Introduction: what is qualitative research?

The question ‘What is qualitative research?’ is frequently asked by occupational therapists and physical therapists, or students exploring, for the first time, the possibility of developing a research idea or question and designing a study to address it effectively. The response to the question is, however, a complicated one. This complexity can be traced to a number of sources, such as the trans-disciplinary nature of qualitative inquiry, the historical contest between the proponents of quantitative and qualitative research approaches, the emergence of qualitative research in health care, and the challenge of evidence-based practice. In our experience, this complexity and the need to grapple with it elicits different reactions from rehabilitation practitioners and students. For some, the theoretical foundations and assumptions of qualitative research approaches appear congruent with their practice philosophy and questions. For others, qualitative inquiry represents a very different “worldview”, one that is unsettling and difficult to comprehend as it challenges the dominant traditional assumptions about the nature and purpose of research, and requires us to reflect critically on the professional and theoretical assumptions influencing rehabilitation practice. In this chapter, we will establish a broad definition of qualitative research and discuss the theoretical context within which rehabilitation practice takes place. Increasingly, qualitative research studies are being reported in the occupational therapy and physical therapy literature, and it is our intention to take advantage of these resources as examples throughout this book.

Defining qualitative research

Qualitative research is historically associated with anthropology, sociology, education and psychology; it is a field of inquiry separate and distinct from survey

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1 Physical therapy is the term used in the United States and physiotherapy is most commonly used outside North America. The terms can be considered synonymous. For consistency, physical therapy will be used in this book.

2 Double quotation marks will be used throughout this book to indicate contentious terms that we consider need to be used critically.
and other forms of quantitative research. As a result, it cuts across disciplines, subject matters and practice areas. Qualitative research is an umbrella term for the concepts, assumptions and methods shared by a complex and interconnected family of research traditions and it has meant different things at different points in its history.

Throughout the nineteenth century and until World War II, qualitative researchers, particularly in sociology and anthropology, were concerned with producing valid, reliable and objective knowledge, reflective of the positivist paradigm about strange and foreign worlds (for example, Malinowski, 1922). As a result, qualitative research in many, if not all its forms (observation, participation, interviewing, ethnography) came to be associated with the classification of indigenous people and the worst excesses of colonization (Denzin & Lincoln, 2005). During the period from the post-war years to the late 1970s many efforts were made to develop interpretive approaches, such as feminism, phenomenology and critical theory, and to formalize qualitative methods in an attempt to justify the rigor of qualitative approaches to research. Qualitative research began to be adopted in health care, primarily by medical sociology (for example, Becker et al., 1961) and nursing (for example, Field & Morse, 1985) during this period. There was an emphasis on the standardization of data collection methods, such as the development of participant observation forms, and a more quantitative approach to data analysis through the use of ‘quasi-statistics’, such as word or code frequencies. Such structured approaches to data analysis were most graphically illustrated in Glaser & Strauss’ (1967) work The Discovery of Grounded Theory, and later two books by Geertz, The Interpretation of Cultures (1973) and Local Knowledge (1983), were particularly influential. During the 1980s, there was a general move away from the influence of the positivist discourse and in the 1990s, qualitative researchers, particularly in health care, experienced what might be called an identity crisis. New models of “truth”, method and representation were sought and issues of objectivity, reliability, validity and generalizability once again became problematic (Denzin & Lincoln, 2005). During this period, qualitative research seemed to have arrived in the research mainstream, with increasing discussion and recognition occurring in medical and other health profession journals and the publication of new journals such as Qualitative Health Research.

In the twenty-first century, the field of qualitative research continues to be a dynamic one, and the use of evaluative criteria in judging the quality, trustworthiness and credibility of qualitative research studies remains controversial and the topic of much debate by qualitative research theorists. A number of influential authors (Denzin & Lincoln, 2005; Miller & Crabtree, 2005) have articulated new challenges for qualitative researchers related to the concept of evidence-based practice in medicine and, in the United States, to the scientifically based research movement or “Bush science”. This movement places experimental quantitative research first among scientific methods in policy statements and relegates qualitative approaches to an auxiliary role (Bloch, 2004; Howe, 2004). This, according to Denzin & Lincoln (2005), ‘endorses a narrow view of science’ (p. 9) and ‘has created a hostile environment for qualitative research’ (p. 8). Despite these
recent challenging developments, Miller & Crabtree (2005) remain convinced that qualitative clinical research is now widely accepted in health care, including medicine. Over the past decade there has been growing theoretical discussion and debate about the congruence of qualitative research with occupational therapy practice (for example Hammell, 2001; Bailey & Jackson, 2003; Ballinger, 2004). The physical therapy profession has been slower to recognize the potential contribution of qualitative research to our understanding of practice (Robertson, 1994; Bithell, 2000) and critical debate in the physical therapy literature remains more limited (for example Shepard et al., 1993; Carpenter, 1997; Johnson & Waterfield, 2004).

All of which brings us back to the thorny problem of defining qualitative research! As Denzin & Lincoln (2005) assert, ‘any definition of qualitative research must work within this complex historical [context]’ (p. 3). These authors suggest the following generic definition:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world [the taken for granted in everyday life] visible [to others]. Qualitative research involves the studied use and collection of a variety of empirical information using a diversity of methods, for example case study, personal narrative, artifacts, cultural texts, interviews, observations, and visual records that describe routine and problematic moments in individuals’ lives with the aim of developing a better understanding of the subject or phenomenon. Qualitative research privileges no single methodological practice over another and has no theory or paradigm that is distinctly its own (pp. 5–6).

This definition suggests an interpretive, naturalistic research approach that uses multiple sources of information and is grounded in a number of philosophical assumptions. Creswell’s (1998) definition conveys similar ideas but focuses more on the elements that characterize qualitative research approaches:

Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in the natural setting (p. 15).

In health care, discussions of qualitative research have largely focused on comparing and contrasting it with assumptions, techniques and strategies developed for quantitative research (Bogdan & Biklen, 1998; Hammell et al., 2000). However, as Creswell (1998) firmly states, ‘qualitative inquiry represents a legitimate mode of social and human science exploration without apology or comparisons to quantitative research’ (p. 9).

While a certain amount of comparison is unavoidable, in this book we have attempted to concentrate on what qualitative research is rather than presenting what it is not and on considering the differences among approaches to qualitative research. There is no “best” approach to research; rather it depends on what is being studied and on the nature of the research question. In a qualitative study,
the research question often starts with *how* or *what*, and aims to describe or explore what is going on. This is in contrast to quantitative questions that ask *why*, and aim to make comparisons between groups or explain cause and effect relationships between variables (Creswell, 1998). According to Miller & Crabtree (2005) the guiding premise of clinical research is that ‘the questions emerging from the embodied, embedded, and mindfully lived clinical experience frame conversations and determine research design [decisions]’ (p. 609). The word ‘research’ is derived from the Middle French verb *recercher*, meaning ‘to go about seeking’ and is variously defined in the Merriam-Webster Online Dictionary (2006) as:

- The collection of information about a particular topic or phenomenon
- Careful or diligent search for explanation or information
- Studious inquiry or examination: especially the investigation or experimentation aimed at the discovery and interpretation of facts, revision of accepted theories or laws in the light of new facts, or the practical application and evaluation of such new or revised theories or laws
- To search or investigate exhaustively

Conducting research, then, has multiple aims and these diverse definitions support the argument that in the rapidly changing and increasingly accountable world of health care no one research approach can be privileged over others. Multiple research approaches are needed if the ongoing generation of new knowledge, and search for evidence about the effectiveness of professional practice, is to be supported. Thus, it is imperative that practitioners develop an in-depth knowledge of different research approaches in order to be critical consumers of research.

The field of qualitative research, like any specialty area, has cultivated a language and terminology that practitioners and students may initially find off-putting and daunting and which, almost assuredly, excludes health care clients from the research dialogue. We learn the distinct languages and professional jargon of occupational therapy and physical therapy as part of the enculturation process to the professions. Similarly, learning the language of qualitative research facilitates our in-depth understanding of the research process and enables us to explain and share our new understanding with clients and research participants. It is our intention in this book to facilitate this learning process by making the qualitative research terms and concepts accessible to the reader.

**Issues of theory in qualitative research**

The aim of this book is to facilitate the knowledge and skills occupational therapists and physical therapists need in order to address the practicalities of conducting and evaluating qualitative research with, and for the benefit of, clients using rehabilitation services. However, the research endeavor is not an atheoretical one and before addressing the practicalities of research, we need to explore the
different theoretical perspectives influencing rehabilitation practice. Hammell (2006) suggests that rehabilitation practitioners rarely question ‘the taken-for-granted nature of traditional knowledge and assumptions within the rehabilitation, health and community care industries’ or ‘contest, critique or challenge the way in which disability [physical and psychological] is understood and managed’ (p. ix). The central issue of theory in qualitative research can be troubling, particularly for those of us primarily educated in the positivist paradigm and quantitative method (Dyck, 2000), where researcher “objectivity” is paramount. Qualitative research, in contrast, is based on the premise that researchers do not enter the research process as a “blank page”. Even if researchers are unaware of their theoretical orientation, or how these issues may influence the proposed study, their choice of research topic and design is necessarily framed by a perspective laden with ideas and concepts arising from a particular professional body of knowledge, and experience in a specific field of practice, as well as personal experiences (Dyck, 2000).

Two examples may help to elucidate what we mean by influence. In exploring the lived experience of disability with participants who had sustained traumatic spinal cord injuries, Carpenter (1994) came to recognize for the first time in a long career as a physical therapist in rehabilitation, how dominant disability theories, in particular stages of adjustment and the personal tragedy model of disability (Swain & French, 2000), had influenced her practice and attitudes towards the value systems of clients in rehabilitation that gave rise to their personal goals and aspirations. Dyck (2000), an occupational therapist, discusses how ideas from social theory, particularly those developed in feminist scholarship, helped her in analyzing women’s workplace experiences following a diagnosis of multiple sclerosis.

According to Denzin & Lincoln (2005) all qualitative researchers are philosophers, in the sense that they are guided by highly abstract beliefs and feelings about the nature of human beings, reality and knowledge. This comprises a conceptual framework that shapes how we view the world and how it should be understood and studied. Such beliefs may be taken for granted, invisible, or merely assumed, whereas others may be revealed as highly problematic and controversial. Therefore, from a qualitative research perspective, all research is interpretive and not a neutral or objective undertaking. We will address these important issues in more detail later in the book in relation to the purpose of research, the dissemination of research findings and the role of the researcher in the process.

**The professional context**

The values, beliefs and principles of a discipline have a major influence on its identity and development, and are known collectively as its philosophy (Baum & Christiansen, 1997). A profession’s philosophy focuses on providing the framework for asking both ontological and epistemological questions about the central values, assumptions, concepts and actions that are the foundation of practice. Examples of ontological questions are, ‘What is the nature of reality?’ Alternatively,
‘What does it mean to be human?’ Ontology is the study of being or existence, of conceptions of reality. It is from these ontological concerns that epistemological questions arise. Epistemology is concerned with theories of knowledge, beliefs about the nature of knowledge, the process by which knowledge is acquired and the reliability of claims to knowledge (Hammell, 2006). A professional philosophy – including such concepts as respect for autonomy and quality of life – is instilled in the process of acquiring an identity as a nurse, occupational therapist, physical therapist or physician. However, the philosophical and historical roots that shape practice are articulated in varying degrees by different professions. For example, according to some authors in physical therapy (Roskell et al., 1998; Richardson, 1999), the values and priorities held by the physical therapy profession today are rarely explored in the literature or taught in the academic programs. The acquisition of knowledge, skills, values, roles and attitudes associated with the practice of a particular profession occurs through a process of professional socialization. This process begins during the period of formal education and continues through interaction with others in a variety of clinical settings. It represents the development of a unique voice and professional view of the world based on, to a greater or lesser degree, shared assumptions.

According to Hammell (2006), among rehabilitation professionals, these shared assumptions ‘concern the nature of their work (apolitical, relevant and useful), the nature of their goals (increasing function, performance and independence to enhance quality of life) and the caliber of their relationships with . . . patients and clients (benevolent, client-centered and helpful)’ (p. 3). These assumptions represent a set of taken-for-granted statements that organized together form a theory of rehabilitation practice. Such a theory can be defined as a framework or system of explanatory principles or ideas that describe, explain, predict or prescribe responses, events, situations or relationships within a specific reality. It is, by definition, speculative and, even when unacknowledged or unstated, informs professional practice (Hammell, 2006). What is not clear is whether these theoretical assumptions and beliefs about rehabilitation practice have a supportive evidence base. Concerns have been raised in the nursing and rehabilitation sciences literature (Fealy, 1997; Roskell et al., 1998) about the perceived widening theory–practice gap. In physical therapy, this gap has been attributed to a poorly articulated and understood professional philosophy and a reliance on positivist approaches to scientific inquiry, resulting in a narrow and incomplete body of evidence (De Souza, 1998; Roskell et al., 1998). Two survey studies highlight concerns related to the use of theory and evidence in practice; one study sought to examine the approaches used in stroke rehabilitation by occupational therapists (Walker et al., 2000) and the other focused on physical therapists (Davidson & Waters, 2000). The two most common approaches used by occupational therapists were the functional approach and the Bobath approach. The main indications

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3 Terms which are uniquely associated with qualitative research and may be new to the reader will be italicized the first time they are introduced in the book.
for the choice of approach were the age of the patient, progress with other approaches and discharge date. Walker et al. (2000) expressed concern that, in the current climate of evidence-based practice, a high number of the survey respondents were unable to describe adequately the theoretical basis for the treatment used. Davidson & Waters (2000) found that there was a great deal of variation in the beliefs held by physical therapists about the treatment of stroke patients even though the Bobath approach was by far the most dominant treatment approach used. These diverse interpretations of how the Bobath approach is applied were unsubstantiated by reference to published evidence.

Findings like these are a concern when we consider that practice (clinical observation and logical speculation) guides theory development, which in turn guides research. Theory provides researchers with a basis for developing lines of inquiry by which practice can be critically investigated and changed. However, some authors (Albrecht & Devlieger, 1999; Johnstone, 2001; Hammell, 2006) argue that the theories of rehabilitation espoused by rehabilitation professionals have been uncritically accepted, are restrictive in nature, and their influence on research is poorly articulated. Traditionally, rehabilitation professionals have privileged their own assumptions, perspectives and knowledge in directing rehabilitation research and services, even though these are frequently unacknowledged and not clearly articulated (Hammell, 2006).

The context of rehabilitation

Corbet (2000) produced a movie about people’s experiences of rehabilitation and described a theme common to everyone’s story. This theme was ‘that early on they’d been told more about what they couldn’t do than what they could do’ (p. 4). It seemed that rehabilitation practitioners had chosen not only to share their knowledge about physical impairments, for example the ability, or in this case the inability, to walk after a spinal cord injury, but also their beliefs about more general societal roles and capabilities that, in their view, would no longer be possible for the clients, for example having children and becoming employed. Such client experiences graphically illustrate aspects of the dominant theoretical models of disability that continue to influence the delivery of rehabilitation services. A model is a conceptual framework that encapsulates, and posits links between, specific knowledge and concepts. Models, according to Finkelstein (2004), act as tools to give us insights into situations that would otherwise be difficult to begin to explain. This section will outline the assumptions of several models of disability and rehabilitation, introduce related key concepts, and briefly examine the consequences for rehabilitation clients and practice.

The medical model of disability

The medical model is characterized by a number of premises: an emphasis on individual autonomy rather than interaction with family and community; a view of
the body as a machine needing to be “fixed”; an emphasis on diseases as entities and on “objective” assessment and diagnosis; a separation of the mind and body; and a scientific, rational and positivist approach to inquiry (Miller & Crabtree, 2005). The medical model privileges professional knowledge and authority and promotes the ideal of the “compliant” patient. It is grounded firmly in a shared understanding of “normality” and the main aim of “treatment” is to cure or restore patients to as nearly ‘normal’ a condition as possible. The underlying assumption is that “treatment” will result in a return to “wholeness” – an optimal level of functioning – to which all human beings should aspire but which, in reality, is not achievable for people with a disability or chronic condition. The resulting functional deficits or restrictions, which cannot be “cured”, are deemed to be the inevitable and tragic consequences of the impairment (Thomas, 2004).

The individual personal tragedy model of disability

In this way, disability came to be perceived as an individual personal tragedy that required ‘a process of psychological adjustment deemed necessary to enable the person to come to terms with their deficits’ (Hammell, 2006, p. 58). This process was articulated in a number of stage theories of adaptation and adjustment, which required the individual to pass through recognizable phases of shock, grief, denial, anger and depression (Oliver, 2004). Failure of disabled people to achieve rehabilitation goals could then be interpreted as the individual’s failure to adjust to an impairment. Such reasoning on the part of professionals leaves the rehabilitation process unchallenged and practitioners uncritically secure in their professional roles. As Hammell (2006) suggests, there is clearly a place for the medical model in an acute care delivery system, for example when an individual has a torn cruciate ligament and there is a legitimate hope of full restoration of “normal” function. However, ‘intervention under such circumstances might reasonably be labeled as “treatment” performed by someone to someone else but it cannot be called rehabilitation’ (Hammell, 2006, p. 59). As a result of a medicalized conception of disability, many rehabilitation practitioners and researchers equate chronic illness with disability, and disabled people become perceived as permanent “patients” (Goble, 2004). In contrast, although people with physical and mental disability and chronic conditions periodically experience physiological consequences related to their impairments or condition that require medical attention, many regard their health as excellent (Wilcock, 1998).

The ideology of independence

The medical model of disability has also given rise to an ideology of independence. This ideology equates independence in terms of self-care activities rather than the ability to take control and make decisions about one’s life. There is an assumption that independence is a universally valued goal, but this is not substantiated by research evidence (Reindal, 1999). However, this preoccupation with physical independence continues to be reflected in rehabilitation practice, where
Qualitative research in the rehabilitation context

a person’s functional capability (or more often incapacity) is assessed using scales and tools that measure performance against “normative” standards. The main aim of rehabilitation programs is to reduce the gap, as much as possible, between the individual’s performance and the ‘normative’ standard.

The principle of autonomy is pervasive in Western ethical, political and educational philosophy and characterizes independence as the ability to govern oneself without outside domination (Sim, 1998). This principle has been criticized by feminists and communitarian theorists as being an ideologically constructed “norm” that does not represent the reality of interdependence experienced by people in the contexts of their lives. The notion of control has given rise to revised interpretations of such terms as self-government, self-rule, self-determination and self-advocacy. The notion of control in principle opens up the possibility of choosing to rely on the judgments or assistance of others in situations where we ourselves may lack the necessary information, knowledge or capability to make a reflective choice or take action (Reindal, 1999).

**The biopsychosocial model**

The biopsychosocial model was first proposed by Engel (1977) as a holistic alternative to the prevailing biomedical model that dominated medicine in industrialized societies. This model seeks to integrate the biological, psychological and social consequences of disability or chronic illness. According to Engel (1977), this model is both a philosophy of clinical care and a practical clinical guide. Borrell-Carrio et al. (2004) suggest that the biopsychosocial model is ‘philosophically a way of understanding how suffering, disease, and illness are affected by multiple levels of organization, from the societal to the molecular’ (p. 576). In this sense, this model has formed the theoretical foundation for the *International Classification of Functioning and Disability (ICF)* (WHO, 2001). At a practical level, ‘it is a way of understanding the patient’s subjective experience as an essential contributor to accurate diagnosis, health outcomes, and humane care’ (Borrell-Carrio et al., 2004, p. 576). Critics of this model argue that it continues to privilege the health care professionals’ role and perspective, and advocate, as an alternative approach, a client-centered model of practice (Bartz, 1999).

**International Classification of Functioning, Disability and Health (ICF)**

The World Health Organization (WHO) published the *International Classification of Impairments, Disabilities and Handicaps (ICIDH)* in 1980. The ICIDH identified the consequences of diseases and disorders at the level of the body (impairment), the person (disability) and the person as a social being (handicap). The ICIDH definitions caused ‘widespread disenchantment among disabled people and their organizations, as well as criticism from mainstream medical researchers’ (Barnes & Mercer, 2003, p. 15). These criticisms focused on the biophysiological interpretation of “normality” embedded in the definitions and the clear linkages
established between “disability” and “handicap”. These implicit assumptions were seen as privileging medical and rehabilitation interventions in the treatment of primarily social and economic disadvantages, and representing the environment as ‘neutral’ (Barnes & Mercer, 2003). These criticisms caused the WHO to undergo major revisions of the ICIDH and resulted in the International Classification of Functioning and Disability (ICF) (WHO, 2001). The influence of the social model of disability on the ICF (also known as the ICIDH-2) can be seen in the acknowledgement that people interact with their environments. The ICF is based on the biopsychosocial model and the assumption that functioning, activity and participation are influenced by a myriad of environmental factors (Barnes & Mercer, 2003) that make up the physical, social and attitudinal environment in which people live and conduct their lives. The concept of disability in the ICF serves as an umbrella term for impairments, activity limitations or participation restrictions. The definition of impairment continues to focus on problems in body function or structure, such as a significant deviation or loss and activity limitations focused on difficulties in executing a task or action. Participation is defined as ‘an individual’s involvement in life situations in relation to the other ICF concepts (Health Conditions, Body Functions and Structure, Activities, and Contextual Factors)’ and participation restrictions are conceived as ‘the problems an individual may have in the manner or extent of involvement in life situations’ (WHO, 2002, p. 10).

The WHO (2002) claims that the ICF can be used to study the impact of health and health states, provide a common language in research and provision of services, identify specific individual needs, structure outcome measures and facilitate planning of services and comparison of services across countries, disciplines, services and time through the use of a systematic coding scheme. For these reasons the ICF approach seems to hold considerable promise; however, as Hammell (2006) warns, the ICF’s primary purpose remains ‘to classify differences and deviations from assumed norms in every area of human life’ (p. 26) and as such it is problematic. It continues to retain individualistic medical notions of disability and the linkages with impairment (Hurst, 2000) and this makes possible the unwelcome and inappropriate control of disabled people’s lives by various medical and health care professions (Hammell, 2006). The issue is not to denigrate the importance of health care services to disabled people but to recognize the need to challenge the authority of professionals to make decisions that have nothing to do with medicine, such as assessing quality of life, monitoring parking permits and motor vehicle licenses, and determining who is capable of employment (Swain et al., 2004; Hammell, 2006). The ICF enables professionals to code, categorize and compile statistics about people with disabilities and chronic conditions. Used judiciously and with this purpose in mind it offers new possibilities for a sociological–medical analysis of disablement (Barnes & Mercer, 2003). However, concerns have been raised (Wade & Haligan, 2003; Hammell, 2006) that the ICF is premised on “expert” assessment; that it is not an assessment tool that embodies client-centered approaches to service delivery nor one that incorporates self-appraisal of quality of life. In addition, Hammell (2004a) points out that
the ICF was not developed in the context of occupational therapy and physical therapy and warns against the enthusiastic, uncritical adoption of the ICF as a framework for occupational therapy and physical therapy research, practice or curriculum development.

**Quality of life as overall goal of rehabilitation**

The notion of control has been shown to be integral to perceptions of quality of life (Johnstone, 2001) and it is generally agreed that quality of life is the ultimate goal of rehabilitation (Pain et al., 1998; Hammell, 2006). However, a common definition of quality of life has proved difficult to establish, despite considerable theoretical discussion and research. It is generally recognized that quality of life is a multidimensional construct encompassing both objective and subjective evaluations of physical, material, social and emotional well-being, together with personal development and purposeful activity, all weighted by a unique set of personal values (Johnstone, 2001). Because there is no consensus among researchers and rehabilitation professionals about what quality of life means in the context of disability and chronic conditions, there is no agreement about how or whether measurement of it is possible or indeed if it should be attempted by the rehabilitation professions (Dijkers, 1999; Hammell, 2004a). Until recently, the majority of research has explored the objective dimensions of quality of life, using primarily quantitative research approaches such as rating scales and questionnaires, with the purpose of comparing levels of health-related quality of life between groups or before and after events or interventions (Post et al., 1998). Concerns have been raised that the standardized research instruments used (for example World Health Organization, 2004), and the interpretation of data and results, inevitably reflect the researcher’s beliefs, values and attitudes towards the experience of living with disability and chronic conditions (Dijkers, 1999) and reinforce the dominant models of disability, such as the medical and personal tragedy models (Swain & French, 2000).

Despite quality of life being consistently articulated as the overall goal of rehabilitation, there is little research evidence available to support the effectiveness or value of rehabilitation in promoting quality of life. This may partly be due to methodological issues associated with quality of life research (Dijkers, 1999). However, other authors suggest that some of the difficulty arises from the assumption that quality of life is a static construct (Gill, 2001) and a general neglect of the subjective evaluation of quality of life (Dijkers, 1999; Hammell, 2004b).

In addition, research (Woodend et al., 1997; Albrecht & Devlieger, 1999) has demonstrated the discrepancy between the objective (that is, the researcher’s) assessment of quality of life and the subjective (that is, the client’s) satisfaction with that life (Hammell, 2004b). As Hammell (2006) suggests, ‘how a researcher or clinician attempts to measure “quality of life” [may] reveal more about their own values, priorities and fundamental orientation to life than it does about the quality of life perceived by people whose lives are ostensibly being studied’ (p. 139). There is an increasing recognition of the need to involve people with experience
of disability and chronic conditions in the evaluation of quality of life. This recognition has prompted many authors (for example Dijkers, 1999; Johnstone, 2001; Hammell & Carpenter, 2004) to argue that the subjective experience of quality of life requires the implementation of rigorous qualitative and mixed methods research approaches. Hammell (2006) reflects her belief that the quality of life can only be appraised by the person whose life it is, when she proposes that the term “quality of life” be simply conceptualized ‘as the experience of a life worth living’ (p. 138).

The social model of disability

The social model of disability arose from the publication of *Fundamental Principles of Disability* by the Union of Physically Impaired Against Segregation (UPIAS) in 1976. This model presented an interpretation of disability not as an individual and personal characteristic but as a shared and collective responsibility (Johnstone, 2001). The fundamental assertion was that society disables people who have impairments: ‘In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society’ (UPIAS, 1976 p. 14). Thus, this model brought to the forefront issues of structural and personal barriers created by society, and recognized the need for the participation of disabled people in decision-making and the limitations of professional expertise. This analysis is built on a clear distinction rather than a causal link between impairment and disability. A medical definition of impairment was adopted as, ‘lacking part or all of a limb, or having a defective limb, organ or mechanism of the body’ (UPIAS cited by Thomas, 2004, p. 25). Disability was defined variously as: ‘A condition in which people with impairments are discriminated against, segregated and denied full participative citizenship’ (Swain et al., 2003), and: the loss or limitation of opportunities which prevent people who have impairments from taking part in the activities of the community on an equal level with others due to physical and social barriers (Swain et al., 2004).

A number of criticisms have been levelled at the social model of disability over the ensuing years. This model appears to ignore, or is unable to deal adequately with, the realities of impairment. Attempts to separate the experience of disability and impairment, and to insist that physical differences and restrictions are entirely socially created, contradicts an individual’s everyday experiences (Barnes & Mercer, 2003). It has been suggested also that the definition of impairment excludes and marginalizes some groups, for example people who describe themselves as ‘mental health system survivors’ and those with learning difficulties, and that ‘it has tended to downplay the potential for considerable variation in experience of both disability and impairment across the disabled population’ (Barnes & Mercer, 2003, p. 70). A related criticism focuses on the issue of “otherness” and argues that it is not the physical and environmental barriers people face, but the way society’s values position disabled people as “other” (Oliver, 2004). However, the social model’s definition of disability has made it possible to identify the range, form and types
of discrimination that make the world a difficult place for disabled people and to differentiate these from impairment issues (Thomas, 2004).

The social model of disability is reflected in recently developed theories of occupational therapy, for example occupational performance (Canadian Association of Occupational Therapists, 2000), and in physical therapy, for example the movement continuum theory (Cott et al., 1995). Both these examples acknowledge the importance of social, cultural, economic, political and legal environments as well as the physical. In general, rehabilitation professionals remain firmly entrenched in a medical model of service delivery that is focused upon individualized health care services (Crichton & Jongbloed, 1998; Hammell, 2003), but there are examples of practitioners who have clearly positioned their research and discussions about practice in relation to the social model of disability (Marquis & Jackson, 2000; Hawkins & Stewart, 2002; Kemp, 2002; Lund & Nygard, 2004). This issue of ‘positioning oneself’ as the researcher in terms of theoretical influences was alluded to earlier in this chapter and will be addressed in more detail in Chapter 7.

Client-centered practice

A review of the rehabilitation literature (for example Law, 1998) clearly indicates that the occupational therapy profession has been debating the concept of client-centered practice for over two decades. Client-centered practice has been recognized as a key professional behavior in physical therapy (MacDonald et al., 2001). However, there has been little consistent discussion to date in the physical therapy literature. During the same period of time an increased prevalence of chronic disability, increasingly sophisticated and well-informed health consumers, and increasing demands for health care practitioners to be accountable have prompted governments to take a more client-oriented approach to health service delivery (for example Department of Health 2001, 2005). In addition, reflective of the underlying philosophy of individualism that is dominant in Western cultures, the principle of respect for autonomy (Beauchamp & Childress, 2001) has given rise to the ethical and legal imperative of informed consent (Sim, 1998). This requires at least a degree of shared information and decision-making between clients and service providers, favouring active engagement over passivity (Hammell, 2006). Client-centered practice has been described as a collaborative approach to practice that encourages client autonomy, choice and control and that respects clients’ abilities and supports their right to enact these choices (Sumsion & Law, 2006). Similarly, Law (1998) defined it as ‘An approach to service which embraces a philosophy of respect for, and partnership with, people receiving services’ (p. 3).

In the current climate of political and ethical imperatives and professional standards, client-centered practice is no longer a practice approach to be discussed theoretically ‘as a mode of service to which professions might aspire if and when they choose’ (Hammell, 2006, p. 154). However, relatively little research (for example Guadagnoli & Ward, 1998; Marquis & Jackson, 2000; Ford et al., 2003; Blank, 2004) has been conducted exploring the meaning and experience of
client-centered practice from the client’s perspective. In fact, some authors (for example Abberley, 2004; Dalley, 1999; Martone, 2001) suggest that professional claims of client-centered rehabilitation practice are more rhetorical than based in reality. However, research does suggest that increasing client participation and control in the rehabilitation process has been linked to favorable outcomes (MacLeod & MacLeod, 1996; Albrecht & Devlieger, 1999; Marquis & Jackson, 2000; Lorig et al., 2001; Ford et al., 2003) and that clients place more importance in the interpersonal qualities and communication skills of health professionals than in their technical skills (Gage, 1999; MacLean et al., 2000; French, 2004).

Research has also indicated that clients want to receive services that are based on evidence that demonstrates their effectiveness (Ford et al., 2003). However, in rehabilitation, where clients are attempting to assimilate the effects of injury and chronic illness into the continuum of their lives, therapy decisions based on the best available evidence derived from predominantly quantitative research may not correspond with therapy practice that focuses on the client’s wishes and preferences, short- and long-term goals, their social support and the impact of chronic disability on their lifestyle. Tensions exist between the philosophies of client-centered practice and evidence-based practice that require negotiation in the delivery of rehabilitation services (Hammell, 2001).

Evidence-based rehabilitation practice

Evidence-based practice (EBP) is ‘a significant movement of fundamental importance in the delivery of health care throughout the developing world’ (Bithell, 2000, p. 58). It represents an expansion of the concept of evidence-based medicine to encompass more aspects of health care, including rehabilitation (Law, 2002). The rehabilitation disciplines have willingly subscribed to the evidence-based movement and its culture of accountability (Carpenter, 2004), and recognize that if ‘evidence-based practice can be incorporated into the practitioner’s repertoire, the professions will see a shift toward a more analytical, certain, and ultimately effective clinical practice’ (Law, 2002, p. 8). Unfortunately, earlier definitions of EBP (Sackett et al., 1996) promoted the idea of a hierarchy of evidence that privileged randomized control trials (RCTs) as a sort of “gold standard.” This association of research evidence with experimental research approaches has served to restrict the sort of questions it has been possible to ask and the sort of issues it has made possible to investigate (Hyde, 2004). A more recent and broader iteration of EBP incorporates three dimensions – the conscientious and judicious use of relevant and current research evidence, clinical expertise and patient values and preferences – into clinical decision-making (Sackett et al., 2000).

Most rehabilitation professionals recognize that the complex issues inherent in rehabilitation practice entail far more than a wholesale application of research to practice, because even best evidence can lead to bad practice if applied uncritically. In addition, authors seldom link the terms evidence-based practice and patient/client-centered practice (Benzing, 2000). This is not surprising given that the concept of evidence-based practice is essentially an impairment or disease-oriented
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Sweeney et al. (1998) observed that EBP continues to focus on the clinician’s interpretation and application of the evidence to intervention decisions, and diminishes the importance of human relationships and the role of the patient. This focus can be seen quite clearly in the broader definition of EBP (Sackett et al., 2000) cited earlier, where the assumption is that practitioners will incorporate the evidence and patient perspectives in making a clinical decision. There is, however, an increasing call in medicine and rehabilitation to strengthen the client-centeredness of EBP (Sweeney et al., 1998; Benzing, 2000; Holm, 2005; Miller & Crabtree, 2005; Hammell, 2006). Such ‘patient-centered clinical research’ (Sackett et al., 2000, p. 1) must include greater methodological diversity, notably by including qualitative research (Bithell, 2000; Ritchie, 2001; Gibson & Martin, 2003; Hammell & Carpenter, 2004; Johnson & Waterfield, 2004; Blair & Robertson, 2005; Miller & Crabtree, 2005) and developing more effective approaches to synthesizing the evidence that is available (Benzing, 2000).

Defining rehabilitation

The way we, as rehabilitation professionals, define rehabilitation and related concepts, and use terminology reveals a great deal about the, often taken-for-granted, professional and personal values and beliefs we hold about our role and responsibilities and the client–professional interaction in the rehabilitation process. As qualitative researchers, it is essential that we reflect and articulate the theoretical, professional and personal influences we bring to the research endeavor. With this in mind, we think that it is important for us to make our use of terminology and concepts as clear as possible throughout the book. Hence, our decision to use double quotation marks to denote terms we consider controversial when used in certain contexts. There has been considerable debate about the definitions and language used in relation to disability and impairment (see, for example, Johnstone, 2001; Barnes & Mercer, 2003; Finkelstein, 2004; Hammell, 2006). Much of this debate has focused on the use of the terms “disabled people” and “people with disabilities”. By adopting the definition of disability as representing the physical, political, economic, legal, social and cultural experiences of living with an impairment (Hammell, 2006) we align ourselves with the social model of disability. Disability theorists argue that the term “disabled people” is preferable to “people with disabilities” because it better reflects ‘the ways social barriers affect life chances’ (Barnes & Mercer, 2003, p. 18) as opposed to representing disability as an individual characteristic. We will use the term “disabled people” throughout this book.

Merriam-Webster’s Online Medical Dictionary (2005) defines rehabilitation as ‘the physical restoration of a sick or disabled person by therapeutic measures and re-education to participate in activities of a normal life within the limitations of the person’s physical disability’. This definition clearly reflects the individual or medical model of disability characterized by the assumptions of “normalization”, physical independence as an aim of the rehabilitative process and the disabled
person’s adaptation to a pre-existing environment. For the purpose of this book we will adopt the more comprehensive definition of rehabilitation as ‘a process of enabling someone to live well with an impairment in the context of his or her own environment and, as such, requires a complex, individually tailored approach’ (Hammell, 2006, p. 8). The brief overview of the models of disability and approaches to health care delivery provided in this chapter highlights the theoretical contexts within which rehabilitation services are delivered and the different ways that rehabilitation can be defined. The following chapter will explore the philosophical systems that form the foundation of qualitative research and the assumptions that characterize qualitative approaches.

References


