC, clinical psychologist, is a professor in Rehabilitation Education and Coordinator of the Clinical Counseling Certificate Program at California State University, Los Angeles.

Acknowledgments

Special thanks to the following people who generously volunteered their time to read, review, critique, and discuss various sections of the book. Their dedication and commitment to individuals with chronic illness and disability is greatly appreciated by the authors as by the individuals they serve.

Bruce Cairns, MD
Director, NC Jaycee Burn Center and
John Stackhouse Distinguished Professor
of Surgery
University of North Carolina School
of Medicine
Chapel Hill, NC

Richard Falvo, PhD
Professor Emeritus
Department of Physiology
Southern Illinois University School of Medicine
Carbondale, IL

Travis Meredith, MD
Emeritus Professor and Chair
Department of Opthalmology
University of North Carolina School
of Medicine
Chapel Hill, NC

Steve Prystowsky, MD
Clinical Associate Professor
Department of Dermatology
New York University School of Medicine
New York, NY

Alfredo C. Rivadeneira, MD
Associate Professor of Medicine
Division of Rheumatology, Allergy and
Immunology
University of North Carolina
Chapel Hill, NC

Carlo Smirne, MD, PhD
Assistant Professor of Internal Medicine
University of Piemonte Orientale
Department of Translational Medicine
Novara, Italy

Mitchell Mass
Reader, reviewer, and good friend
Chapel Hill, NC

CHAPTER 1

Conceptualizing Functioning, Disability, and Health

Revised by David Peterson

INTRODUCTION

From the time an individual is born, life unfolds in an environment that is both physical and social. Throughout history, attitudes toward health and disability have reflected broad social and cultural values of the time. As social patterns change and evolve, so do concepts of health and disability. As a way to conceptualize disability and its relationship to health, a number of models have emerged throughout history. Each model carries with it fundamental assumptions about health and disability and about these concepts' relationship to the social norm. These assumptions affect the attitudes, expectations, and actions of individuals with disability, as well as individuals within society as a whole, and have the potential to influence social and political policies related to disability issues.

PAST MODELS TO CONCEPTUALIZE HEALTH AND DISABILITY

The Medical Model

In the United States, for many years, the understanding of chronic illness and disability was delineated by the *medical model*, which focused on specific medical conditions that were viewed as "problems" and were intrinsic to the individuals experiencing them (Smart, 2001). The medical profession was considered the authority, central to curing, altering, or managing the specific medical condition, while the individual with the condition was viewed as the passive recipient of medical care. The medical model was diagnosis driven, emphasizing pathology, defining and characterizing the condition by standardized measures, and focusing on medical treatments and solutions to "eliminate" or control the condition, thereby returning the individual to "normal" (Fowler & Wadsworth, 1991; Longmore, 1995; McCarthy, 1993). The underlying philosophy of the medical model emphasized "normalcy" based on valued societal roles and norms. When an individual deviated from the "norm" in some way, the goal was to return that person to "normal." Given this premise, it followed that anyone who was in need of "cure," yet proved incurable, deviated from the "norm" and was, consequently, considered "abnormal," "dysfunctional," or "disabled." This conceptualization of disability carried with it a notion of social incapacitation that often engulfed an individual's social identity, which was subsumed by medical labels. The medical model emphasized the diagnosis and any corresponding limitation or functional incapacity relative to the societal norm (Stucki, Cieza, & Melvin, 2007).

While there are limitations to the medical model, it bears mentioning that the medical model has benefited health care. Diagnoses developed from this perspective and their health-related presentations have been used to quickly triage services that preserve life and to select appropriate treatments that minimize or ameliorate acute problems following the onset of health conditions. Generally speaking they have allowed us to develop a language that helps us keep track of what makes us sick and ends life, information critical in planning for the use of resources to optimize world health (Peterson & Elliott, 2008).

However, the medical model has difficulty accommodating the types of permanent and chronic long-term care needs that promote optimal health and quality of life for people living with a disability. This is due in part to the context of people dealing with chronic health conditions not adequately addressed by service delivery systems focused on acute, short-term conditions (Peterson & Elliott, 2008).

Further, the medical model relies heavily on measures and tests of the disease process, placing limited value on subjective reports of health and functioning, leading health providers to undervalue patient input concerning their treatment (Peterson & Elliott, 2008).

A growing body of research suggests that diagnostic labels alone, without functional data, may not adequately reflect an individual's health condition (see Peterson & Elliott, 2008). Diagnostic information alone can neither predict nor describe actual functional capacity of the individual within the context of his or her daily life. Emphasis on the medical condition alone not only ignores the individual's function within his or her environment or within the broader context of society but also overlooks the roles that society and the environment play in the individual's ability to function.

The Social Model

The *social model* of disability represented a reaction to the medical model (Paley, 2002). Rather than viewing disability as a condition of the individual to be cured so that the person can conform to social norms, the social model emphasized societal and environmental barriers as primary contributors to disability. A key component of the social model was equality (Hurst, 2003); thus a major focus was not to "cure" the individual but rather to make changes in society and the environment that would provide equality and opportunity. The social model paralleled the civil rights/human rights movements, which were the catalyst for the development of a number of social policies and legislative actions. In the United States, the Americans with Disabilities Act, enacted in 1990, established the right of individuals with disability to receive reasonable accommodations that would enable them to function in the environment and prohibited discrimination based on their disability.

In accordance with the social model, disability was viewed not as a specific medical condition but rather as the result of the restrictions imposed through society's lack of attention and accommodation to the needs of individuals with disability. The social and physical environments within which individuals live and interact can either enhance their ability to function or exaggerate a disability. Consequently, social and physical environments can determine the extent and type of function that individuals experience (Pledger, 2003). Although it recognized that individuals with disability may experience functional limitations as a direct result of their condition, the social model emphasized society's failure to take these limitations into account as the major contributor to disabling effects of the condition.

The social model, as with the medical model is not without its limitations. In contrast with the specific information defining what comprise diagnoses in the medical model, the social model has not historically distinguished who qualifies as a person with a disability, or how disability is measured or determined. Proponents of this tradition have not established a distinct body of research that systematically posits empirically testable and potentially falsifiable hypotheses. Complicating matters further, some proponents appear to regard such research as a continuation of a medical model that equates disability with person-based pathology that is largely independent of environmental and social factors (see Olkin & Pledger, 2003; Peterson & Elliott, 2008).

The Biopsychosocial Model

The *biopsychosocial model* was proposed as an alternative to prevailing medical and social models, which were perceived as being excessively narrow (Engel, 1977). The biopsychosocial model uses useful aspects from both the medical model and the social model of disability (Peterson & Rosenthal, 2005a; Simeonsson et al., 2003; Ueda & Okawa, 2003). Philosophically, rather than focusing solely on the medical condition or solely on the societal or environmental barriers as contributors to disability, the biopsychosocial model posits that it is the complex interaction of biological, psychological, and social factors in combination that play a significant role in an individual's ability to function. Consequently, the effects of any one health condition would be dependent on the individual involved and the social context and circumstances surrounding that person. The biopsychosocial model implies that many variables, not simply the chronic illness or disability itself, determine the extent and type of function that individuals with a health condition experience. Conceptualizing chronic illness and disability as *health conditions* in terms of functional capacity rather than as a medical diagnosis permits a greater understanding of the individual's subjective experience of his or her health condition.

THE EXPERIENCE OF DISABILITY

The experience of disability is individual, is dynamic, and varies in different circumstances and in different environments. The term *experience* implies that not all individuals—even those with the same medical condition—are affected by disability in the same way. How individuals perceive disability and the impact such disability has on function are not only the result of the condition itself, but also the result of personal factors and the circumstances that the individual encounters within his or her own particular social and physical environment (Imrie, 2004).

Personal factors can relate to gender, race, age, fitness, religion, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience, overall behavior pattern and character, individual psychological assets, other health conditions, or any number of other factors that contribute to an individual's experience of disability (WHO, 2001). Social environments exist at many levels, extending from the insular level of family and friends, to the larger social environment of community and work, and finally to the broader level that encompasses cultural, economic, and political environments. Physical environments include not only physical barriers within the immediate environment but also other factors such as climate, weather, housing, and transportation (WHO, 2001).

Developmental factors also affect an individual's experience of disability. Each age group and each life stage present new challenges associated with that particular stage of life, which would occur whether or not an individual had a disability. These life-stage challenges, in turn, influence individuals' experience with disability. For instance, the experience of disability during childhood is different from the experience of the same condition in adulthood. The experience of disability in adolescence is different from what would be experienced with the same disability in later years of life.

Social environments also affect a person's experience with disability. The degree to which an individual has strong social support in terms of family or friends, the beliefs and attitudes of the community, and cultural expectations and norms of the individual's social group all influence how the affected person will experience disability.

The experience of disability also varies with the environment. The experience of disability at home may differ significantly from the experience in the workplace. The experience of disability while conducting household tasks may be much different than the experience of disability during recreational activities.

In short, there is a dynamic interaction between individuals' experience with disability and their consequent functional capacity within a given context. The experience of disability is multidimensional and unique to each individual. Individuals with the same disability do not experience disability in the same way.

CLASSIFYING DISABILITY

The concept of disability is complex and has been interpreted in a variety of ways. As the concept evolved from an emphasis on a cure to an emphasis on the individual experience and functional capacity within the context of the environment, it became evident that a medical diagnosis alone revealed little about how an individual would experience a health condition in terms of functional outcomes. Likewise, a medical diagnosis alone was insufficient to determine the types of accommodations needed to enhance an individual's ability to function in his or her environment. It became evident that there was a need to develop a common language by which consequences of health conditions and individual outcomes could be measured.

In response to these changes in perception, the World Health Organization (WHO) worked to develop a unified, standard classification of consequences of health conditions. The result was a classification system entitled the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980). A complement to the International Statistical Classification of Diseases and Related Health Problems (ICD, now in its 10th revision (WHO, 1992)), the ICIDH was intended to provide a classification of function that complemented the diagnostic and mortality information historically classified by the ICD.

The ICIDH was influenced by the medical model but defined consequences of medical conditions with classifications related to function. The terms *impairment*, *disability*, and *handicap* were used to indicate the level and type of impact that the medical condition had on the individual's function. *Impairment* was defined as an abnormality in body structure or appearance; *disability* was defined as a restriction or lack of ability to perform an activity; and *handicap* was defined as a disadvantage the individual experienced as result of the impairment or disability.

As concepts continued to evolve and the medical model fell increasingly out of favor, the ICIDH was revised (De Kleijin-De Vrankrijker, 2003). In 2001, WHO adopted a new model to conceptualize functioning, disability, and health. The revised classification system, called the International Classification of Functioning, Disability and Health (ICF), was developed through a process of international consensus building including 652 individuals from 18 countries over a 7-year period (see Peterson, 2011; WHO, 2001).

PHILOSOPHICAL UNDERPINNINGS OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

The ICF (WHO, 2001) presents a different way of conceptualizing chronic illness and disability; that is, it is a classification of *health and functioning* rather than *disease*. In the past, from the perspective of the medical model, the focus was on diagnostic labels and causes of disability, with emphasis on deficits and limitations and medical interventions to treat them. This perspective had the potential to overshadow the individual's potential and abilities, failed to recognize the degree to which his or her potential and abilities were hampered or enhanced by the social and physical environment, and did not typically seek out or value the individual's perspective on his or her health and functioning. The ICF changed this paradigm by placing a positive focus on function and health, emphasizing the integration of health conditions (disease, injury, or other biological factors) and personal, societal, and environmental factors. The ICF places health on a continuum, acknowledging that everyone has the potential to experience a decline in health with some degree of disability. Rather than viewing disability as a personal attribute that is directly caused by disease or injury and that requires medical care to correct the problem, the ICF addresses disability as a social construct that is a synthesis of biological, individual, and social factors and reflects the interaction between the individual and his or her social and physical environment (WHO, 2001). Thus the ICF promotes the concept of disability not as a problem within the person but rather as the result of assets or barriers found within the social or physical environment (Peterson & Kosciulek, 2005). This new conceptualization recognizes that the potential for disability is a universal human experience and not limited to a minority of the population.

Using the ICF classification system, disability is viewed as more than a medical diagnosis or a medical or biological dysfunction; rather, it is seen as a part of the health continuum as it affects function. Consequently, health and disability are viewed as a universal human experience with emphasis on the integration of biological, individual, social, and environmental aspects of a health condition.

GENERAL USES OF THE ICF

The ICF provides an international standard for describing and measuring health domains and is a universal classification of functional status associated with a number of health conditions (Peterson, 2005, 2015; Peterson & Rosenthal, 2005a). Its unified and standard definition of health and disability helps to provide a basis for common understanding.

The uses of the ICF are varied. The ICF can provide a structure to facilitate communication within and between multidisciplinary groups (Steiner et al., 2002); clarify team roles and enhance clinical reasoning (Tempest & McIntyre, 2006); organize service provision (Bruyére & Peterson, 2005; Rauch, Cleza, & Stucki, 2008; Stucki, Bedirhan Ustun, & Melvin, 2005); serve as a catalyst for research (Threats, 2002; Wade & deJong, 2000); and provide a framework for legislative, regulatory, social, and health policy related to disability (Peterson, 2011; WHO, 2001). In addition, it provides a means of comparison for individual experience with disability (Khan, Amatya, & Ng, 2010) and highlights the impact of environmental factors in enhancing or hindering function (Khan & Pallant, 2007).

The ICF classification system serves as a tool not only for standardizing concepts related to functional impact of disability but also for measuring the efficiency and effectiveness of rehabilitation services (Peterson, 2011; Üstün, Okawa, Bickenbach, Kastanjsek, & Schneider, 2003).

CONCEPTUAL FRAMEWORK OF THE ICF

The ICF addresses more than disability; that is, it also classifies health and health-related states with or without disability because the emphasis is on function and health conditions, both of which may be on a continuum. The *experience* of disability focuses on the individual and his or her personal resources, health condition, and individual environment. Health, as portrayed by the ICF, is a dynamic interaction between function and disability within the context of the individual's environment and personal factors (Stucki & Melvin, 2007).

The ICF (WHO, 2001) defines key terms in its conceptual framework as follows:

- **Health** refers to *components of health* (physical or psychological function) and *components of well-being* (capacity to function within the environment).
- **Function** refers to all body functions, activities, and participation in society.
- **Disability** refers to any impairment, activity limitations, or participation restrictions that result from the health condition or from personal, societal, or environmental factors in the individual's life.
- **Impairment** refers to a deviation from certain generally accepted population standards of function.

Although impairments associated with a number of health conditions cause some degree of disability in most people (e.g., spinal cord injury), the degree to which an impairment results in disability is also determined by an individual's unique circumstances. What may appear to be a relatively minor disruption of function may actually have major consequences for the life of the individual affected. For example, loss of an index finger would be more disabling for a baseball pitcher than it would be for a heavy-equipment operator. Spinal cord injury resulting in paraplegia would have a different impact on someone who is an accountant than it would have on someone who is a construction worker. Rather than imposing preconceived ideas about the extent of a disability associated with a particular health condition, determining the extent of disability requires that consideration be given to the condition in the context of the individual's life, particular circumstances, and goals.

A health condition that results in a disability for one individual may not result in a disability for another individual with the same health condition. Therefore, the degree of disability an individual experiences as a result of a health condition depends on both the individual's goals and those facilitators or barriers that are present in the physical and social environment.

The ICF emphasizes functional capacity in the individual's natural environment. Evaluation and assessment of an individual's functional capacity in a laboratory or testing environment may not be an accurate reflection of his or her level of function. What individuals are able to do in a standardized environment may be quite different from what they are able to do in their natural environment. For example, an individual, after suffering a stroke resulting in hemiplegia, may be able to ambulate to the bathroom in a laboratory setting; in contrast, at home, with no indoor plumbing and only outdoor facilities, the same person may be unable to perform this task. Without assessing function in the context of the individual's everyday life, a realistic view of function may not be obtained. Likewise, there may be a discrepancy between the individual's capacity to function and his or her actual performance. Individuals may have the capacity to perform a task yet lack the motivation or social support to carry it out. For instance, an individual with emphysema may have the ability to carry out household chores but because of overprotective family members may be discouraged from doing so. Function, therefore, is more complex than merely having the ability to carry out a task or action.

STRUCTURE OF THE ICF

The core structure of the ICF is divided into two parts, each with two components (see **Table 1-1**).

The first part, *function and disability*, is divided into two components: *body function and structure* and *activity and participation*. In the first component, *body function* refers to physiological functioning of body systems, such as mental function, sensory function, function of the heart, or function of the immune system; *body structure* refers to anatomical components of the body, such as the structure of the nervous system or the structure of the cardiovascular system.

The second component, *activity and participation*, is conceptualized by qualifiers of *capacity* and *performance*. *Activity* refers to tasks or actions that individuals carry out in daily life, such as reading, writing, managing daily routines, dressing, and bathing. *Participation* refers to the individual's involvement in activities of daily life or in society. It includes the individual's ability to fully participate in activities in the broader social system, such as going to school, holding a job, engaging in recreational activities, or being integrated into the community. The qualifier *capacity* refers to the individual's *actual ability*, or level of function to perform a task or action, whereas *performance* refers to what the individual *actually does* in his or her current environment. For instance, an individual may have the capacity to walk from the front porch to the mailbox, but might not do so because a neighbor brings the mail to the individual's door each day.

The second part of the core structure of the ICF, *contextual factors*, consists of two components: *environmental factors* and *personal factors*. Both components include factors that can be either *facilitators* or *barriers* in helping individuals acquire full participation.

The first component, *environmental factors*, refers to more than the physical environment, such as accessibility of buildings or the availability of accessible transportation. That is, it also includes products and technology (such as telephones or computers), climate (such as dry, humid, hot, or cold), and factors in the social environment (such as social attitudes, norms, services, and political systems). In this context, environmental factors are divided into three levels:

- Individual level: individual systems of support; support network
- Services level: services and resources available
- Cultural/legal systems level: societal and cultural attitudes; political and legal factors (Peterson & Rosenthal, 2005b)

Table 1-1 Core Structure of the International Classification of Functioning, Disability, and Health

Part 1: Function and Disability	Part 2: Contextual Factors
A. Body functions and structures	A. Environmental factors
B. Activities and participation	B. Personal factors

The second component, *personal factors*, is recognized as an important interactive component in defining function, but is not coded in the ICF because of the complexity and highly individualized nature of these factors. Personal factors include gender, race, education, occupation, and difficult-to-quantify human factors, such as past personal experiences, individual temperament, and other intrinsic characteristics, such as state of mind. Although these factors are not coded, they are considered and recognized as contributing to the overall function of the individual.

The core structure of the ICF provides a perspective on health conditions from the standpoint of function. It offers a perspective on how body structure and function affect individuals' ability to function in the context of their particular social and physical environment as well as the direct impact of the social and physical environment on function. The ICF focuses on the dynamic and interactive nature of biological, social, personal, and environmental factors in determining individuals' functional capacity.

OPTIMUM VERSUS MAXIMUM FUNCTION, CAPACITY, AND PERFORMANCE

The domains of the *activities* and *participation* described above are operationalized through the use of the qualifiers *capacity* and *performance*. Capacity "describes an individual's ability to execute a task or an action," or more specifically, "the highest probable level of functioning that a person may reach in a given domain at a given moment" (WHO, 2001, p. 15). One must apply the capacity qualifier in the context of a "uniform" or "standard" environment; a heuristic for capacity could be what a person *can* do. The performance qualifier describes "what a person does in his or her current environment" (p. 15); a heuristic for performance could be what a person *does* do. The gap between capacity and performance can be very useful in intervention targeting, informed by the ICF's conceptual framework. If an individual is not performing at his or her capacity and that is that individual's desired goal, the health professional can explore interventions at the individual and contextual levels that may increase functioning. Medications and therapy to treat body functions and structures and modifications in the home or work environments can have great effect on helping an individual perform at maximum capacity (Peterson, 2011).

However, for individuals to achieve full functional capacity, there must be an awareness of not only the functional implications of various health conditions but also the implications of the strengths and barriers that are found in the social and physical environment, particularly from the individual's unique perspective. One of the remarkable strengths of the ICF is that it is intended to be used *in collaboration* with the person whose health and functioning is being classified (Peterson & Threats, 2005). This collaborative approach is consistent with the social and biopsychosocial approaches to healthcare and provides the health professional with the benefit of the individual's unique perspective on his or her health and functioning (Peterson, 2011).

It is commonly assumed that achieving *maximum function* is the ideal goal; however, *optimal function* rather than *maximum function* is emphasized in the ICF. Although *maximum* refers to the greatest degree of function possible, defined in the ICF as capacity, maximum function for an individual may not be, in his or her opinion, optimal. *Maximum function* is based on an objective viewpoint, whereas *optimal function* is based on the subjective viewpoint of the individual and derived from his or her own goals and experience. Optimizing function requires a comprehensive understanding of the individual within the context of his or her environment and unique frame of reference. The emphasis is on building and strengthening personal resources, with the goal of helping individuals achieve *optimal functioning* and full *inclusion* and *participation* in all aspects of life. In this context, it is most useful for both strengths and limitations to be identified from both professional and personal, individual perspectives.

CONCLUSIONS

Conceptualizing chronic illness and disability as *health conditions* in the context of the continuum of health and function helps to decrease the stigmatization and isolation that have been associated with chronic illness and disability in the past. By emphasizing functional capacity rather than deficits, and by focusing on personal goals and the ability to perform in the context of the environment, optimal function can be achieved. Greater understanding of health conditions as an experience rather than as a medical condition can help to decrease the discrimination and prejudice that too often accompany chronic illness and disability and that too often are the major barriers to achievement of optimal activity and participation in the broader community, social, and vocational environments (Peterson, 2011).

REFERENCES

Bruyére, S. M., & Peterson, D. B. (2005). Introduction to the special section on the International Classification of Functioning, Disability and Health (ICF): Implications for rehabilitation psychology. *Rehabilitation Psychology, 50*, 103–104.

De Kleijin-De Vrankrijker, M. W. (2003). The long way from the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) to the International Classification of Functioning, Disability, and Health (ICF). *Disability and Rehabilitation, 25*, 561–564.

Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*, 129–136.

Fowler, C. A., & Wadsworth, J. S. (1991). Individualism and equity: Critical values in North American culture and the impact on disability. *Journal of Applied Rehabilitation Counseling, 22*, 19–23.

Hurst, R. (2003). The international disability rights movement and the ICF. *Disability and Rehabilitation*, *25*, 572–576.

Imrie, R. (2004). Demystifying disability: A review of the International Classification of Functioning, Disability and Health. *Sociology of Health and Illness, 26*, 287–305.

Khan, F., Amatya, B., & Ng, L. (2010). Use of International Classification of Functioning, Disability and Health to describe patient reported disability: A comparison of Guillain-Barré syndrome with multiple sclerosis in a community cohort. *Journal of Medical Rehabilitation, 42*(8), 708–714.

Khan, P., & Pallant, J. F. (2007). Use of International Classification of Functioning, Disability, and Health (ICF) to describe patient reported disability in multiple sclerosis and identification of relevant environmental factors. *Journal of Rehabilitation Medicine, 39*(1), 63–70.

Longmore, P. K. (1995). Medical decision-making and people with disabilities: A clash of cultures. *Journal of Law, Medicine, and Ethics, 23*, 82–87.

McCarthy, H. (1993). Learning with Beatrice A. Wright: A breath of fresh air that uncovers the unique virtues and human flaws in us all. *Rehabilitation Education, 10*, 149–166.

Olkin, R., & Pledger, C. (2003). Can disability studies and psychology join hands? *American Psychologist, 58*, 296–304.

Paley, J. (2002). The Cartesian melodrama in nursing. *Nursing Philosophy, 3*(3), 189.

Peterson, D. B. (2005). International Classification of Functioning, Disability and Health (ICF): An introduction for rehabilitation psychologists. *Rehabilitation Psychology, 50*, 105–112.

Peterson, D. B. (2011). *Psychological aspects of functioning, disability and health.* New York, NY: Springer Publishing Company.

Peterson, D. B. (2015). The International Classification of Functioning, Disability & Health: Applications for professional counseling. In I. Marini & M. Stebnicki (Eds.), *The professional counselor's desk reference* (2nd ed.). New York, NY: Springer Publishing Company.

Peterson, D. B., & Elliott, T. R. (2008). Advances in conceptualizing and studying disability. In S. Brown & R. Lent (Eds.), *Handbook of counseling psychology* (4th ed.). Hoboken, NJ: John Wiley & Sons.

Peterson, D. B., & Kosciulek, J. F. (2005). Introduction to the special issue of *Rehabilitation Education*: The International Classification of Functioning, Disability and Health (ICF). *Rehabilitation Education, 19*(2 & 3), 75–80.

Peterson, D. B., & Rosenthal, D. (2005a). The ICF as an historical allegory for history in rehabilitation education. *Rehabilitation Education, 19*, 95–104.

Peterson, D. B., & Rosenthal, D. A. (2005b). The International Classification of Functioning, Disability and Health (ICF): A primer for rehabilitation educators. *Rehabilitation Education, 19*(2 & 3), 81–94.

Peterson, D. B., & Threats, T. T. (2005). Ethical and clinical implications of the International Classification of Functioning, Disability and Health (ICF) in rehabilitation education. *Rehabilitation Education, 19*, 129–138.

Pledger, C. (2003). Discourse on disability and rehabilitation issues: Opportunities for psychology. *American Psychologist, 58*, 279–284.

Rauch, A., Cleza, A., & Stucki, G. (2008). How to apply the International Classification of Functioning, Disability, and Health (ICF) for rehabilitation management in clinical practice. *European Journal of Physical and Rehabilitation Medicine, 44*(3), 329–342.

Simeonsson, R. J., Leonardi, M., Lollar, D., Bjorck-Akesson, E., Hollenweger, J., & Martinuzzi, A. (2003). Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disability and Rehabilitation, 25*, 602–610.

Smart, J. F. (2001). *Disability, society and the individual.* Austin, TX: Pro-Ed.

Steiner, W., Ryser, L., Huber, E., Uebelhart, D., Aeschlimann, A., & Stucki, G. (2002). Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation medicine. *Physical Therapy, 82*(11), 1098–1107.

Stucki, G., Bedirhan Ustun, T., & Melvin, J. (2005). Applying the ICF for the acute hospital and early post-acute rehabilitation facilities. *Disability and Rehabilitation, 27*(7/8), 349–352.

Stucki, G., Cieza, A., & Melvin, J. (2007). The International Classification of Functioning, Disability and Health: A unifying model for the conceptual description of the rehabilitation strategy. *Journal of Rehabilitation Medicine, 39*, 279–285.

Stucki, G., & Melvin, J. (2007). The International Classification of Functioning, Disability and Health: A unifying model for the conceptual description of physical and rehabilitation medicine. *Journal of Rehabilitation Medicine, 39*, 286–292.

Tempest, S., & McIntyre, A. (2006). Using the ICF to clarify team roles and demonstrate clinical reasoning in stroke rehabilitation. *Disability and Rehabilitation, 28*(10), 663–667.

Threats, T. (2002). Evidence based practice research using the WHO framework. *Journal of Medical Speech-Language Pathology, 10*, 17–24.

Ueda, S., & Okawa, Y. (2003). The subjective dimension of functioning and disability: What is it and what is it for? *Disability and Rehabilitation, 25*, 596–601.

Üstün, S., Okawa, Y., Bickenbach, J., Kastanjsek, N., & Schneider, M. (2003). The International Classification of Functioning, Disability and Health: A new tool for understanding disability and health. *Disability and Rehabilitation, 25*, 565–571.

Wade, D. T., & deJong, B. A. (2000). Recent advances in rehabilitation. *Behavioral Medicine Journal, 320*, 1385–1388.

World Health Organization (WHO). (1980). *International Classification of Impairments, Disabilities, and Handicap*s *(ICIDH).* Geneva, Switzerland: Author.

World Health Organization (WHO). (1992). *International Statistical Classification of Diseases and Related Health Problems,* 10th revision *(ICD-10).* Geneva, Switzerland: Author.

World Health Organization (WHO). (2001). *ICF: International Classification of Functioning, Disability and Health.* Geneva, Switzerland: Author.

CHAPTER 2

Psychosocial and Functional Aspects of Health Conditions

THE EXPERIENCE OF HEALTH CONDITIONS AND ALTERED FUNCTION

The way individuals experience health conditions with associated alterations in functional capacity encompasses many different areas and is influenced by numerous factors, including the following:

- Personal factors (such as gender, race, age, coping styles, and past experience)
- Social and family relationships and social support
- Socioeconomic status
- Culture
- Environment (physical, social, and political)
- Activities (including those related to daily living, recreation, school, and work)
- Goals of the individual

The extent to which a health condition is "disabling" depends on the interplay between the condition and the factors listed previously. Any alteration in functional capacity experienced with a health condition may not be so much a function of the condition itself as it is a function of elements in the environment. Individual reactions to health conditions vary considerably. The individual with a health condition who has associated alteration in function, for example, may not place as much importance on the condition and its associated features as do members of society.

Social groups establish their own standards with regard to idealized physical and emotional traits, roles, and responsibilities. Individuals with health conditions who do not fit the societal determined "norm" may find that, regardless of their strengths and abilities, society as a whole focuses more on the limitations and "disability" associated with the condition rather than focusing on "ability" and what an individual is actually able to do.

People vary in terms of their personal resources, such as their tolerance of manifestations of a health condition, functional capacity, general ability to cope, and social supports. Consequently, each individual must be considered in the context of all aspects of his or her life, and specifically in terms of the capacity to function within the environment.

Functional capacity goes beyond specific tasks and activities—it also includes significant events and relationships with family, friends, employers, and casual acquaintances. No relationship exists in isolation. Just as individuals' reactions to their health condition influences the reactions of others, so the reactions of others affect individuals' self-concept and perception of their own strengths and abilities.

Participation in family, social, and work events assumes interaction and the capacity to perform a variety of activities. As interactions or capacities change, or as they become limited or restricted, alterations in roles and relationships may also occur. Although some changes and adjustments may be made with relative ease, other changes can have repercussions in many areas of daily life.

The meaning and importance that individuals and their families attach to these associated changes influence their ability to accept the condition and to make necessary adjustments. The health condition itself is merely one factor that determines an individual's ability to function effectively.

DISEASE AND ILLNESS VERSUS HEALTH CONDITION

Words are powerful conveyers of concepts. Using a standard definition of terms facilitates communication and understanding of what each term implies. The term *disease* is derived from the *medical model*, which refers directly to changes in structure or function of body systems and focuses on treatment and elimination of symptoms. The term *illness* refers to individuals' perception of manifestations of their condition and how they and their families respond to it (Morof Lubkin & Larsen, 2002).

The *biopsychosocial model*, which is the basis of the *International Classification of Functioning, Disability, and Health* (ICF), defines *health conditions* by focusing on how biological, psychological, and social factors in combination interact to determine functional capacity. Professionals working with individuals experiencing chronic illness or disability must understand manifestations, functional ability, and progression of a health condition to better understand individuals' experience and to support their ability to achieve optimal functional capacity. Insight into the nature of each individual's health condition helps guide professionals in assessments and interventions as well as in understanding each individual's functional capacity and general experience (Dudgeon, 2002). It is also important for professionals to have insights into individuals' perception of their condition, the personal relevance and meaning that the condition has for them, and their goals so that interventions can be directed toward meeting individual needs and goals (Shaw, Segal, Polatajkos, & Harburn, 2002).

There must be an understanding of the individual's strengths, resources, and abilities, as well as how these attributes affect functional capacity. Professionals should possess an understanding of personal factors, activities, and social and physical environments to effectively assess how the condition will affect an individual's daily life and goals in relationship to functional ability at home, at work, and in the community.

TERMINOLOGY

Although understanding the experience of the individual in regard to his or her health condition is crucial, understanding terms and concepts utilized by the medical community as a whole is also important to facilitate communication and avoid misinterpretation. Two key concepts that influence the management of a health condition by medical personnel are *acute* and *chronic*. **Acute** refers to sudden onset of symptoms that are short term in nature and affect functional capacity on a temporary basis. **Chronic** refers to symptoms that last indefinitely and are attributed to a cause that may or may not be able to be identified. Some conditions begin acutely but are not resolved, thus becoming ongoing and chronic.

When health conditions are chronic, depending on the nature of the condition and the circumstances, *activities* and *participation* may be affected, and changes in activities may be needed to accommodate manifestations of the condition. In some instances, if manifestations of the condition progress or as other personal, social, or environmental factors change, accommodations may be needed to manage the condition. The course of a health condition over time, plus actions taken by individuals and their families to manage or shape the course of the condition, is called a *trajectory* (Corbin, 2001). This concept is important to professionals working with individuals with health conditions because it implies a continuum and emphasizes the social and environmental effects of the condition.

The *course* of the condition refers to the nature or stages of the condition. Some conditions are classified as *stable*, meaning that the condition is being managed, manifestations of the condition are not progressing, and the health status of the individual is not deteriorating. In other instances, conditions are known as *progressive*, meaning that manifestations of the condition continue to progress, while health and functional capacity continue to decline. Other conditions are classified as *episodic*, meaning that manifestations may not always be present, but flare up occasionally. The term *degenerative* refers to conditions characterized by continuing breakdown of structure or function. Some conditions have periods of **exacerbations** (periods when manifestations become worse) and periods of **remissions** (periods of time when symptoms remain stable or do not progress).

The course of a health condition can have a major influence on individuals' experience of the condition as well as on their functional capacity. For instance, individuals who have a progressive condition have continuing adaptation and adjustment as their health and function continue to decline, whereas individuals with a stable condition may have an initial period of adjustment but no ongoing functional loss.

STRESS IN HEALTH CONDITIONS

Change is an unavoidable part of life. Change of job, change of home, change of family composition, or changes brought about through the normal aging process are all events that everyone experiences. Depending on individuals' perceptions and the circumstances involved, change may be positive or negative. Whether positive or negative, change requires some adjustment or adaptation, which produces a certain degree of stress.

Health conditions can produce significant change—and consequently stress associated with both physical imbalance and psychological turmoil as individuals adjust to changes in customary lifestyle, loss of control, disruption of physiological processes, pain or discomfort, and potential change of role, status, independence, and financial stability. When individuals have confidence in their ability to maintain control over their destiny, and when they believe that changes—although inevitable—are manageable, stress is less pronounced. When individuals perceive changes associated with a health condition as insurmountable or beyond their ability to cope, stress can be overwhelming.

Causes of Stress with Health Conditions

The degree of stress associated with health conditions is often related to the degree of threat it represents to individuals. Potential threats posed by health conditions can include the following:

- Threats to life and physical well-being
- Threats to body integrity and comfort as a result of the illness or disability itself, diagnostic procedures, or treatment
- Threats to independence, privacy, autonomy, and control
- Threats to self-concept and fulfillment of customary roles
- Threats to life goals and future plans
- Threats to relationships with family, friends, and colleagues
- Threats to the ability to remain in familiar surroundings
- Threats to economic well-being

In addition to threats associated with health conditions, another source of stress may be the individual's perception of the meaning or purpose of his or her life. If individuals feel that their life has no meaning or that they have already fulfilled their purpose, the stress experienced may be quite different from that experienced by individuals with the same condition who believe they still have a significant role and purpose to fulfill.

Responses to stresses associated with health conditions depend on individuals' perceptions of the impact the condition has on various areas of their life as well as on their capacity to cope. Stress cannot easily be quantified, but it can be interpreted through behaviors or actions. When demands exceed psychological, social, or financial resources, stress may be manifested through a variety of behaviors, such as nonadherence with recommended management strategies, self-destructive behaviors such as substance abuse, and emotional reactions such as irritability, hostility, or depression.

Reactions to and stress related to health conditions are highly individualized. In other words, individuals with the same health condition do not necessarily experience the same degree of stress. The amount of change or adjustment required with a health condition is not necessarily an indicator of the amount of stress an individual experiences. Individuals who are able to adapt and cope effectively and mobilize resources are more successful in managing stress and achieving more stable outcomes than those who have few resources and limited coping skills.

Coping

Coping is not a single entity but rather an individualized constellation of many acts that are constantly changing. Coping skills are learned and developed over time as a way to manage, tolerate, or reduce stress associated with significant life events and to restore psychological equilibrium. Everyone develops a variety of coping skills through life experiences, although each individual relies on a predominant coping style to reduce anxiety and restore equilibrium when confronted with a stressful situation. Coping is manifested through behavior. Coping is *effective* and *adaptive* when it helps individuals reduce stress and enhance potential. It is *ineffective* and *maladaptive* when it inhibits growth or potential or when it contributes to physical or mental deterioration.

Coping skills may be required when individuals first learn about a new health condition, as well as for managing subsequent events associated with that condition. Health conditions that are progressive and accompanied by compounding, ongoing changes in functional capacity necessitate continuing coping and adjustment.

Individuals cope with health conditions in different ways. Some cope by actively confronting their condition, learning new skills, and becoming proactive in management of their health condition. Others defend themselves from stress and the realities of the condition by denying the seriousness of the health condition, ignoring recommendations for management, or refusing to learn new skills or behaviors to enhance functional ability. Still others cope by engaging in self-destructive behavior, such as actively continuing behavior that has detrimental effects on their health status.

Effective coping enables individuals to attain emotional equilibrium, to achieve a positive mental outlook, and to avoid incapacitation from fear, anxiety, anger, or depression. Effective coping must be viewed in the context of each individual's personal background and experiences, life situation, and perception of his or her own circumstances. Coping strategies that have worked successfully for individuals in the past are more likely to be used in the future. When old strategies are no longer effective or are not appropriate to the new situation, individuals may implement new coping strategies to neutralize stress and adjust to associated changes.

Coping, however, does not occur in a vacuum. The individual's social environment can facilitate or discourage effective coping. In general, an environment that helps individuals gain a sense of control through active participation in decision making and take responsibility for their own destiny as much as possible best enables them to cope effectively with their health condition.

Coping Strategies

Coping strategies are subconscious mechanisms used to cope with stress. Although coping strategies are useful to reduce anxiety and maintain balance and productivity, their overuse can also be detrimental. Examples of some common coping strategies include the following:

- Denial
- Regression
- Compensation
- Rationalization
- Diversion of feelings

Denial

Learning about a new health condition and its associated implications can be anxiety provoking. As a way to deal with anxiety, individuals may subconsciously use *denial* to negate the reality of the situation. Specifically, they may deny that they have the condition by forgoing management recommendations or by rejecting the implications of the condition. In the early stages of adjustment, denial may be beneficial, in that it enables individuals to adjust to the reality of their situation at their own pace, preventing excessive anxiety. When denial continues, however, it can interfere with adequate management of the condition or impede the process of learning new skills that would enhance functional capacity.

Depending on the nature of the health condition, an individual's denial of his or her condition can have a negative impact on others by placing them at risk. For example, if the health condition has an infectious component—as is true for tuberculosis and HIV—individuals in denial may avoid use of proper precautions to prevent the spread of the condition to others. In other situations, individuals may put others in jeopardy by denying limitations in function, such as by continuing to drive even though they are legally blind.

Regression

Regression is a coping strategy in which individuals subconsciously revert to an earlier stage of development, so that they become more dependent, behave more passively, or exhibit more emotionality than would normally be expected at their developmental level. In the acute or early stages of a health condition, returning to a state of dependency experienced in an earlier stage of development can be helpful, especially if management of the condition requires rest and inactivity. When individuals remain in a regressive mode, however, it can interfere with their adjustment and attainment of a level of independence that allows them to reach optimal functional capacity. For example, after a **myocardial infarction** (heart attack), individuals may be encouraged to walk several miles each day to increase their strength and endurance. Individuals continuing to cope with regression, however, may refuse to engage in strength and endurance activities that would enhance their functional capacity and instead remain inactive and dependent on others.

Compensation

Individuals using *compensation* as a coping strategy learn to counteract functional incapacitation in one area by becoming stronger or more proficient in another area. That is, when function is compromised in one area, individuals may find ways to excel in another sphere. Compensatory behavior is generally highly constructive when new behaviors are directed toward positive goals and outcomes. For example, individuals who are unable to maintain their level of activity because of physical manifestations associated with their condition may turn to creative writing or other means of self-expression. Compensation as a coping strategy can be detrimental, however, if the new behaviors used in compensating for functional changes are self-destructive or socially unacceptable. For example, an individual who experiences disfigurement as a result of a health condition may become promiscuous as a way of compensating for his or her perception of physical unattractiveness.

Rationalization

As a coping strategy, *rationalization* enables individuals to find socially acceptable reasons for their behavior or to excuse themselves for not reaching goals or not accomplishing tasks. Although rationalization can soften the disappointment of dreams unrealized or goals not reached, it can also produce negative effects if it becomes a barrier to adjustment, prevents individuals from reaching their full potential, or interferes with effective management of the health condition itself. For example, an individual with visual impairment who is a student may rationalize that he or she failed the test because of the difficulty with vision rather than admitting that the test failure occurred because he or she went to the beach with friends rather than studying.

Diversion of Feelings

One of the most positive and constructive of all coping strategies can be the *diversion* of unacceptable feelings or ideas into socially acceptable behaviors. Individuals with health conditions may have particularly strong feelings of anger or hostility about their condition or the circumstances surrounding their condition. If their emotional energy can be redefined and diverted into positive activity, the coping strategy can be beneficial, making virtue out of necessity and transforming deficit into gain. As with all coping strategies, diversion of feelings can, however, have negative effects if anger or hostility is channeled into negative behaviors or socially unacceptable activities. For example, an individual with diabetes may have neglected to follow foot care precautions, which resulted in lower leg amputation. Rather than acknowledging self-anger, the individual may instead express hostility and blame toward family members.

POTENTIAL EMOTIONAL REACTIONS TO HEALTH CONDITIONS

Sudden, unexpected, or life-threatening situations related to health conditions can engender a variety of reactions. How individuals view their condition, its causes, and its implications greatly affects what they do in the face of it. They may view their condition as a challenge, an enemy to be fought, a punishment, a sign of weakness, a relief, a strategy for gaining attention, an irreparable loss, or an uplifting spiritual experience. Although emotional reactions vary both in type and in intensity, the following reactions are common. Each emotional reaction is discussed individually, but it is important to note that reactions are often experienced simultaneously.

Grief

Grieving is a natural reaction to loss, albeit one that is dependent on the meaning of the experience to the individual. What is perceived as a loss by one individual may be perceived as a hidden blessing by another. Assumptions regarding the meaning or degree of loss to an individual cannot be made, nor can assumptions be made regarding how, how long, or whether an individual will go through a grieving process. Although health conditions can involve what would appear to be a variety of associated losses, including changes in body composition, function, role, or social status, which could result in a reaction of grief, perceptions of loss and reactions to it are highly individualized.

Some individuals may have an initial reaction to a new health condition and associated implications of shock, disbelief, or numbness; others may accept the loss with little reaction. Whether an initial grieving period is experienced or not, after a period of adaptation, many individuals begin to accept changes resulting from the condition, and make adjustments and adaptations that are necessary to reestablish their place within the everyday world.

In some instances the grief reaction is prolonged, and individuals may develop a pathological grief reaction, which may interfere with functional ability more than the health condition itself.

Fear and Anxiety

Individuals naturally become anxious when confronted with a threat. Health conditions can pose a threat because of the potential loss of function, loss of love, loss of independence, or loss of financial security. Some individuals fear the unknown or unpredictability of the condition, which provokes anxiety. For others, hospitalizations that immerse them in a strange and unfamiliar environment away from home, family, and the security of routine produce anxiety. When conditions are life threatening, fear and anxiety may be associated not only with loss of function, but also with loss of life. Fear and anxiety associated with health conditions may render some individuals psychologically immobile and unable to act.

Assisting individuals to regain a sense of control over their situation through information and shared decision making can be an important step in reducing anxiety and facilitating rehabilitation. Note, however, that fear experienced by individuals may have both rational and irrational aspects. Fear and anxiety are oftentimes future oriented, having to do with perceptions of what could occur rather than being based on what is actually known in the present.

Anger

Individuals with health conditions may experience anger at themselves or at others for perceived injustices or loss associated with their condition. They may believe that their condition was caused by negligence or that their condition could have been avoided. If they perceive themselves as victims, anger may be directed toward the persons or circumstances they blame for the condition or situation. If they believe that their own actions were partly to blame for the health condition, anger may be directed inward.

Anger can also be the result of frustration. Individuals may vent their frustration and anger by displacing hostility toward others, even when those parties have no relationship to the development of the health condition and no influence over its outcome. Anger may also be an expression of the realization of the seriousness of the situation and associated feelings of helplessness. At times, anger may not be openly expressed, but rather hidden in quarreling, arguing, complaining, or being excessively demanding, in an attempt to gain some control. Helping individuals express anger in appropriate ways and enabling them to regain a sense of control over their situation can help to resolve anger that would otherwise be detrimental to successful rehabilitation.

Depression

Some individuals may experience feelings of depression after they realize the implications of their condition (Katon et al., 2010). They may express feelings of helplessness and hopelessness, apathy, or feelings of dejection and discouragement. Signs of depression include sleep disturbances, changes in appetite, difficulty concentrating, and withdrawal from activity. Not all individuals with health conditions experience significant depression, and, in those who do, depression may not be prolonged. The extent to which and whether depression is experienced vary from person to person. Prolonged or unresolved depression can result in self-destructive behaviors, such as substance abuse or attempted suicide. Individuals with prolonged depression should be referred for mental health evaluation and treatment.

Guilt

Guilt can be described as self-criticism or blame. Individuals or family members may feel guilty if they believe they contributed to, or in some way caused, the health condition. For instance, individuals who develop lung cancer or emphysema after years of tobacco use or those who experienced a spinal cord injury owing to an accident that occurred because they were driving while intoxicated, may experience guilt because of the role they played in the development of their condition. In other instances, they may experience guilt because they believe their health condition places a burden on their family or because they are unable to fulfill former roles. Still other scenarios of guilt include the concept of survivor guilt, in which an individual survives a situation when others in the same situation did not. For example, an individual who, although sustaining severe injuries, survives a tornado when none of his or her family members did may experience intense guilt, questioning why he or she survived when other family members perished.

Family members may also experience guilt because of feelings of anger or resentment they have toward the individual. Guilt may also be associated with blame if family members believe the individual is actively to blame for his or her health condition. For instance, if an individual develops cirrhosis of the liver due to heavy alcohol use, but had been told previously to reduce alcohol consumption because of impending liver failure, family members may actively blame the individual for his or her condition, causing the person to experience more guilt.

Guilt may be expressed or unexpressed and can occur in varying dimensions. It can be an obstacle to successful adjustment to the condition and its implications. Self-blame or blame ascribed by others is detrimental not only to the individual's self-concept but also to rehabilitative efforts as a whole. Guilt that affects rehabilitation potential or well-being is an indication that referral to appropriate professionals for evaluation and treatment may be appropriate.

DEVELOPMENTAL STAGES

Development is neither static nor finite but rather a continuous process from infancy to old age and death. Each developmental stage is associated with certain age-appropriate behaviors, skills, and developmental tasks, which allow for psychological and cognitive transitions from one stage to another. Individuals' age and developmental stage influence their reactions to chronic illness or disability and the problems and consequences they experience.

Each developmental stage of life has its own particular stresses or demands, apart from those experienced as a result of a specific health condition. A health condition at various stages of development can influence the independence and self-control associated with the developmental stages and can impede development of qualities and life skills associated with different developmental stages. The needs, responsibilities, and resources of adults differ from those of children;

as a consequence, the impact of a health condition in later years is different from the impact of a health condition experienced in young adulthood.

Family members and others generally adjust their behavior to accommodate and appropriately interact with individuals as they pass from one developmental stage to the next. When individuals experience a health condition, however, others may modify expectations of age-appropriate behavior. These modified expectations may then interfere with the individual's mastery of the skills required to meet the challenges of future developmental stages.

All aspects of development are related, so each developmental stage must be understood within the context of the individual's past and current experiences. Individuals with a health condition must be considered in the context of their particular developmental stage and the way in which the changes associated with their condition influence attitudes, perceptions, actions, and behaviors characteristic of their stage of development. Individuals' stage of development serves as a guideline not only in assessing their functional capacity but also in determining potential stressors and reactions.

Problems and stresses at different developmental stages are similar whether or not individuals have a specific health condition. Although no clear lines of demarcation separate life stages, and all individuals certainly develop at different rates, some commonalities are nevertheless associated with different life stages.

Ideally, those with a specific health condition should be encouraged to progress through each stage of development as naturally as possible, despite their condition. Individuals whose emotional, social, educational, or occupational development has been thwarted may be more incapacitated by their inability to cope with the subsequent challenges of life than by any limitations experienced because of illness or disability per se.

Childhood

Although the majority of children with a specific health condition and their families adapt successfully, children with a health condition are at increased risk of emotional and behavioral disorders (Gledhill, Rangel, & Garralda, 2000). In early life, children develop a sense of trust in others, a sense of autonomy, and an awareness and mastery of their environment. During these years, they begin to learn communication and social skills that enable them to interact effectively with others. They also learn that limits are set on their explorations, expressions of autonomy, and behaviors. Important to their development is a balance between encouraging initiative and setting limits consistently.

A health condition in childhood can impede attainment of developmental goals. Repeated or prolonged hospitalizations may deprive children of nurturing by a consistent and loving caregiver. Physical incapacity associated with the condition or management issues may prevent regular activities, socialization, and exploration of the environment. In some cases, overly protective family members may restrict activities or prohibit the child from displaying typical emotional expression. In other instances, overly sympathetic parents may condone inappropriate behaviors rather than correct them.

Conditions affecting development of communication skills may also affect children's interaction with the environment as well as their future development. *Developmental disabilities* (conditions present at birth or occurring during childhood) require adjustments throughout individuals' development. Any incapacity associated with such a developmental disability must be confronted and compensated for with every new aspect of development. Maintaining awareness of developmental needs and facilitating experiences that foster development will enhance children's ability to reach their maximal potential.

For most children, entering school expands their world beyond the scope of their family. Before children attend school, the values, rules, and expectations that they experience are, for the most part, largely those expressed within the family. When they enter school, however, they are exposed to a larger social environment. Not only do they learn social relationships and cooperative interactions but they also begin to develop a sense of initiative and industry. Children gradually become aware of their special strengths. As new skills begin to develop, school-aged children gain the capacity for sustained effort that eventually results in the ability to follow through with tasks to completion. The approval and encouragement of others and acceptance by their peers help children to build self-confidence, further enhancing development.

When children with a health condition enter school, they may not need special education placement, but they may require coordinated school interventions to maximize attendance and facilitate educational and social growth. Children with a health condition may experience school-related problems reflected in their psychological well-being, interactions with other children, or academic performance. When physical or cognitive incapacities affect children's ability to perform skills usually valued at this developmental stage, acceptance by peers may be affected. School attendance may be disrupted by the need for repeated absences, resulting in an inability to interact on a consistent basis within the peer group, which in turn may diminish social interactions.

In an attempt to shield the child from hurt and emotional pain, family members may further isolate the child from social interactions, creating the potential for reduced self-confidence. Reluctance of sympathetic family members to allow the child to participate in activities in which the child may experience failure can interfere with the child's ability to accurately evaluate his or her potential. Encouragement of social interactions and activities to the greatest degree possible allows the child the opportunity to develop the skills and abilities that are needed for later integration into the larger world.

Adolescence

Adolescence, as a period of transition between childhood and adulthood, is a unique developmental period that can influence future health and development. Chronic illness or disability may affect the adolescent's development, or the adolescent's stage of development may affect the adolescent's health condition (Katzman & Neinstein, 2016). Perceptions of and interactions with peers become increasingly important as adolescents further define their identity apart from membership in their family. With the need to establish independence, adolescents begin to emancipate themselves from their parents and may rebel against the authority of parents or others. Physical maturation brings a strong preoccupation with the body and appearance. Adolescents' need to identify themselves as someone attractive to others often becomes paramount. Awareness of and experimentation with sexual feelings present a new dimension with which the adolescent must learn to cope. Dating and expression of sexuality are important aspects of maturation. Any alteration in physical appearance caused by the health condition can influence adolescents' perception of body image and self-concept, thereby thwarting expression of sexual feelings.

Adolescents with a health condition may be at risk for secondary incapacities associated with psychosocial factors. A health condition during adolescence can disrupt relationships with peers, resulting in delayed social and emotional development. Alterations experienced because of the condition, its treatment, or sympathetic and protective reactions by family members may emerge as barriers to the adolescent's attainment of independence and individual identity. Parents may be overprotective to the point of infantilizing the adolescent, which decreases the youth's self-esteem and self-confidence.

In the attempt to become independent, regular characteristics of adolescent development, such as rebellion against authority or the need to be accepted by a peer group, may sometimes interfere with management of the health condition. If adolescents deny alterations associated with their health condition or ignore management recommendations, such behavior can have further detrimental effects on physical and functional capacity.

Young Adulthood

In young adulthood, individuals establish themselves as productive members of society, integrating vocational goals, developing the capacity for intimate relationships, and accepting social responsibility. When a health condition occurs during this stage of the development, associated manifestations—rather than interests or abilities of individuals—may define social, vocational, and occupational goals.

Physical manifestations may also inhibit individuals' efforts to build intimate relationships or to maintain relationships that they have already established. At this developmental stage, established relationships are likely to be recent, and the level of commitment and willingness to make necessary sacrifices may vary. Depending on the nature of the condition, procreation may be difficult or impossible. If the individual already has young children, childcare issues may be the source of additional concerns in light of the functional incapacities inherent in a specific health condition. Young adults who had not fully gained independence or left their family of origin at the time of the onset of the health condition may find gaining independence subsequent to the health condition's emergence more difficult. In some cases, the family's overprotectiveness may prevent individuals from having experiences appropriate to their own age group.

Middle Age

Individuals in middle age are generally established in their careers, have committed relationships, and are often providing guidance to their own children as they leave the family to establish their own careers and families. At the same time, middle-aged individuals may be assuming greater responsibility for their own aging parents, who may be becoming increasingly fragile and dependent. During middle age, individuals may begin to reassess their goals and relationships as they begin to recognize their own mortality and limited remaining time.

A health condition during middle age can interfere with further occupational development and even result in early retirement. Such changes can have a significant impact on the economic well-being of individuals and their families, as well as on individuals' identity, self-concept, and self-esteem. It may be necessary to alter established roles and associated responsibilities within the family. At the same time, individuals' partners, even when the relationship is a long-term one, may be reevaluating their own life goals. They may perceive a health condition as a violation of their own well-being and may choose to leave the relationship. Responsibilities for children and aging parents add more financial and emotional stress to that experienced as a result of a health condition.

Older Adulthood

Ideally, older adults have adapted to the triumphs and disappointments of life and have accepted their own life and imminent death. Although physical manifestations associated with aging are variable, older adults may experience diminished physical strength and stamina, as well as diminishing visual and hearing acuity. A health condition during older adulthood can impose physical or cognitive incapacities in addition to those caused by aging. The spouse or significant others of the same age group may also have decreased physical stamina, making physical care of individuals with a health condition more difficult. When older adults with a health condition are unable to attend to their own needs or when care in the home is unmanageable, they may find it necessary to change their lifestyle and move to another environment for care and supervision. Many individuals in the older age group live on fixed retirement incomes, so the additional expenses associated with a health condition may place a strain on an already tight budget. Not all older individuals, of course, have retirement benefits, savings, or other resources to draw on in times of financial need.

SELF-CONCEPT AND SELF-ESTEEM

Self-concept is tied to self-esteem and personal identity and includes individuals' perceptions and beliefs about their own strengths and weaknesses, as well as others' perceptions of them. *Self-esteem* can be defined as "the evaluative component of an individual's self-concept" (Corwyn, 2000, p. 357). It is often thought of as individuals' assessment of their own self-worth with regard to attained qualities and performance (Gledhill et al., 2000).

Self-concept influences the perceptions of others about an individual. A negative self-concept can produce negative responses in others, just as a positive self-concept can increase the likelihood that others will react in a positive manner. Individuals' self-esteem is related to their self-concept as well as to how others respond to them. Consequently, self-concept has a significant impact on interactions with others and the psychological well-being of the individual.

Social Identity

Social identity refers to an individual's self-concept that is derived from perceived membership in a social group (Tajfel & Turner, 1986). Depending on the social context, individuals may have different social identities at different levels according to their internalized perception of group membership. For example, an individual may identify himself or herself as a medical student but may also identify himself or herself as a member of the Young Republicans or Young Democrats, or according to an ethnic group, such as Native American. Group membership involves defining the self in terms of characteristics of the group rather than as an individual. Group membership can be an aspect of self-concept and can provide grounds for group comparisons. The more individuals view group membership as central to their self-definition, the stronger their social identity with the group (Haslam, 2001).

Social identity can influence how individuals think, act, and feel based on their perception of group inclusion or exclusion. If an individual views a group positively, his or her perception of inclusion in the group can boost self-esteem. Conversely, perceptions of exclusion from the group can have the opposite effect. Likewise, if an individual perceives a group negatively but identifies as part of the group, the person's self-esteem can be negatively affected.

Body Image

Body image, which is an important part of self-concept, involves individuals' mental view of their body with regard to appearance, sexuality, and ability to perform various physical tasks. It is influenced by bodily sensations, social and cultural expectations, and reactions of and experiences with others (White, 2000). Body image is influenced by each individual's personal conception of attractiveness, which is also determined by social and cultural influences and is related to both self-concept and self-esteem.

Body image is influenced by biological, cultural, social, and historical factors. It changes over time as alteration of appearance, capabilities, functional status, and social role occurs over the life cycle. Individuals' perceptions of their body are associated with more than cosmetic concerns; they also influence individuals' general health, personal relationships and intimacy, and general well-being (Biordi et al., 2002).

Health conditions may modify body image by requiring an alteration of self-view to accommodate the associated changes. The following factors influence the degree of alteration:

- Visibility of the change
- Functional significance of the change
- Speed with which the change occurred
- Importance of the physical change or associated functional limitations to the individual
- Reactions of others

(de Moore, Hennessey, Kunz, Ferrando, & Rabkin, 2000)

Body image is a reflection of individuals' image of themselves and how they believe others see them. Individuals' feelings and thoughts about their body image influence not only social relationships but also psychological characteristics and perceptions of the world. The degree to which the alteration of self-view is perceived by the individual in a negative way influences social and intrapersonal interactions, functional capacity, and success or failure in the workplace (Cusack, 2000).

The extent to which individuals incorporate change into their body image also depends on the meaning and significance of the change to the particular individual. The degree of physical change or disfigurement is not always proportional to the reaction it provokes. Indeed, a change considered minimal by one individual may be considered catastrophic by another.

Changes do not have to be visible to alter body image. Burn scars on parts of the body normally covered by clothing or the introduction of an artificial opening or stoma such as with colostomy, for example, may cause significant alteration in body image even though physical changes are not readily apparent to others.

The concept of body image is complex and individually determined. Body image incorporates not only the way individuals perceive themselves but also the way they perceive others as seeing them. Negative views of body image can be a barrier to psychological well-being, social interactions, functional capacity, and workplace adjustment. Consequently, the ultimate goal is to help individuals adapt to changes brought about by chronic illness or disability, integrating changes into a restructured body image that can be assimilated and incorporated into daily life.

Stigma

Stigma is a socially constructed concept that is a universal phenomenon and has evolved throughout history. This concept is generally associated with individual feelings of shame due to disapproval of others and guilt resulting from being discredited or devalued by others. Stigma may preclude an individual's full social acceptance. The degree of stigma varies from setting to setting, and from person to person. Although the concept of stigma is universal, it is socially constructed. As a consequence, a number of factors within different societies as well as within different cultures may modify what is considered stigmatizing.

Overall, stigma is related to what a certain society considers to be deviations from the norm in a number of different areas. These areas are defined by societally determined categories, which include those attributes, characteristics, and behaviors that individuals exhibit in each category. Because these categories are based on the expectations of the majority, they define what is considered acceptable or the norm based on majority standards. Categories may include age, race, gender, ethnic background or nationality, religion, occupation, or social roles. Individuals who meet the expectations of the majority regarding appearance, behavior, or group association are generally accepted and valued. In contrast, individuals who deviate from the expectations of the majority regarding what is acceptable in these categories are labeled as different from the majority and, therefore, less desirable. Thus individuals deviating from these expectations are often stigmatized. Because stigma is socially defined, it can vary from setting to setting, depending on the views of the majority. What is stigmatizing in one setting may not be stigmatizing in another venue.

Most stigmas are viewed as anxiety provoking and threatening to others. For example, older adults are often stigmatized because aging is a reminder of mortality and vulnerability. Individuals from different ethnic backgrounds, nationalities, or religions may be stigmatized because of lack of understanding by the majority of the meanings of traditions or beliefs in different groups. Individuals with HIV/AIDS are often stigmatized based on moral judgments. Likewise, individuals with health conditions often experience stigma owing to negative value judgments. Stigma results in discrimination, social isolation, disregard, depreciation, devaluation, and, in some instances, threats to safety and well-being.

The power of stigma may overshadow the positive characteristics of individuals who experience stigma. Individuals who are stigmatized may find it difficult to overcome the negative social reactions of others regardless of their positive attributes. For example, individuals with psychiatric disability may face continued stereotypes and prejudices regarding psychiatric disability regardless of their level of success in the workplace or community (Lyons & Ziviani, 1995).

Individuals with health conditions continue to experience stigma. Modern society's emphasis on youth, attractiveness, self-sufficiency, and productivity contribute to the tendency to devalue those who are perceived as deviating from these valued characteristics (Saylor, Yoder, & Mann, 2002). Stigma can have a profound effect on the ability to regain and maintain functional capacity and on the individual's acceptance of his or her health condition. Gender and race or ethnic background may be secondary sources of prejudice and subsequent stigma, causing additional stress and creating additional barriers to effective functioning (Nosek & Hughes, 2003).

Stigma affects not only the individual but also members of his or her family. Family members may experience social isolation and prejudice because of their association with the individual. Family members' ability to cope with their family member's health condition may be severely compromised by societal stigma. If there are unresolved family problems, societal stigma may merely exacerbate shame and guilt they may already feel.

Stigma has an impact on individuals' self-concept and self-esteem and can produce barriers that prohibit them from achieving their maximal potential. In an effort to avoid stigma, individuals may deny, minimize, or ignore their condition or management recommendations. If the condition is not readily discernible, hiding the health condition may be more easily accomplished. As time goes by and the individual's attempt to hide the condition becomes reinforced, he or she may become proficient in concealing the health condition so as to reduce the associated stigma. Although stigma may be reduced, pretending not to have the condition can become detrimental. Not only can denial interfere with needed management of the condition, but it may also delay acceptance and adjustment (Saylor et al., 2002).

Although efforts to reduce or obliterate stigma in society should continue, stigma is most likely to be overcome through positive interactions with individuals. It is possible to reduce negative implications of societal stigma through public education programs and by helping individuals establish a sense of their own intrinsic worth.

Uncertainty

Uncertainty in the lives of individuals with a health conditions can exist for a variety of reasons but is often related to concerns about an unknown future, the erratic nature of manifestations of the condition, the unpredictability of progression of the condition, or the ambiguity of manifestations. Some health conditions have immediate and permanent effects on functional capacity; in other cases, the course of the health condition is more variable. Deterioration may occur slowly over the span of several years or rapidly within months. Some conditions have periods of remission, when manifestations become less noticeable or almost nonexistent, only to be followed by periods of unpredictable exacerbation, when manifestations become worse. In some cases, the same condition progresses at different rates for different individuals—progressing rapidly for some, but slowly for others. With some conditions, it is difficult to determine when or whether the condition will reach the point of severe incapacitation or whether a dramatic change of functional capacity will take place.

Uncertainty of outcome or progression of the condition can make planning and prediction of the future difficult and can sometimes render an individual immobile. The unpredictability of health conditions can be frustrating for both affected individuals and those around them. There may be reluctance to plan for the future at all, so that inability to predict the future becomes more incapacitating than the actual physical manifestations of the condition itself. In other instances, given the unpredictability of their condition, individuals may elect to follow a different life course than they would have otherwise chosen. Decisions not to have children, to cut down on the number of hours spent in the work environment, or to suddenly relocate to a different part of the country may be misinterpreted by those unaware of the individual's condition or its associated unpredictability. For those persons having conditions in which manifestations or residual effects are unapparent to others, such decisions may be met with misunderstanding or criticism. Criticism of such decisions may be particularly distressing to individuals who do not wish to disclose or share intimate details of their condition with the casual observer.

Insecurity about the course of the condition may also be reflected by the attitudes of those closest to the individual, who, in an attempt to protect the person from potential future loss, withdraw emotional interactions or support. Uncertainty about progression of a condition imposes particular challenges on individuals and their families and can be a source of stress. Emphasizing the importance of living in the present, rather than dwelling on events that may or may not occur in the future, can help to reduce the amount of stress and anxiety experienced as well as enhance the quality of life currently experienced.

INVISIBLE HEALTH CONDITIONS

Some chronic illnesses or disabilities have associated physical changes that can be objectively assessed by others or have functional implications that necessitate the use of adaptive devices. The *visibility* of a condition has often been associated with stigmatization and marginality (Livneh & Wilson, 2003). Some conditions, such as diabetes or cardiac conditions, have no outward signs that alert casual observers to individuals' health status. The term *invisible condition* is used to refer to these conditions. Because there are no outward physical signs or other cues to indicate limitations associated with the condition, others have no basis on which to alter expectations with regard to individuals' functional capacity. Although this lack of reaction can be positive (in the sense that it prevents actions by others that are based on prejudice or stereotypes), it can also be negative in the sense that it can enable individuals to deny or avoid acceptance of their condition and its associated implications.

The degree to which a condition remains invisible may be a function of the closeness of the observer's association with the individual. Although casual acquaintances might not notice manifestations or alterations associated with the condition, those more closely involved with the individual in day-to-day activities may more readily observe them. Other conditions under regular circumstances may offer no visible signs or cues, no matter how close the association with the individual.

The unapparent aspect of manifestations in invisible disability may be a unique element related to individuals' adjustment and acceptance of those manifestations and resulting alterations that are needed. Without environmental feedback to create a tangible reality of the condition, individuals with an invisible condition may postpone adaptation or ignore management recommendations necessary for regulating the condition and prevention of further manifestations.

Sexuality

Human sexuality is more than genital acts or sexual function; it is intrinsic to a person's sense of self. It is an ever-changing, lived experience, affecting the way individuals view themselves and their bodies (Hordern & Currow, 2003). Sexuality encompasses the whole person and is reflected in all of the individual's behavior. It is an important part of identity, self-image, and self-concept (Brodwin & Frederick, 2010). Each person is a sexual being with a need for intimacy, physical contact, and love. The effects of health conditions on sexuality are multifactorial and can affect all phases of sexual response (McInnes, 2003).

Expression of sexual urges is one form of sexuality. Health conditions can affect sexual expression through physical manifestations, depression, lack of energy, pain, alterations in self-image, or the reactions of others. In some conditions, the main barrier to sexual expression may be issues of self-concept and body image; with other conditions, physical changes may present physical barriers that affect sexual function directly. In other instances, attitudes of others or of society as a whole can be a major barrier to sexual expression. For example, although there has been increased acceptance of expression of sexuality by adults with intellectual disability, sexual expression that includes marriage or desire to start a family remains contentious (Cuskelly & Bryde, 2004).

Regardless of the types of alterations associated with a health condition, sexual expression remains an important part of function that should be addressed (McBride & Rines, 2000). In some instances, it may be necessary to help individuals overcome their own misperceptions and fears to establish a means for sexual expression. In other instances, individuals may need assistance to overcome barriers or to learn methods of sexual expression different from those used previously. In any case, sexual adjustment is a significant element in the restoration of an individual's optimal functional capacity.

FAMILY ADAPTATION

Family is the social network from which individuals derive identity and with which individuals feel strong psychological bonds. Family has different meanings for different people and is not always defined based on blood relationships or law. Family provides protection, socialization, physical care, support, and love. Each individual within the family structure plays some role that is incorporated into everyday family function.

Health conditions have both emotional and economic impacts on families as well as on individuals. Family reactions to a health condition may be similar to those experienced by the individual and may include shock, denial, anger, guilt, anxiety, and depression. Families must make adaptations, adjustments, and role changes both as a unit and as individual family members. The way in which families react and adapt to a health condition will influence affected individuals' subsequent adjustment. Whether families foster independence or dependence, show acceptance or rejection, or encourage or sabotage adherence with alterations and management recommendations has profound effects on individuals' ultimate functional capacity.

Specific issues for families when a family member develops a health condition are loss related to family functioning and loss related to functioning of the individual. There may be a strong desire to be a "normal" family again. Family members' prior expectations for the individual's future or "what might have been" may lead them to experience anger, resentment, or disappointment if they see the health condition as interfering with achievement of their expectations.

Family members can also act as advocates for the individual. They may need to become more involved with health professionals and service agencies or become increasingly assertive to obtain necessary services. If individuals with a health condition require significant care or interventions to be administered at home, family members may become fatigued because of the extra responsibility and tasks required, especially if respite services are limited.

Families, like individuals, have differing resources, depending on life circumstances, previous experiences, and the personalities involved. Individual family members may be called upon to provide not only emotional support but also physical care, supervision, transportation, or a variety of other services necessitated by the individual's condition. In addition, changes of roles or financial circumstances due to a health condition may alter goals and plans of other family members, such as college plans of a sibling or early retirement plans of a parent. The amount of care and attention required by individuals with a health condition may create emotional strain among family members, resulting in feelings of resentment, antagonism, and frustration. Role change and ambiguity may make it necessary to redefine family relationships as new and unaccustomed duties and responsibilities arise.

QUALITY OF LIFE

Successful rehabilitation entails more than assisting individuals to reach their optimal functional capacity; it also means assisting individuals to achieve and enhance their quality of life. *Quality of life* is subjective in nature, with no universal meaning. No two people define the term in quite the same way. Although quality of life may be viewed by some as optimal functioning at the highest level of independence, others may place greater emphasis on life itself, regardless of level of function. Only the individual can determine the personal meaning of the quality of life. Individual value systems, cultural backgrounds, spiritual perspectives, and the attitudes and reactions of those within the environment all influence the interpretation of quality of life.

Each individual's situation and experience are unique. Perceptions of the same condition and its impact vary from individual to individual (Burker, Carels, Thompson, Rodgers, & Egan, 2000; Crews, Jefferson, Broshek, Barth, & Robbins, 2000). As a consequence, people with similar conditions, symptoms, and limitations may perceive their condition in totally different manners.

The perception of a health condition depends on characteristics of the condition and its management, the age and developmental stage of the affected individual, the degree and extent of alterations needed, and the manner in which manifestations of the condition affect the individual's definition of quality of life. Manifestations or alterations that one individual accepts and to which he or she adapts may be perceived as overwhelming and intolerable to another individual. The impact of a health condition on the overall quality of life often determines daily choices and day-to-day management of the condition.

Assessment of quality of life is made difficult by the ambiguous nature of the concept. Attempts to discover and accurately measure quality of life have caused considerable confusion and resulted in the development of multiple indicators. Indicators of quality of life have ranged from physiologic parameters, to the ability to return to work, to the ability to participate in social activities, to the number of psychological problems experienced by the individual. In addition, studies of quality of life have often identified discrepancies between the judgment of service providers and that of consumers regarding quality-of-life outcomes (Leplege & Hunt, 1997).

Individuals' perception of quality of life is one of the main determinants of demand for services, adherence with management recommendations, and satisfaction with services provided. How some individuals assess the impact of their condition on their quality of life is determined by the degree to which they feel they have control over their life circumstances or destiny. Accurate knowledge about their condition and its management, together with active participation in decision making about the management of the condition, can enable individuals with a health condition to make judgments that will enable them to enhance quality of life in terms of their own needs, goals, and circumstances.

ADHERENCE TO MANAGEMENT RECOMMENDATIONS

Most health conditions require ongoing management, monitoring, or alteration of activity to regulate the condition or to prevent complications. However, many individuals with a health condition fail to follow management recommendations, potentially imperiling their own well-being (Dunbar-Jacob et al., 2000; Graham, 2003). Neglecting to take medications as recommended, resisting alteration of activities, or engaging in behaviors that are likely to cause complications of the condition can significantly influence individuals' outcomes and functional capacity (Dolder, Lacro, Leckband, & Jeste, 2003; Schmaling, Afari, & Blume, 2000; Vergouwen, Bakker, Katon, Verheij, & Koerselman, 2003; Zygmunt, Olfson, Boyer, & Mechanic, 2002). The best rehabilitation plan is of little value if individuals do not follow management plans designed to regulate the condition or to prevent complications or progression from occurring (Kovac, Patel, Peterson, & Kimmel, 2002; Loghman-Adham, 2003).

Although individuals who purposely behave in a way that makes their condition worse seem irrational, a number of explanations for nonadherent behavior are possible. Health conditions elicit many responses from individuals and their families. Different reactions, experiences, and motives direct behavior and can help or hinder adherence to management recommendations.

Individuals' lives are guided by a set of standards and values—both expressed and unexpressed. Each individual has a personal, unique perspective on health, illness, and health care itself. Consequently, a remarkable difference in perceptions of and reactions to apparently similar health conditions is possible. The meaning of a health condition and the significance ascribed to adherence to management recommendations are based mainly on individuals' perceptions of the condition and its associated alterations as well as their perceptions of management recommendations and their implications. While some individuals react mildly to a condition that might devastate another person, others display substantial emotional and physical discomfort with conditions that most people would consider minor. Obviously, various psychosocial factors determine individuals' reactions to a health condition and, consequently, their reactions to the recommendations given.

Health conditions can disrupt the way an individual views his or her self and the world, and can produce distortions in thinking. Most individuals initially experience a feeling of vulnerability and a shattering of the magical belief that they are immune from illness, injury, or even death. With this realization, they may lose their sense of security and cohesiveness. Life may seem a maze of inconveniences, hazards, and alterations. Nonadherence to recommendations may be an attempt to exert self-determination, to regain a sense of autonomy and control, and to claim some mastery over individual destiny. In other instances, resistance to management recommendations may be a denial of the condition itself.

Nonadherence can also reflect the individual's feelings about his or her life circumstances. For some individuals, having a health condition is not a positive role; for others, it may be far preferable to the social role that they held previously. Some persons may vacillate between the wish to be independent and the wish to remain dependent. Health conditions can be a means of legitimizing dependency as well as a means of increasing the amount of attention received. Subsequently, an individual may be reluctant to return to his or her former roles and obligations. The motivation to retain the sick role is at times greater than the motivation to gain optimal function. As a result, rehabilitation may be hampered.

Failure to adhere to recommendations is sometimes a response to guilt that has been incorporated into the reaction to or beliefs about the health condition. If health and well-being are perceived as rewards for a life well lived, onset of a health condition may be viewed as punishment for real or imagined actions of the past. Adherence to management recommendations that helps to regulate the condition may be perceived as interference with a punishment believed to be deserved. In other instances, individuals may feel guilty because they believe that the health condition is a direct result of their own negligence or overt actions.

Guilt or shame at being different may also hinder adherence to management recommendations. Some individuals may attempt to hide their condition from others and, therefore, fail to follow recommendations that they fear may call attention to their condition.

The impact of a health condition on an individual's general economic well-being can also affect his or her ability and willingness to follow management recommendations. While many occupations offer fringe benefits, such as paid sick days or even time off with pay during which to seek health care, other occupations provide no such benefits. In the latter case, days taken off from work because of a health condition or healthcare appointments can decrease income. The economic consequences of health conditions may also cause the opposite reaction. If an individual is receiving disability benefits and has little opportunity to find satisfactory employment, he or she may not follow recommendations that would increase the ability to return to work, thereby decreasing or eliminating benefits.

Finally, quality of life is a relative concept, uniquely defined by each individual. If treatment recommendations, or side effects of treatment, result in pain, discomfort, or inconvenience greater than the benefit perceived by the individual in terms of his or her own subjective definition of the quality of life, adherence with prescribed recommendations may not be perceived as worth the psychological, social, or physical cost. Management recommendations can sometimes—but not always—be adjusted to make adherence to recommendations more palatable. Individuals' right to self-determination must be carefully balanced with assurance that the choice of nonadherence is based on solid information and full understanding of the implications.

Some individuals readily adjust to the challenges and alterations necessitated by a health condition. Other individuals actively subvert management recommendations, to their own detriment. In such instances, professionals' goals should be to attempt to understand the underlying problems and motivations of individuals and to help them make the necessary adjustments and adaptations to optimize functional outcomes. Rather than criticizing individuals with a health condition for disinterest, a lack of motivation, or failure to follow recommendations, it is important to identify the barriers that inhibit adherence and to recognize that such reactions may indicate difficulty in accepting the condition or incorporating recommendations into the individual's own unique way of life. The best way to achieve adherence is to consider the individual's perceptions, goals, environment, and lifestyle, and to tailor recommendations to best meet those needs (Falvo, 2011).

HEALTH INFORMATION

Although health care, support, and auxiliary services are important aspects of helping individuals reach their optimal potential, successful management of health conditions requires considerable individual and family effort. Regardless of the complexity of the condition, many individuals are now expected to carry out management recommendations in their home rather than depend on the assistance of healthcare personnel in healthcare settings. Individuals' understanding of their condition, manifestations, and management recommendations is one of the basic components of self-determination and responsible care. Not only must they understand how to integrate these management recommendations into their daily routines and how to carry out daily care activities, but they must also understand how preventive healthcare measures can help them retain function and avoid further health-related problems (Falvo, 2011). In addition to individuals' motivation to learn and manage their condition, as well as family support, creation of more accessible environments increases the likelihood that individuals will be able to effectively manage their condition (Rimmer, 2005).

Because of increasing public awareness of the need for individuals to accept this greater role of responsibility and self-determination, a number of programs and counseling services have been established to help individuals and their families reach this goal. Patient and family education can take place either on an individual basis or in a group setting, can be formal or informal, and can include ongoing counseling or referral to resources for self-directed learning. Regardless of the type of setting in which educational services are delivered, the most effective education will consider the specific circumstances and goals of the individual (Falvo, 2011).

STAGES OF ADAPTATION AND ADJUSTMENT

A host of personal, social, and environmental experiences, demands, supports and resources, and coping strategies interact to influence adaptation outcomes (Livneh, 2001). The process of adjustment includes a search for meaning in the experience and an attempt to regain control and self-determination over the events that affect one's life. Most individuals with a health condition experience some form of loss—either a direct physical loss or a more indirect loss of the ability to participate in some previously performed activity. Regardless of the nature of the loss, a variety of reactions may take place while individuals attempt to make necessary adaptations and changes.

Stages of adjustment are both individual and varied. The shock of diagnosis and its consequent implications may have a numbing effect, such that initially individuals demonstrate little emotional reaction. As the reality of the situation becomes clear, individuals may experience a sense of hopelessness and despair, mourning for a self, a role, or a function that is lost. They may also experience feelings of anger that alternate with depression. Many individuals go through a period of mourning and bereavement similar to that experienced when a loved one is lost. Mourning is a natural reaction to loss and allows time for reflection and reestablishment of emotional equilibrium. As individuals begin to appraise their condition realistically, examine the alterations that it requires, and adjust to the associated losses, they may gradually seek alternatives and adaptations to achieve their integration into a broader world.

The ultimate outcome of adjustment is acceptance of the condition and its associated alterations, along with a realistic appraisal and implementation of strengths. Acceptance does not mean passivity regarding implications of the condition but rather that individuals are ready to move forward in reaching optimal functional capacity. The amount of time that individuals need to reach acceptance depends on personality, reactions of family and significant others, life circumstances, available resources, and the types of challenges that confront each individual. Some individuals never reach acceptance. Nonacceptance may be characterized by immobility, marked dependency, continued anger and hostility, prolonged mourning, or participation in detrimental or self-destructive activities. Just as coping strategies are vital parts of human nature that protect against stress, reduce anxiety, and facilitate adjustment, so overuse or negative use of coping strategies can postpone or inhibit adjustment.

MULTICULTURAL ISSUES

Culture consists of more than race or ethnicity. It can be defined by a shared system of values, beliefs, and patterns of behavior that is shaped by many factors, including country of origin, language, religion, and sexual orientation (Taylor, 2016). Cultural factors shape individuals' perception of self as well as define views of health and health conditions and their meaning in the context of culture. Concepts related to causes of and reasons for various health conditions, values, and accepted ways of managing a condition are all cultural variables that determine attitude, adjustment, expectations, and outcomes related to chronic illness and disability. Adjustment and adaptation to a health condition are related to a variety of cultural aspects, including race, gender, ethnicity, spiritual or religious beliefs, and sexual orientation.

FUNCTIONAL ASPECTS

Functional effects of health conditions are many and varied. Each individual has different needs, abilities, and circumstances that determine how a health condition affects his or her functional capacity. The extent to which the individual experiences limitation as a result of the condition depends to a great extent on his or her goals and perception of the condition, the environment, and the reactions of family, friends, and the societal and political environment. The severity of the condition as measured by tests is not always an indication of functional capacity. Moreover, individuals' ability to function is not always directly correlated with the severity of the condition. Rather, function is determined by an interaction of factors related to the person and his or her environment. As a consequence, individuals' reactions may differ even though they have similar health conditions.

Professionals working with individuals with health conditions need an understanding of the potential alterations associated with a specific condition or management recommendations to help individuals and their families make appropriate changes to gain optimal functional capacity. The effects of health conditions are far-reaching and include psychological, social, and vocational effects as well as changes and adjustments in both general lifestyle and activities of daily living. The condition per se is not as important as the individual's goals and the degree to which function in each area of the individual's life is affected. The interactive nature of function between each of the areas determines the extent to which individuals can reach their optimal level of function. Thus a focus on any one area without full consideration of the impact of the health condition on all other areas can dilute the effectiveness of rehabilitative efforts. Understanding and working effectively with individuals who have a health condition requires adopting a broad outlook that goes beyond labeling the condition; it requires recognition that the most important factor is individuals' ability to function with the condition within their environment and all areas of their life.

Personal and Psychosocial Issues

Individuals react both cognitively and emotionally to events that involve them. These reactions, in turn, affect the later course of those events. Personal and psychological factors are always present in all aspects of health conditions, and they influence individuals' response to the health condition. Sometimes psychological factors are part of the manifestations of the condition itself. These factors affect not only individuals' adjustment and subsequent functional capacity but also outcomes.

Activities and Participation

Life activities consist of the tasks and activities of daily living within an individual's environment. They include the ability to perform tasks related to grooming, housekeeping, and preparing meals. They also include activities related to transportation, daily schedules, need for rest or activity, recreation, sexuality, and privacy. At times, limitations in performing the activities of daily living may result from environmental considerations that serve as barriers to effective functioning. Modifications such as widening doorways to permit the passage of a wheelchair, placing handrails in a bathroom, or installing more effective lighting may be required to increase functional capacity. Other modifications may be necessary because of the additional tasks and time commitments related to medical treatment of a specific condition. In some instances, alterations of diet or activity, continued treatments, medical appointments, and related activities may require significant changes in the individual's daily schedule.

The social environment can be defined as individuals' perceived involvement in personal, family, group, and community relationships and activities. Interpersonal support has been found to be significant in enabling persons with health conditions to effectively manage their condition (Bisschop, Kriegsman, Beekman, & Deeg, 2004; Chapman, Craven, & Chadwick, 2005; Glasgow, Strycker, Toobert, & Eakin, 2000). Social well-being is based on emotionally satisfying experiences in social activities involving those within the individual's social group. Health conditions can lead to changes in social status. Individuals with a health condition may find themselves in a socially devalued role. As a result, they may experience changes in social relationships or interactions, or limit the number of social activities; any of these changes can result in social isolation. Even when individuals with a health condition attempt to remain socially active, they may have difficulty entering community facilities because of environmental barriers or because of prejudice or stereotyping. Many factors contribute to an individual's adaptation or adjustment to any social alterations associated with a particular health condition.

In addition, individuals' perception or misperception of the reactions of others in social groups may determine the level of acceptance that they receive. The degree to which individuals are able to adapt, accept, and adjust to their condition is determined in part by their interactions with others in their environment as well as by their interpretation of the reactions of others.

VOCATIONAL ISSUES

The significance of work in the rehabilitation of people with health conditions has been well documented (Cunningham, Wolbert, & Brockmeier, 2000). Work involves more than remuneration for services rendered, and it does not necessarily include only activity related to financial incentives. Work provides a sense of contribution, accomplishment, and meaning to life (Ben-Shlomo, Canfield, & Warner, 2002; Bond et al., 2001; Corrigan, Bogner, Mysiw, Clinchot, & Fugate, 2001). Consequently, loss of ability to work extends beyond financial considerations to social and psychological well-being. Loss of ability to work means more than the loss of income; it also means the loss of a socially valued role. For many individuals, work is not merely a major part of their identity but a source of social interaction, structure, and purpose in life.

The degree to which a health condition affects an individual's ability and willingness to work depends on a variety of factors in addition to the alterations associated with the health condition (Young & Murphy, 2002). These factors include the nature of the work, the physical environment of the work setting, and the attitudes of employers and coworkers. Psychosocial variables may also complicate functional capacity and, therefore, the rehabilitation process. At times, individuals with a health condition may continue to perform the same work they performed before the onset of the condition. At other times, certain work tasks, environmental conditions, or work schedules may need to be modified to accommodate alterations associated with the health condition. If modifications cannot be made in these cases, individuals must change employment. Some individuals must assume disability status because appropriate modifications cannot be made or because manifestations of their condition preclude work in their previous occupation. Job stress and attitudes of employers or coworkers can also significantly interfere with individuals' ability to return to the workforce. Problems with transportation to and from work because of manifestations or alterations associated with a health condition may make a return to work more difficult. In other instances, time required to carry out management recommendations related to the condition may make completing a full day at work virtually impossible.

Individuals' capacity to function at a job can depend on cognitive, psychomotor, and attitudinal factors as well as on the physical aspects of the health condition. Accurate assessment of individuals' capacity to return to work incorporates more than evaluation of physical factors alone; that is, success or failure at work is often determined by factors other than physical skill or ability. Individuals' fear of reinjury, vocational dissatisfaction, or legal issues can hamper return to work. Individuals' ability to relate to and interact with others within the work environment must also be considered. Interests, aptitudes, and abilities are always pivotal factors in determining vocational success, regardless of manifestations or alterations related to the health condition. Effective rehabilitation that enables individuals to function effectively in their job often involves interdisciplinary efforts of many types of professionals to conduct assessment, evaluation, therapy, and offer vocational guidance.

REFERENCES

Ben-Shlomo, Y., Canfield, L., & Warner, T. (2002). What are the determinants of quality of life in people with cervical dystonia? *Journal of Neurology and Neurosurgical Psychiatry*, *72,* 608–614.

Biordi, D. L., Boville, D., King, D. S., Knapik, G., Warner, A., Zartman, K. A., & Zwick, D. M. (2002). In: I. Morof Lubkin & P. D. Larsen (Eds.)., *Chronic illness: Impact and interventions* (5th ed*.,* pp. 261–277). Sudbury, MA: Jones and Bartlett.

Bisschop, M. I., Kriegsman, D. M. W., Beekman, A. T. F., & Deeg, D. J. H. (2004). Chronic diseases and depression: The modifying role of psychosocial resources. *Social Science & Medicine, 59,* 721–733.

Bond, G. R., Resnick, S. G., Bebout, R. R., Drake, R. E., Xie, H., & McHugo, G. J. (2001). Does competitive employment improve nonvocational outcomes for people with severe mental illness? *Journal of Consulting Clinical Psychology, 69,* 489–501.

Brodwin, M. G., & Frederick, P. C. (2010). Sexuality and societal beliefs regarding persons living with disabilities. *Journal of Rehabilitation, 76*(4), 37–41.

Burker, E. J., Carels, R. A., Thompson, L. F., Rodgers, L., & Egan, T. (2000). Quality of life in patients awaiting lung transplant: Cystic fibrosis versus other end-stage lung diseases. *Pediatric Pulmonology*, *30,* 453–460.

Chapman, J. J., Craven, J. J., & Chadwick, D. D. (2005). Fighting ft? An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *Journal of Intellectual Disabilities, 9,* 131–144.

Corbin, J. (2001). Introduction and overview of chronic illness and nursing. In R. Hyman & J. Corbin (Eds.)., *Chronic illness: Research and theory for nursing practice* (pp. 1–15). New York, NY: Springer.

Corrigan, J. D., Bogner, J. A., Mysiw, J. W., Clinchot, D., & Fugate, L. (2001). Life satisfaction after traumatic brain injury. *Journal of Head Trauma Rehabilitation, 16,* 543–555.

Corwyn, R. F. (2000). The factor structure of global self esteem among adolescents and adults. *Journal of Research and Personality, 34*, 357–379.

Crews, W., Jefferson, A., Broshek, D., Barth, J., & Robbins, M. (2000). Neuropsychological sequelae in a series of patients with end-stage cystic fibrosis: Lung transplant evaluation. *Archives of Clinical Neuropsychology, 15,* 59–70.

Cunningham, K., Wolbert, R., & Brockmeier, M. B. (2000). Moving beyond the illness: Factors contributing to gaining and maintaining employment. *American Journal of Community Psychology*, *28*(4), 481–493.

Cusack, L. (2000). Perceptions of body image: Implications for the workplace. *Employee Assistance Quarterly, 15*(3), 23–29.

Cuskelly, M., & Bryde, R. (2004). Attitudes toward the sexuality of adults with an intellectual disability: Parents, support staff and a community sample. *Journal of Intellectual and Developmental Disability, 29*(3), 255–264.

de Moore, G. M., Hennessey, P., Kunz, N. M., Ferrando, S., & Rabkin, J. G. (2000). Kaposi's sarcoma: The scarlet letter of AIDS. The psychological effects of a skin disease. *Psychosomatics*, *41*(4), 360–363.

Dolder, C. R., Lacro, J. P., Leckband, S., & Jeste, D. V. (2003). Interventions to improve antipsychotic medication adherence: Review of recent literature. *Journal of Clinical Psychopharmacology*, *23*(4), 389–399.

Dudgeon, B. J. (2002). Physical disability and the experience of chronic pain. *Archives of Physical Medicine and Rehabilitation*, *83*(2), 229–235.

Dunbar-Jacob, J., Erlen, J. A., Schlenk, E. A., Ryan, C. M., Sereika, S. M., & Doswell, W. M. (2000). Adherence in chronic disease. *Annual Review of Nursing Research, 18*, 48–90.

Falvo, D. R. (2011). *Effective patient education: A guide to increased adherence.* Burlington, MA: Jones & Bartlett Learning.

Glasgow, R. E., Strycker, L. A., Toobert, D. J., & Eakin, E. (2000). A social-ecologic approach to assessing support for disease self-management: The Chronic Illness Resources Survey. *Journal of Behavioral Medicine, 23,* 559–583.

Gledhill, J., Rangel, L., & Garralda, E. (2000). Surviving chronic physical illness: Psychosocial outcomes in adult life. *Archives of Disease in Childhood*, *83*(2), 104–110.

Graham, H. (2003). A conceptual map for studying long-term exercise adherence in a cardiac population. *Rehabilitation Nursing, 28*(3), 80–86.

Haslam, A. S. (2001). *Psychology in organizations: The social identity approach.* London, England: Sage.

Hordern, A. J., & Currow, D. C. (2003). A patient-centered approach to sexuality in the face of life-limiting illness. *Medical Journal of Australia, 179*(6 Suppl), S8–S11.

Katon, W. J., Lin, E. H. B., Von Korff, M., Ciechanowski, P., Ludman, E. J., Young, B., . . . McCulloch, D. (2010). Collaborative care for patients with depression and chronic illnesses. *New England Journal of Medicine, 363*(27), 2611–2620.

Katzman, D. K, & Neinstein, L. S. (2016). Adolescent medicine. In: L. Goldman & A. I. Schafer (Eds.)., *Goldman-Cecil medicine* (25th ed.). Philadelphia, PA: Elsevier Saunders.

Kovac, J. A., Patel, S. S., Peterson, R. A., & Kimmel, P. L. (2002). Patient satisfaction with care and behavioral compliance in end-stage renal disease patients treated with hemodialysis. *American Journal of Kidney Disease, 39*(6), 1236–1244.

Leplege, A., & Hunt, S. (1997). The problem of quality of life in medicine. *Journal of the American Medical Association, 278*(1), 47–50.

Livneh, H. (2001). Psychosocial adaptation to chronic illness and disability: A conceptual framework. *Rehabilitation Counseling Bulletin, 44*(3), 150–160.

Livneh, H., & Wilson, L. M. (2003). Coping strategies as predictors and mediators of disability-related variables and psychosocial adaptation: An exploratory investigation. *Rehabilitation Counseling Bulletin, 46*(4), 194–208.

Loghman-Adham, M. (2003). Medication noncompliance in patients with chronic disease: Issues in dialysis and renal transplantation. *American Journal of Managed Care, 9*(2), 155–171.

Lyons, M., & Ziviani, H. (1995). Stereotypes, stigma, and mental illness: Learning from fieldwork experiences. *American Journal of Occupational Therapy, 49*(10), 1002–1008.

McBride, K. E., & Rines, B. (2000). Sexuality and spinal cord injury: A road map for nurses. *SCI Nursing*, *17*(1), 8–13.

McInnes, R. A. (2003). Chronic illness and sexuality. *Medical Journal of Australia*, *179*(5), 263–266.

Morof Lubkin, I., & Larsen, P. D. (Eds.). (2002). *Chronic illness: Impact and interventions* (5th ed.). Sudbury, MA: Jones and Bartlett Publishers.

Nosek, M. A., & Hughes, R. B. (2003). Psychosocial issues of women with physical disabilities: The continuing gender debate. *Rehabilitation Counseling Bulletin*, *46*(4), 224–233.

Rimmer, J. H. (2005). The conspicuous absence of people with disabilities in public fitness and recreation facilities: Lack of interest or lack of access? *American Journal of Health Promotion, 19,* 327–329.

Saylor, C., Yoder, M., & Mann, R. J. (2002). Stigma. In I. Morof Lubkin & P. D. Larsen (Eds.)., *Chronic illness: Impact and interventions* (5th ed.). Sudbury, MA: Jones and Bartlett Publishers.

Schmaling, K. B., Afari, N., & Blume, A. W. (2000). Assessment of psychological factors associated with adherence to medication regimens among adult patients with asthma. *Journal of Asthma*, *37*(4), 335–343.

Shaw, L., Segal, R., Polatajkos, H., & Harburn, K. (2002). Understanding return to work behaviors: Promoting the importance of individual perceptions in the study of return to work. *Disability & Rehabilitation, 24*(4), 185–195.

Tajfel, H., & Turner, J. C. (1986). The social identity theory of inter-group behavior. In S. Worchel & L. W. Austin (Eds.), *Psychology of intergroup relations*. Chicago, IL: Nelson-Hall.

Taylor, V. M. (2016). Cultural context of medicine. In L. Goldman & A. I. Schafer (Eds.), *Goldman-Cecil medicine* (25th ed.). Philadelphia, PA: Elsevier Saunders.

Vergouwen, A. C., Bakker, A., Katon, W. J., Verheij, T. J., & Koerselman, F. (2003). Improving adherence to antidepressants: A systematic review of interventions. *Journal of Clinical Psychiatry, 64*(12), 1415–1420.

White, C. A. (2000). Body image dimensions and cancer: A heuristic cognitive behavioural model. *Psycho-Oncology, 9,* 183–192.

Young, A., & Murphy, G. A. (2002). A social psychology approach to measuring vocational rehabilitation intervention effectiveness. *Journal of Occupational Rehabilitation, 12,* 175–189.

Zygmunt, A., Olfson, M., Boyer, C. A., & Mechanic, D. (2002). Interventions to improve medication adherence in schizophrenia. *American Journal of Psychiatry, 159*(10), 1653–1654.

CHAPTER 3

Introduction to the Structure and Function of the Nervous System

STRUCTURE AND FUNCTION OF THE NERVOUS SYSTEM

The nervous system is a complex regulatory system that, along with the *endocrine system,* controls and coordinates activities and functions throughout the body, internally and externally, by sending, receiving, and sorting electrical impulses and chemical signals. Disruption of any part of the nervous system affects body function in some way, either internally or externally.

The nervous system consists of the *central nervous system,* which includes the *brain* and *spinal cord,* and the *peripheral nervous system,* which includes *nerve fibers* extending from the brain and spinal cord that carry information between the central nervous system and the rest of the body. The peripheral nervous system is further divided into two parts: the *afferent* (sensory) *system,* which carries messages from other parts of the body *to* the central nervous system, and the *efferent* (motor) *system,* which carries messages *from* the central nervous system to other parts of the body (see **Table 3-1**).

Function of the Nervous System

Functions of the nervous system include the following:

- Organizing and directing motor responses of the *voluntary muscle system,* enabling the body to move more effectively as a whole and to achieve purposeful movement. This coordination of voluntary muscles makes possible complex activities, such as walking, running, playing a piano, and using a computer, as well as simple activities, such as maintaining muscle tone and posture while at rest.
- Monitoring and recognizing stimuli (and information) within the environment, and then directing an appropriate response to the stimuli. This function makes possible reflex actions, such as pulling away one's hand from a hot surface, as well as perceiving music being played in the next room.
- Monitoring and coordinating internal body states so that internal organs function as a unit, internal body constancy (**homeostasis**) is maintained, and protective action is taken. For example, in response to a lack of oxygen, more rapid breathing occurs; the body shivers in response to cold; and when threat or danger is encountered, the heart beats more rapidly.

Other functions, such as display of personality traits, language, speech, learning, remembering, feeling emotion, reasoning, and generating and relaying thoughts, are also controlled by the nervous system—specifically, by the brain.

Table 3-1 The Nervous System (Central and Peripheral)

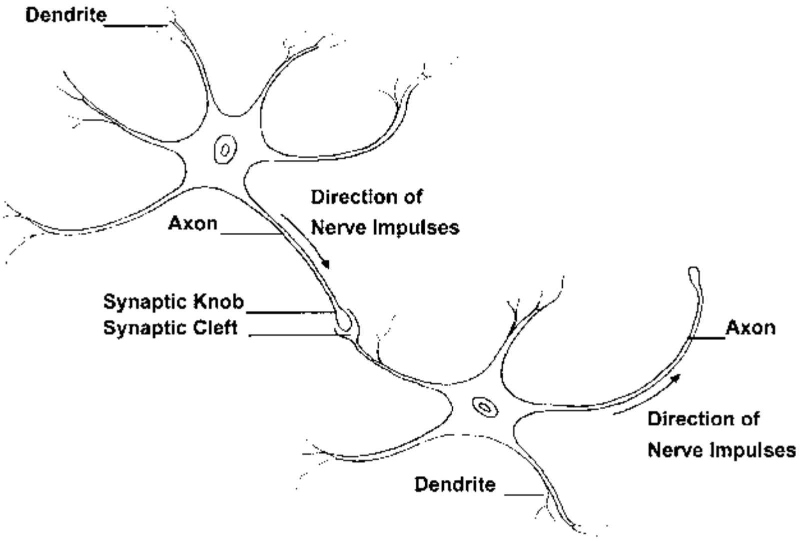
- I. Central nervous system
    - A. Brain
    - B. Spinal cord
- II. Peripheral nervous system
    - A. Afferent (sensory)
    - B. Efferent (motor)
        - 1. Somatic nervous system
        - 2. Autonomic nervous system
            - a. Sympathetic nervous system
            - b. Parasympathetic nervous system

Nerve Cells

Specialized cells called **neurons** are the functional units of the nervous system. Neurons transmit messages to and from the brain. They consist of a cell body and processes (*nerve fibers*) that extend beyond the cell body. In most cases, a single long nerve fiber called an *axon* conducts nerve impulses (and information) away from the cell body to other neurons. Smaller, shorter nerve fibers called **dendrites** conduct nerve impulses toward the cell body after receiving information from other neurons. Fibers that carry information from parts of the body to the brain are called **afferent neurons** (sensory neurons). Fibers that carry information from the brain to other parts of the body are called **efferent neurons** (motor neurons).

Surrounding neurons is a fatty sheath called **myelin**, which, much like the covering of electrical cords, provides insulation, ensuring that electrical impulses are able to flow smoothly and reliably. Information is passed from neuron to neuron by both electrical and chemical impulses. The electrical impulse, which has been picked up by the dendrites, is passed through the cell body to the axon. The electrical impulse then moves down the full length of the axon until it reaches its tip. At the tip of the axon are tiny processes, which release chemicals known as **neurotransmitters**. Neurotransmitters, chemically transfer the impulse from one neuron to another across a space between the two neurons called the **synapse**. The electrical impulse, through the vehicle of neurotransmitters, then moves to the next neuron's dendrites and the process begins again (see **Figure 3-1**). After

Figure 3-1 Neurons



© Jane Tinkler Lamm.

neurotransmitters are released, they are either taken up again by the neuron or destroyed.

Longer axons are generally grouped in bundles. When they are transmitting impulses within the central nervous system, these bundles are referred to as *tracts.* Those bundles located outside the central nervous system are referred to as *nerves.*

The Central Nervous System

The *central nervous system* is made up of the brain and spinal cord. Bony coverings protect both the brain and the spinal cord. On the interior of these bony coverings are three membranes (**meninges**) that provide additional protection:

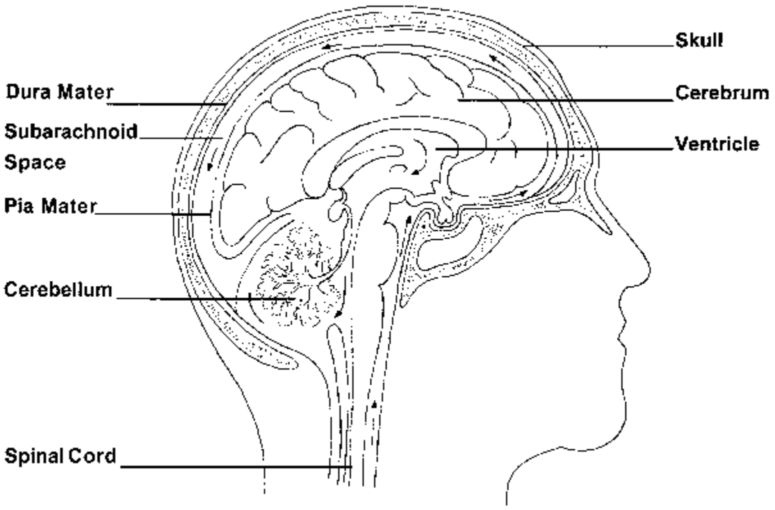
- The **dura mater** is the outer membrane, lying closest to the bony covering of the brain and spinal cord.
- The **arachnoid membrane** is the middle membrane, a **cobweb**-appearing membrane.
- The **pia mater** is the inner membrane, which lies closest to the brain and spinal cord.

Between each of the membrane layers are spaces. The space between the dura mater and the inner surface of the bony covering is the *epidural space*; the space between the dura mater and the arachnoid membrane is the *subdural space*; and the space between the arachnoid membrane and the pia mater is the *subarachnoid space.*

The central nervous system is also protected and cushioned by **cerebrospinal fluid** (CSF), which is formed by specialized capillaries called the *choroid plexus* in inner chambers within the brain called **ventricles**. The cerebrospinal fluid bathes the brain and spinal cord, circulating from the ventricles into the subarachnoid space (see **Figure 3-2**). From the subarachnoid space, the CSF flows to the back of the brain, down around the spinal cord, and then back to the brain, where it is reabsorbed into the blood through the arachnoid membrane. The amounts of cerebrospinal fluid produced and absorbed are equally balanced so that under normal conditions, the amount of CSF within the central nervous system remains constant.

Another protective device is the *blood–brain barrier*, a structural arrangement of capillaries that selectively determines which substances can move from the blood into the brain. While substances such as oxygen and glucose are necessary

Figure 3-2 Circulation of Cerebrospinal Fluid



© Jane Tinkler Lamm.

for brain survival and consequently move freely across the blood–brain barrier, other potentialharmful substances, such as toxins, are prevented from crossing into the brain.

The central nervous system is composed of white matter and gray matter. **White matter** makes up the inner part of the brain and the outer portion of the spinal cord and consists of myelinated covered axons that conduct nerve impulses. It is called white matter because of its whitish appearance due to the myelin covering. **Gray matter** makes up the thin outer layer of the brain and the inner portion of the spinal cord. Small segments of gray matter are also embedded deep within certain parts of the white matter of the brain. Gray matter consists of groups of neuron cell bodies. It is called gray matter because of its grayish appearance. Gray matter of the brain receives, sorts, and processes nerve messages, while gray matter of the spinal cord serves as a center for reflex action (automatic response to stimuli).

STRUCTURE AND FUNCTION OF THE BRAIN

The brain is directly connected to the spinal cord and serves as the primary center for the integration, coordination, initiation, and interpretation of most nerve messages. It regulates and monitors many unconscious body functions, such as heart and respiratory rate and coordinates most voluntary movements. In addition, it is the site of higher cognitive processes such as learning, generating and relaying thoughts, reasoning, judgment, memory, consciousness, and emotion. The brain also has a sensory function, which is responsible for vision, hearing, touch, taste, and smell. Language function, including the ability to communicate and to comprehend, is also controlled by the brain. Finally, the brain controls basic behavior patterns and the display of general personality traits, which are characteristic of how each individual responds to stimuli.

The brain is protected by the bony covering of the skull (**cranium** or *cranial bones*). The largest part of the brain, the **cerebrum**, is covered with a thin outer layer of gray matter called the **cortex**, which contains billions of nerve cells. The cortex has three specialized areas, which serve three major areas of function:

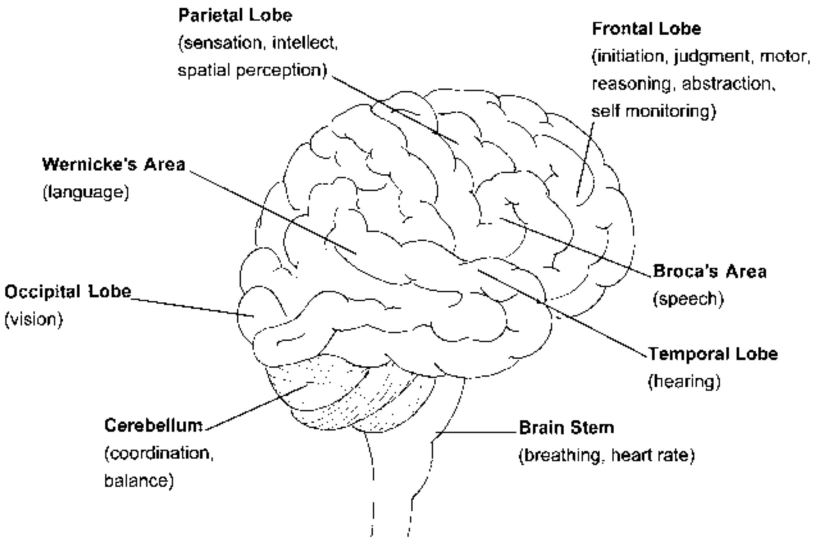
- The *motor cortex* coordinates voluntary movements of the body.
- The *sensory cortex* is responsible for the recognition or perception of sensory stimuli, such as touch, pain, smell, taste, vision, and hearing.
- The *associational cortex* is involved in cognitive functions such as memory, reasoning, abstract thinking, and consciousness.

The cerebrum is divided into two halves, called the *right hemisphere* and the *left hemisphere.* These two hemispheres communicate with each other. Dividing the hemispheres and connecting specific areas of the two hemispheres are bundles of nerve fibers called the *corpus callosum.* Each hemisphere has centers for receiving information and for initiating responses. The left hemisphere mostly receives information from and sends information to the right side of the body, whereas the right hemisphere mostly receives information from and sends information to the left side of the body.

Deep within the cerebral hemispheres are groups of gray matter called **basal ganglia**, which are part of the *extrapyramidal system.* (*Extrapyramidal* denotes nerve fiber tracts that lie outside the pyramidal tract, a relatively compact group of nerve fibers that originate from cells in the outer layer of the brain.) Extrapyramidal function is concerned with postural adjustment and gross voluntary and automatic muscular movements. The basal ganglia help to maintain tone in muscles in the trunk and extremities, enabling individuals to maintain balance and posture and to engage in movements such as walking. The basal ganglia also play a role in enabling individuals to react swiftly, appropriately, and automatically to stimuli that demand an immediate response, such as after tripping, enabling the individual to adjust his or her movement to avoid a fall.

Each hemisphere of the cerebrum is divided into lobes that contain areas related to specific functions (see **Figure 3-3**). The **frontal lobe** is located in the front of each hemisphere and contains motor areas that initiate voluntary movement and skilled movements, such as those involved in handwriting.

Figure 3-3 Areas of Brain Function



© Jane Tinkler Lamm.

Other areas in the frontal lobe control higher intellectual functions such as foresight, analytical thinking, and judgment. The **parietal lobe** is located in the middle of each hemisphere and is primarily the sensory area, integrating and interpreting sensation such as touch, pressure, pain, and temperature. Some memory functions are also located in the parietal lobe, especially those responsible for storage of sensory memory. The **temporal lobe** is located under the frontal and parietal lobes and is primarily responsible for the interpretation of and distinction between auditory stimuli. The **occipital lobe** is located at the back or posterior portion of each hemisphere. It is the primary area for reception and interpretation of visual stimuli.

Several parts of the cerebrum are involved in the language function, which consists of the process of receiving, interpreting, and integrating visual and auditory stimuli as well as the ability to express thoughts in a coordinated way so that others can comprehend them. Language function is located in the left hemisphere of the cerebrum in most individuals, whether they are right- or left-handed. An area located over the temporal and parietal lobes, called **Wernicke's area**, is the major area responsible for *receptive function* (speech understanding), or the ability to integrate visual and auditory information so as to understand communication received. An area located in front of the temporal lobe and in the frontal cortex, called **Broca's area**, is responsible for speaking ability and is closely associated with motor areas that control the muscles needed for articulation. This area contributes to *expressive function* (speech formation), or the ability to integrate and coordinate words so that the meaning can be comprehended.

A structure known as the *thalamus* lies within the center of the brain. The thalamus acts as a relay station that sorts, interprets, and directs sensory information. Below the thalamus is the *hypothalamus*, which coordinates neural and endocrine activities. This structure helps regulate the body's internal environment and behaviors that are important to survival, such as eating, drinking, and reproduction. Below the hypothalamus is the *pituitary*, an endocrine gland.

The *limbic system* comprises a group of structures consisting of both gray and white matter that surround the thalamus. The limbic system plays a role in expression of instincts, drives, and emotions as well as the formation of memories. A band of gray matter called the *hippocampus* is involved in learning and long-term memory, helping to determine where important and relevant aspects of facts will be stored.

Beneath the occipital lobe of the cerebrum is a structure called the *cerebellum*. The cerebellum is primarily responsible for the coordination and integration of voluntary movement and for the maintenance of equilibrium, posture, and balance of the body. It also regulates and coordinates fine movements of the extremities, which are initiated by the frontal lobe.

The **brain stem**, which is located beneath the cerebellum at the base of the brain just above the spinal cord, acts as a relay station, transmitting nerve impulses between the spinal cord and the brain. It is the primary center of involuntary functions. Control of vital organ functions, such as regulation of heartbeat or respiration, occurs in the brain stem. Areas in the brain stem also regulate the diameter of blood vessels, contributing to the control of blood pressure. Reflex actions, such as coughing and swallowing, are controlled in the brain stem as well. Finally, the brain stem contains scattered groups of cells, called the **reticular formation**, which are involved in the initiation and maintenance of wakefulness and alertness.

The brain requires both oxygen and nourishment in the form of *glucose* in order to function and to survive. Oxygen and glucose are transported to the brain by blood carried by four major arteries: two *carotid arteries* and two *vertebral arteries*. The vertebral arteries join to form the *basilar artery*. The carotid and basilar arteries then connect at the base of the brain to form the *circle of Willis,* from which *cerebral arteries* branch out to carry blood to the rest of the brain.

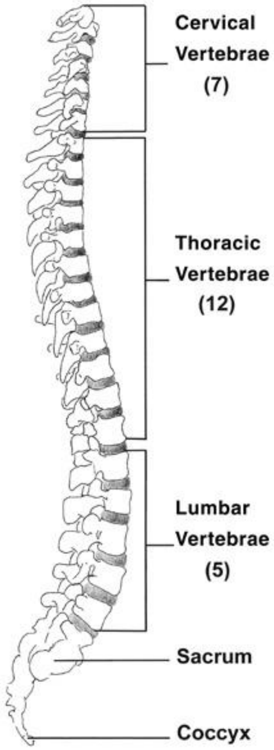
STRUCTURE AND FUNCTION OF THE SPINAL CORD AND PERIPHERAL NERVOUS SYSTEM

The Spinal Cord

The spinal cord is part of the central nervous system and extends from the brain stem to the lower part of the back. Bony coverings called *vertebrae* surround the spinal cord and protect it. This bony covering, as a whole, forms the vertebral column. The *vertebral column* consists of 7 *cervical vertebrae*, located in the neck area; 12 *thoracic vertebrae*, located in the upper and middle back; and 5 *lumbar vertebrae*, located in the lower back. The *sacrum*, located below the lumbar vertebrae, consists of fused (joined) bone. At the tip of the sacrum is the *coccyx*, or tailbone (see **Figure 3-4**).

The spinal cord conducts impulses to and from the brain. The outer white matter of the spinal cord, which consists of bundles or tracts of myelinated fibers of sensory (*afferent*) and motor (*efferent*) neurons, conveys electrical impulses up and down the spinal cord between the **peripheral nervous system** (those nerves lying outside the central nervous system) and the brain. In most instances, sensory information traveling up the right side of the spinal cord

Figure 3-4 The Spine



© Jane Tinkler Lamm.

crosses over to the left side of the brain, so the left hemisphere of the brain would, for example, interpret pain in the right hand. Conversely, motor impulses originating in the left brain cross to the right side of the spinal cord and initiate a response to the right side of the body. Because of this crossover effect, damage on one side of the brain typically causes manifestations on the opposite side of the body.

The inner gray matter of the spinal cord, which is composed of cell bodies and *unmyelinated* neurons, acts as a coordinating center for reflex and other activities, such as voluntary movements and control of internal functions. A reflex center in the gray matter of the spinal cord is where sensory and motor neurons connect; this part of the spinal cord serves as a center for spinal reflexes. A **reflex** can be defined as an automatic response to a given stimulus. Spinal reflexes control not only muscle reflexes but also the reflexes of internal organs.

The gray matter within the spinal cord resembles the letter "H." The projections of the H are named according to the direction to which they project. The *posterior horns* extend toward the back, and the *anterior horns* project toward the front. Cerebrospinal fluid, which nourishes and protects the spinal cord, fills both the *central canal*, located within the center of the gray matter, and the subarachnoid space surrounding the outer portion of the spinal cord.

Motor (efferent) impulses originate in the motor cortex of the brain, extend down the spinal cord through *descending tracts*, and exit through motor spinal nerve roots that extend through openings between the vertebrae that surround the spinal cord. Sensory (afferent) impulses from the body enter the spinal cord through spinal nerve roots that also extend through openings between vertebrae and then travel up *ascending tracts* in the spinal cord to the brain.

Spinal nerve roots are named for the vertebral level from which they exit. For example, the nerve roots that leave the spinal cord at the *cervical* level are labeled C1 through C8, and the nerve roots that leave at the **thoracic** level are labeled T1 through T12 (see **Figure 3-5**). The sensory (afferent) nerve fibers from outside the central nervous system carry body sensations into the *sensory nerve roots* (posterior roots) at the back of the spinal cord, where they are then carried up the spinal cord to the brain. Motor (efferent) impulses travel from the brain down the spinal cord and exit from *motor nerve roots* (anterior roots) at the front of the spinal cord. Motor nerve fibers then carry impulses to the voluntary muscles of the body.

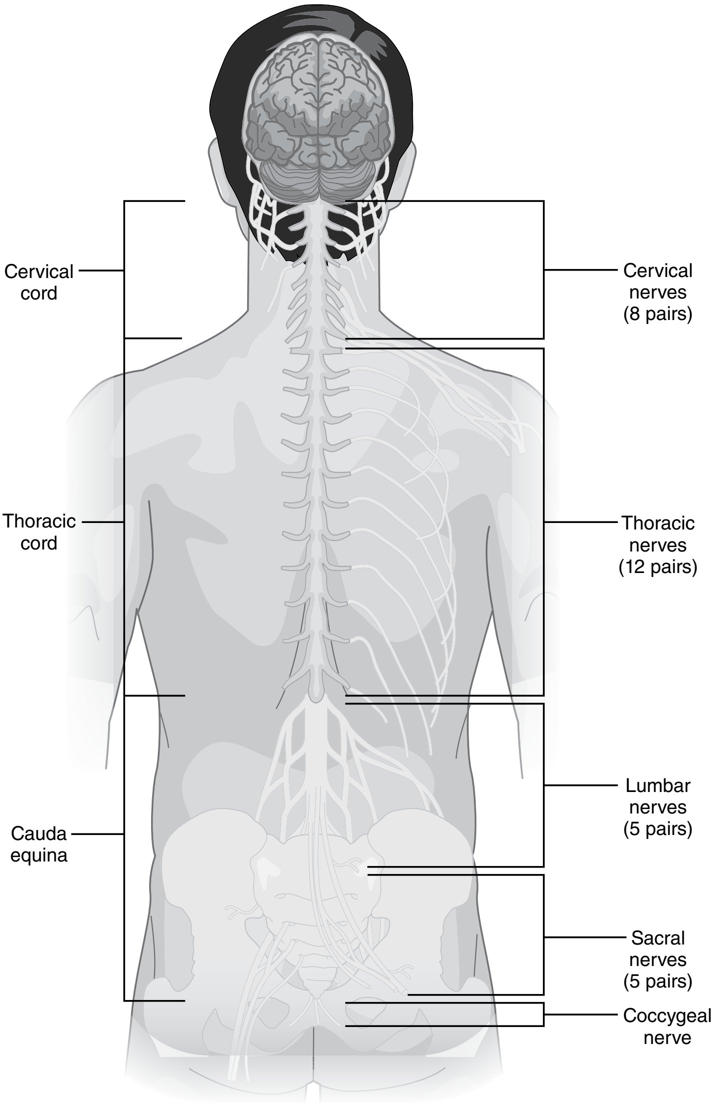
Many types of neurons work together to transmit impulses through the spinal cord. Sensory impulses entering the spinal cord at the lumbar region are relayed vertically to the brain through a number of connecting sensory neurons. Motor impulses from the brain to the peripheral nerves, however, are conducted through two separate categories of motor neurons. *Upper motor neurons* originate in the brain and are contained entirely within the central nervous system. *Lower motor neurons*, although originating in the central nervous system, have fibers extending to the peripheral nerves in voluntary muscles. Alteration of function of either upper or lower motor neurons can generally affect the voluntary muscles. The location of the alteration of function determines the nature of the manifestations.

Peripheral Nervous System

A nerve is a bundle of fibers outside the central nervous system that transmits information between the central nervous system and various parts of the body. The peripheral nervous system consists of all nerves that extend from the brain and spinal cord. To function effectively, the peripheral nerves must be connected to the central nervous system. Some peripheral nerves connect directly to the brain (*cranial nerves*); others connect directly to the spinal cord (*spinal nerves*). Cranial and spinal nerves are essential links between the rest of the body and the central nervous system.

The 12 pairs of peripheral nerves that connect and transmit messages directly to the brain are called **cranial nerves**. Some cranial nerves contain only sensory fibers, whereas others contain both sensory and motor fibers. Cranial nerves mediate many aspects of sensation and muscular

Figure 3-5 Spinal Nerves



activity in and around the head and neck. Cranial nerves and their related functions are described in **Table 3-2**.

The 31 pairs of peripheral nerves that connect and transmit messages directly to the spinal cord are called **spinal nerves**. Each nerve divides and then subdivides into a number of branches. Nerves at each level travel to specific parts of the body, conveying information between those areas and the central nervous system. Spinal nerves and their related functions are described in Figure 3-5.

Nerves control both voluntary and involuntary functions in the body. Nerves that control voluntary functions (such as movement of the muscles in the extremities) are called **somatic nerves**. Nerves that are concerned with the control of