

Representations of disability in nursing and healthcare literature: an integrative review

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Abstract

Title. Representations of disability in nursing and healthcare literature: an integrative review.

Aim. This paper is a report of an integrative review to explore the way in which disability has been considered in the multidisciplinary health and nursing literature.

Background. In the multidisciplinary health and nursing literature, two ways are presented in which disability can be understood: the traditional, functional perspective and a more contemporary, social perspective.

Data sources. Computerized databases of the CINAHL, Proquest Nursing and Allied Health Sources, EBSCO and Evidence Based Medicine Reviews Multifile and Cochrane databases were conducted for papers published in English in the period 1963–2007 using the keywords ‘models of disability’, ‘disability and nursing research’ and ‘theories of disability’.

Methods. An integrative review was performed and, of the 11,578 papers identified, 65 were included.

Results. The concept of functional disability refers to an individual who is physically ‘disabled’ and unable to perform expected roles. The concepts of social stigmatization and normalcy are associated with functional disability. In contrast, social disability concerns functional limitations within an individual’s experience of living with disability, examining how socially constructed barriers actually ‘disable’ people. Conventionally, disability research has been conducted from an etic perspective. Researchers contend that a shift towards an understanding from the emic perspective is needed for disability research to be emancipatory.

Conclusion. Adoption of a social perspective is necessary to inform an understanding of disability that addresses stigmatization and oppression. Research-informed nursing practice, complemented by supportive health and social policies, could transform the experience of living with disability.

Keywords: chronic illness, disability, functional perspective, impairment, integrative review, nursing, social perspective

Introduction

Etymologically, the Latin prefix *dis* – means lack of, not, whereas the suffix – ability expresses ability or capacity derived from the Latin word ‘*habilitas*’. Thus, the word disability means ‘a physical or mental condition that limits a person’s movements, senses, or activities’ (Soanes 2003).

A number of authors suggest that the way in which society views disability has implications for the health and wellbeing of people labelled as disabled. We contend that a critical mass of nurses with a contemporary theoretical understanding of the language and nature of disability could have a positive impact on the care and lives of people living with disability. In the health-related multidisciplinary and nursing literature, two major ways in which disability can be understood are presented: the traditional, functional perspective and a more contemporary, social perspective.

Historically, disability has been understood exclusively from a physiological orientation, being conceptualized as a functional limitation. Functionalists described disability as a deviation from normal societal expectations in which people are no longer seen as able to perform expected roles. More recently, there has been a social movement promoting a new understanding of disability. This broader social perspective contextualizes functional limitations within an individual’s experience of living with disability. Such an understanding challenges the traditional, functional perspective by examining how socially constructed barriers actually ‘enable’ people living with impairment; that is, disability is socially constructed.

It has been suggested that there is a need to differentiate between the term impairment and disability (Oliver 1983, Jablensky 2000, Thomas 2004). Impairment has been referred to as cognitive and physiological limitations. In this perspective, disability refers to the disabling barriers of unequal access and negative attitudes that are externally imposed on an individual. An understanding of the associated concepts of stigmatization and normalcy and the language within disability discourse facilitates this re-conceptualization of disability.

The review

Aim

The aim of the review was to explore the way in which disability has been understood in the multidisciplinary health and nursing literature.

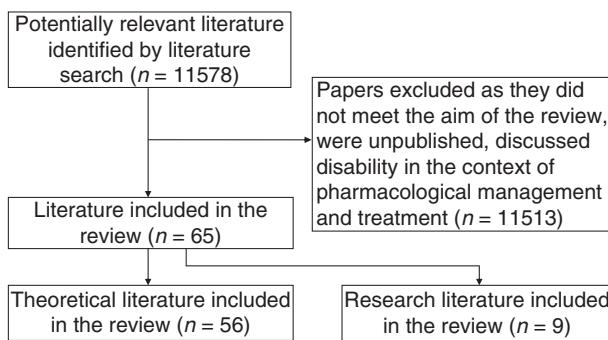


Figure 1 Design of the review.

Design

An integrative review method (Whittemore & Knafl 2005) was used to identify published literature to determine the state of the knowledge of disability, particularly within the multidisciplinary health and nursing research and theoretical literature. The design of the review is summarized in Figure 1.

Search methods

The computerized databases CINAHL, Proquest Nursing and Allied Health Sources, EBSCO and Evidence Based Medicine Reviews Multifile, including Cochrane databases, were searched using the keywords ‘models of disability’, ‘disability and impairment’, and ‘disability and nursing research’, and ‘theories of disability’. No restrictions were placed on the time of publication.

Search outcome

A total of 11,578 English language papers published between 1963 and 2007 were identified. Little qualitative and quantitative nursing research that examined disability was identified. Reports were excluded if they were unpublished, did not meet the aim of the review or discussed disability in the context of pharmacological management. There was a great deal of overlap among the papers extracted from the various databases searched. Only work that discussed the theoretical aspect of disability, disability research and models of disability were included in this review.

Sixty-five papers met the inclusion criteria and were therefore included in this integrative review. The final sample included research and theoretical literature from both primary and secondary sources. The majority of this literature was theoretical.

Quality appraisal

According to Whittemore and Knafl (2005), evaluating quality of sources in an integrative review is complex. Quality assessment for the present review was undertaken by the first author. Because of the diversity of the included research and theoretical literature, it was evaluated based on methodological quality, informational value and representativeness. Sources of evidence were excluded as a result of low theoretical or methodological quality, low informational value or lack of representativeness.

Synthesis

The included sources were grouped by either the traditional, functional perspective or the contemporary, social perspective on disability (Table 1). For each perspective, a narrative synthesis was created to describe how the literature could inform our understanding of disability.

Results

Functional perspective on disability

Traditionally, in the health-related and nursing literature disability has been understood from a physiological orientation and conceptualized as a functional limitation (Fraley 1992, Oliver 1993b, Goodall 1995). In this perspective it is assumed that an individual is 'disabled' or unable to function fully as a result of impairment. Hence, functionalists describe disability as a deviation from the societal norm, and as a condition in which people are no longer able to perform expected gender and occupational roles (Myers 1965, Fraley 1992, Brandt & Pope 1997, Scullion 1999a, Gignac *et al.* 2000, Wendell 2001, Lutz & Bowers 2003). Thus, Brandt & Pope (1997) define disability as a limitation in performing certain roles and tasks that society expects an individual to perform. Generally in this perspective, disability is the expression of the gap between a person's capabilities and the demands of the environment.

Social perspective on disability

More recently, there has been a social movement leading to a new understanding of disability (Goodall 1995, Barnes & Mercer 1997, Oliver 1998, Spruill 1999, Finkelstein 2004, Goodley 2004). In the social perspective on disability, functional limitations are contextualized in terms of an individual's experience of living with disability. Such an

Table 1 Reviewed literature discussing the functional and social perspectives of disability

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- | |
|-------------------------------|
| Abberley (1993) |
| Barbotte <i>et al.</i> (2001) |
| Finkelstein (1993) |
| Finkelstein and French (1993) |
| French (1993) |
| Gill (2001) |
| Goodley (2004) |
| Jette (2006) |
| Marks (2000) |
| Marks (2007) |
| Michalko (2002) |
| Mitra (2006) |
| Morris (1992) |
| Morris (1993) |
| Morris (2001) |
| Noonan <i>et al.</i> (1968) |
| Oliver (1992) |
| Oliver (1993b) |
| Oliver (1996a) |
| Oliver (1996b) |
| Oliver (1997) |
| Oliver (2004) |
| Spruill (1999) |
| Thomas (2004) |
| Titchkosky (2000) |
| Wendell (2001) |
-

understanding challenges the traditional, functional perspective (Spruill 1999) by examining how socially constructed barriers actually 'disable' people living with a perceived impairment (Goodall 1995, Barnes & Mercer 1997, Oliver 1998). For example, Spruill (1999) contends that most people understand their disability as a functional limitation, and as a result of environmental and social barriers rather than intrinsic pathology. Goodley (2004) suggests that the social model of disability encompasses all disabled people. Swain and French (2000) argue that there is a need to further advance the social model of disability to an affirmation model of disability that builds on the social model. They contend that such a model encompasses positive social identities for disabled people grounded in the benefits of lifestyle and life experiences of being impaired and disabled.

Hence, from this alternate perspective, disability is socially constructed (Table 2). Indeed, authors using this approach assert that a traditional, functionalist understanding of disability excludes people who are living with impairment from mainstream activity or reality; they are 'others' (Oliver 1992, 1993b, 1996a, 1996b, Finkelstein & French 1993, French 1993, Oliver 1997, 1998, 2004, Michalko 2002,

Table 2 Reviewed literature suggesting that disability is socially constructed

Finkelstein (1993)
Finkelstein (2004)
Finkelstein and French (1993)
French (1993)
Gill (2001)
Kitchin (2000)
Marks (2000)
Marks (2007)
Michalko (2002)
Mitra (2006)
Morris (1992)
Morris (1993)
Morris (2001)
Noonan <i>et al.</i> (1968)
Oliver (1992)
Oliver (1993b)
Oliver (1996a)
Oliver (1996b)
Oliver (1997)
Oliver (2004)
Spruill (1999)
Thomas (2004)
Tighe (2001)
Titchkosky (2000)
Wendell (2001)
Williams (1989)

Spruill 1999, Kitchin 2000, Wendell 2001, Thomas 2004, Finkelstein 1993). They maintain that functional disability, by definition, eliminates opportunities for people to perform what would be considered normal role activities. These authors assert that functional disability, like racism or sexism, is discriminatory and socially oppressive (Morris 1992, 1993, Oliver 1997, 1998, 2004, Kitchin 2000, Morris 2001, Oliver 1992, 1993b, 1996a, 1996b, Wendell 2001, Michalko 2002).

Indeed, review of this literature demonstrates that the term disability is habitually associated with a negative understanding or connotation. As might be expected, not only is disability viewed as a deviation from normal, but it also seen as a personal tragedy or misfortune. This perception of reality predisposes those 'who are disabled' to oppression and marginalization (Goffman 1963, Fraley 1992, Oliver 1993a, 1996a, 1996b, Goodall 1995, Barnes & Mercer 1997, Williams 1999, Kitchin 2000, Titchkosky 2000, Morris 2001, Wendell 2001, Michalko 2002). Many claim that the development of a social understanding of disability has had a liberating effect for people living with disability, shifting the process and function of disability research (Morris 2001). For example, researchers now consistently argue against the functional perspective, insisting that what

appears to be an individual experience of disability is in fact a socially constructed reality.

The language of disability: disability and impairment

A number of authors in the literature related to the social perspective of disability suggest that, to clarify the meaning of living with disability, it is essential to explicate the language used in disability discourse (Oliver 1983, 1993b, Finkelstein & French 1993, French 1993, Barnes & Mercer 1997, Scullion 1999a, Jablensky 2000, Morris 2001, Thomas 2004). Although the dominant descriptors used by a number of authors are disability and impairment (Noonan *et al.* 1968, Williams 1989, Morris 1992, Finkelstein 1993, Finkelstein & French 1993, French 1993, Morris 1993, 2001, Michalko 2002, Oliver 1997, 2004, Spruill 1999, Kitchin 2000, Titchkosky 2000, Tighe 2001, Wendell 2001, Oliver 1992, 1993b, 1996a, 1996b, Thomas 2004, Jette 2006), the meaning of these words is related to their contextual use.

For functionalists, the terms disability and impairment are used interchangeably and refer to an individual's physical or mental inability to function normally (Myers 1965, Fraley 1992, Wendell 2001, Thomas 2004). In contrast, social disability authors assert that the term disability refers not to physical limitations but rather to the disabling barriers of unequal access and negative attitudes imposed by society (Oliver 1983, 1993b, Finkelstein & French 1993, French 1993, Barnes & Mercer 1997, Scullion 1999a, Morris 2001, Thomas 2004). These authors define impairment as physiological and cognitive limitations and argue that the impairment may affect an individual's appearance in a way which is not socially acceptable, leading to an imposed label of disability. For social disability authors, only people who are disabled by society can be understood as someone living with disability.

Associated concepts of disability: stigma and normalcy

Concepts commonly associated with disability are social stigmatization and normalcy. In the social perspective, disability is understood as a social phenomenon that leads to the labelling of people as unique or different (Lewis 1983, Gordon *et al.* 1998, Michalko 2002). A number of authors suggest that the use of conceptual labels such as normal have individual and social implications for stigmatization, and thus must be examined in the context of disability. These authors argue that exclusionary terms such as normal potentially lead to decreased self-esteem and oppression for people who do not fit into social norms (Morris 1992, 1993,

Oliver 1997, 2004, Kitchin 2000, Morris 2001, Oliver 1992, 1993b, 1996a, 1996b, Michalko 2002).

Stigma

Disability discourse is frequently grounded in the writings of Goffman (1963) (Noonan *et al.* 1968, Abberley 1993, Gordon *et al.* 1998, Scullion 1999a, Titchkosky 2000, Michalko 2002). Titchkosky (2000) suggests that Goffman's (1963) presentation of stigma represents a more traditional sociological examination of disability. Gordon *et al.* (1998) consider that Goffman's (1963) investigation of the concept of stigma has been instrumental in denoting attributes that contemporary society considers discrediting. They argue that stigma places preconceived notions and negative expectations on an individual or group as a result of either physical or behavioural characteristics that differ from those of the masses.

Goffman (1963) spoke of society's reaction to abominations of the body and described stigma as a social phenomenon. He suggested that people were 'marked' as different and contended that, in the creation of difference, stigmatized individuals were unlike other human beings, thus making them not quite human. For Goffman (1963), not only can stigma be associated with a variety of disabilities and impairments, but it can also be associated with physical abnormalities such as unusual body shapes or marks or mental illnesses. Based on Goffman's (1963) work, Michalko (2002) suggests that everyone manages a self and there is a continual redefinition of this self. He further argues that, in the context of disability, a dichotomy exists between 'normal' and abnormal. He further contends that as a result of the social construction of disability, those who are disabled feel that they have to 'pass' in an attempt to be viewed as 'normal.' In the language of Goffman (1963), passing is possible in situations when the stigma is invisible and known only to the person who possesses it. Hence, Michalko (2002) asserts that people, such as those living with disability/impairment, often try and pass as 'normal' in an attempt to maintain their identity.

Normalcy

Gignac *et al.* (2000) assert that normalcy, that is maintaining independence, is viewed as pivotal to quality of life, and they propose that a primary fear of people living with impairment is being dependent on others, of not being 'normal'. They consider that, initially, an individual's withdrawal from recreational activities such as hobbies, going out to eat and traveling, functions as a compensatory mechanism to maintain some form of independence or normalcy in which no assistance is required. This withdrawal is a self-sacrifice to

maintain a perception of normalcy. Gignac *et al.* (2000) concludes that people living with impairment employ such compensatory mechanisms in an attempt to maintain control, independence and to appear normal.

Disability and research

Traditionally, disability research has been conducted from the etic, positivist perspective, and people living with disability have not participated in the design or management of these studies (Oliver 1992, 1993a, 1996a, 1996b, Beazley *et al.* 1997, Oliver 1997, 1998, Marks 2000, Vernon 1997, Kitchin 2000, Barnes & Mercer 1997, Michalko 2002). As a result, Oliver (1993a) suggests that this research has made a limited contribution to our knowledge of disability and, by extension, to the quality of life of people living with disability. In particular, he believes that research performed by people not living with disability lacks commitment to the issues involved in the social causation of disability. He further notes that, as a result of this emancipatory philosophical shift, many people living with disability are now refusing to participate in research that is designed, controlled and published by able-bodied researchers.

More recently, a number of researchers, in their criticisms of the disability literature, have called for emancipatory inquiry as a complementary methodology (Morris 1992, Oliver 1992, 1993a, 1996a, Oliver 1996b, Oliver 1997, Michalko 2002, Kitchin 2000, Marks 2000, Marks 2007, Barnes & Mercer 1997). These researchers support the need to understand the experience of disability from an emic perspective. Some claim that the exclusion of people living with disability and impairment from the discourse has been the catalyst for the adoption of research strategies that are emancipatory and empowering (Oliver 1992, 1993a, Kitchin 2000, Barnes 2004). The emphasis on emancipatory principles in critical social research is now the central goal of disability research (Barnes & Mercer 1997), with those being researched viewed as 'expert knowers'.

Disability in the context of nursing

Many nurse researchers have examined disability in the context of chronic illness (Pohl & Winland-Brown 1992, Thorne 1993, Thorne 2001, Goodall 1995, Northway 1997, Northway 2000, Thorne & Paterson 2000, Scullion 1999a, 1999b, Marks 2000, Marks 2007). They assert that nurses may be viewed as part of a system that disables people living with impairments, and argue that the representation of disability and impairment within nursing practice is problematic as it supports oppression and minimal emancipation

of people living with disability. Northway (1997, 2000) suggests that, since the 1970s, disability labelling in this body of literature has been a form of oppression. She considers that nurses have not clearly examined the nature and extent of this phenomenon, and argues that nurses have the potential either to reduce or compound such oppression. Northway further contends that, in relation to the unequal distribution of power between people living with disability and nurses, research is needed to examine professional behaviours in the context of disability and impairment.

For Northway (1997, 2000), it is essential that nurses be aware of their position within a system that has oppressed people living with disability and impairment, and that they understand whose interests are served by nursing disability research. Blackford (1998) suggests that a more appropriate understanding of the disability experience is one where there is a dynamic interaction between the social oppression and emancipation of disabled people in the development of self-knowledge. Indeed, according to Blackford, such practice requires researchers to reflect on their personal and professional values and research practice.

More recently, a number of nurse researchers have identified an evolutionary shift in the manner in which disability and chronic illness are understood (Thorne 1993, 2001, Northway 1997, Thorne & Paterson 1998, Thorne & Paterson 2000, Marks 2000, 2007, Thorne *et al.* 2002, 2003). They contend that this alternative view provides an insider's perspective on the experience from those who have lived it. They assert that this shift reorients people from being recipients of professional health care to active partners who are experts in their own health challenges. In addition, these researchers argue that this alternative perspective highlights the competence in decision-making and skill in self-care management of people living with disability. This inclusionary view redefines the role of nurses from caregivers to care partners so that they assist disabled people to liberate themselves from the conscious and unconscious societal constraints placed on them. Furthermore, they consider that this evolutionary shift includes the assumption that people living with disability and impairment are competent and capable of decision-making and self-management. Finally, as Northway (1997) suggests, these authors argue that it is important to develop nursing research in which people living with disability are actively involved.

Discussion

The literature identified in this review was predominantly theoretical in nature. Limited qualitative and quantitative research literature, specifically in the nursing literature, was

identified. Thus, an integrative review as opposed to a systematic review of the literature was warranted. Much of the theoretical and research literature identified was discipline specific.

In this review of the literature, disability has been presented from a traditional, functional perspective and a more contemporary, social perspective. Regardless of orientation, however, disability and impairment are the dominant descriptors used by most authors (Noonan *et al.* 1968, Williams 1989, Morris 1992, Finkelstein 1993, French 1993, Morris 1993, Michalko 2002, Spruill 1999, Titchkosky 2000, Morris 2001, Oliver 1997, 1998, 2004, Oliver 1992, 1993b, 1996a, 1996b, Thomas 2004, Tighe 2001, Wendell 2001, Kitchin 2000, Finkelstein & French 1993). Both the functional and social perspectives contain language that describes limitations in the actions and/or behaviours of people. Indeed, past and present definitions of disability reflect functionalist assumptions about deviations from normal functioning and a conviction that people labelled/stigmatized as disabled are no longer able to perform expected 'normal' roles (Myers 1965, Fraley 1992, Scullion 1999a, Gignac *et al.* 2000, Wendell 2001, Lutz & Bowers 2003). More recently, functional disability has been redefined by social disability authors as impairment, a restriction or inability to perform activities in a way that would be considered normal (Barbotte *et al.* 2001). Although writers adopting a functionalist understanding of disability or the social definition of impairment both address cognitive and physiological limitation, in the social perspective, disability solely refers to the disabling barriers of unequal access and negative attitudes externally imposed on an individual by society (Oliver 1983, 1993b, Finkelstein & French 1993, French 1993, Barnes & Mercer 1997, Scullion 1999a, Morris 2001, Thomas 2004).

Implications for nursing practice

Caring for and conducting research with people living with disabilities poses a potential challenge to nurses. Nurses and researchers may contribute to a system that disables people living with impairments (Northway 1997, Northway 2000, Scullion 1999a, 1999b). Therefore, they must examine their own understanding, values and beliefs about disability. It is important to engage people living with illness as active participants in care and decision-making processes. For this to occur, nurses must recognize and understand the experience of people living with disabilities and the implications of their experience related to their physical, emotional, psychological, psychosocial and spiritual health. It is imperative that nurses advocate for people living with disabilities so that an

understanding of disability evolves which will ultimately lead to appropriate differentiation between impairment and disability by healthcare professionals and society in general.

Nurses function in many roles when working with those living with disability and their families, including practitioner, advocate, case manager, educator, counsellor, researcher and consultant (Fraley 1992, Barr 2007). They are vital agents in assisting people to adapt to a chronic disability. Thorne and McCormick (1997) suggest that healthcare providers often lack specialized training about the socio-political aspects of disability. This limited preparation results in inappropriate use of language, incomplete assessment and non-evidence-based interventions and a deficit of evaluation strategies. Although stigmatizing the experiences of those who are living with disability is likely to occur in the wider social milieu, healthcare professionals are expected to demonstrate a greater understanding of health issues which is free from stigmatization (Thorne & McCormick 1997).

Nurses should advocate cooperatively with those living with disability in an attempt to educate and transform negative labelling and stigmatization against those viewed as helpless, dependent, and as less able to contribute to society. Before this can be achieved, nurses must further the understanding of disability and recognize their own values, beliefs, views, prejudices and thoughts about disability. Enhanced awareness of the complexities involved in the social constructions of illness and disability has the potential to promote a balance of competing perspectives in the healthcare system (Thorne & McCormick 1997). Further, nurses must advocate for the people living with disability during interactions with other healthcare professionals.

The review results illustrate the multiple theoretical and limited research understandings of disability, whether through the lens of the functional or social perspective. Researchers must examine their personal and professional behaviours and be aware of their position within a system that has oppressed people living with disability, and determine whose interests are served by nursing research in this field (Northway 1997, Northway 2000). Each of these requires them to reflect on their personal and professional values and their research practice from an emic perspective.

Oliver (1998) suggests that more research is needed that is based on social theories of disability if research is to improve the quality of life of people living with disability and their families. Furthermore, Oliver suggests that disability research has been dominated by positivist theories and that research funding predominantly supports positivist research. Therefore, funded disability research based on critical theory and

social constructionism and understanding of the emic experience of people living with disability would offer a more complete understanding of disability (Alderson 1998, Oliver 1998). Further examination of the stigmatization experienced by people living with disability would be beneficial. Much of the theoretical and research literature surrounding disability is discipline specific, and more interdisciplinary work is needed.

There is a critical need to involve those who are living with disability in the knowledge generation process to reveal the emic perspective. Researchers should involve people in every step of the research process, including choice of methodology. It should be possible to develop research that actively involves those living with disability in establishing a research agenda, agreeing to methods of inquiry, report writing, and knowledge dissemination (Northway 1997, Oliver 1998, Barr 2007). In the 21st century, legislation, policy and practice have evolved rapidly to include a focus on the social model of disability. For example, most research funding bodies in Canada, such as the Canadian Institute for Health Research, the Canadian Health Services Research Foundation and the Social Sciences and Humanities Research Council of Canada require that the perspectives of consumers inform and assist in the development of research proposals. This review also highlights the need to explore further how people living with disability view and understand how others perceive them to be. A perception of others' understanding has the potential to influence how those with disability live their experiences.

The manner in which people, society and the government acknowledge, conceptualize and understand disability greatly affects the emergence of health and social policies. Based on this review, those responsible for policy development should consider the implications of language to promote emancipation and abolish stereotypes associated with disability. According to Mitra (2006), the manner in which disability is defined can have far-reaching social, economic, and political implications. Further, generic policies affecting people living with disabilities fail to address this population and thus support oppression and stigmatization. Opportunities to remediate such situations must be explored. For example, an informed nursing presence in activities such as environmental health initiatives, planning of accessibility in public settings and the coordination of health services could assist in developing transformational protocols, procedures and ultimately policies that affect those living with disability. Further, authors who explore disability in relation to social policy suggest that, in developed countries such as Canada, Australia the United States and the United Kingdom, there is a need to develop

What is already known about this topic

- Health-related, multidisciplinary literature presents two prominent ways in which disability can be understood: a traditional, functional perspective and a more contemporary, social perspective.
- The term disability refers to a social construction, whereas impairment refers to physical and/or social limitation as a result of chronic illness.
- Disability research has been conducted from the etic perspective, and people living with disability have not participated in the design or management of these studies.

What this paper adds

- Adoption of a social perspective is necessary to inform an understanding of disability that addresses stigmatization and oppression.
- People with disabilities should be involved in all stages of research and policy-making so that generic work takes account of their experiences.
- Nurses need to engage in socio-political action to transform the social context of disability.

disability politics (Drewett 1999, Priestley 2000, Beresford 2001, Schroeder *et al.* 2001, Harrison 2002, Ellis 2005). In response to this need, the emergent social model of disability has the potential to have a positive impact on service models and policies.

Conclusions

The way that disability is generally viewed in society has implications for the health and wellbeing of people labelled as disabled. The continued and exclusive use of the restrictive, functional understanding of disability will not allow for an informed understanding of this experience. Without an appreciation and integration of a social perspective on disability, people living with disability will continue to experience stigmatization and oppression. Research-informed nursing practice, complemented by supportive health and social policies, has the potential to transform people's experiences of living with disability.

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Author contributions

CMB and PB were responsible for the study conception, design and drafting of the manuscript. CMB performed the data collection. CMB, PB and SM performed the data analysis and made critical revisions to the paper for important intellectual content.

References

- Abberley P. (1993) Disabled people and 'normality'. In *Disabling Barriers-Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 107–115.
- Alderson P. (1998) The importance of theories in health care research. *BMJ* 317, 1007–1010.
- Barbotte E., Guillemin F., Chau N. & the Lorhandicap Group (2001) Prevalence of impairments, disabilities, handicaps and quality of life in the general population: a review of recent literature. *Bulletin of the World Health Organization* 79(11), 1047–1055.
- Barnes C. (2004) Reflections on doing emancipatory disability research. In *Disabling Barriers-Enabling Environments* (Swain J., French S., Barnes C. & Thomas C., eds), Sage, London, pp. 47–53.
- Barnes C. & Mercer G. (1997) Breaking the mould? An introduction to doing disability research. In *Doing Disability Research* (Barnes C. & Mercer G., eds), The Disability Press, Leeds, pp. 1–14.
- Barr O. (2007) Research in learning disability nursing: importance and relevance to all areas of nursing. *Journal of Research in Nursing* 12, 107–109.
- Beazley S., Moore M. & Benzie D. (1997) Involving disabled people in research: a study of inclusion in environmental activities. In *Doing Disability Research* (Barnes C. & Mercer G., eds), The Disability Press, Leeds, pp. 142–157.
- Beresford P. (2001) Service users, social policy and the future of welfare. *Critical Social Policy* 21(4), 494–512.
- Blackford K. (1998) Mother to daughter: the shaping of a girl's values in the context of a parent with a chronic illness. In *Redefining Motherhood: Changing Identities and Patterns* (Abbey S. & O'Reilly A., ed), Second Story Press, Toronto, pp. 145–158.
- Brandt E.N. & Pope A.M. (1997) *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*. National Academic Press, Washington, DC.
- Drewett A. (1999) Social rights and disability: the language of 'rights' in community care policies. *Disability & Society* 14(1), 115–123.
- Ellis K. (2005) Disability rights in practice: the relationship between human rights and social rights in contemporary social care. *Disability & Society* 20(7), 691–704.
- Finkelstein V. (1993) Disability: a social challenge or an administrative responsibility. In *Disabling Barriers-Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 34–43.
- Finkelstein V. (2004) Representing disability. In *Disabling Barriers-Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 13–20.
- Finkelstein V. & French S. (1993) Towards a psychology of disability. In *Disabling Barriers Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 26–33.

- Fraley A.M. (1992) *Nursing and the Disabled: Across the Lifespan*. Jones and Bartlett Publishers, Boston, MA.
- French S. (1993) Disability, impairment or something in between. In *Disabling Barriers Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 17–25.
- Gignac M.A., Cott C. & Badley E.M. (2000) Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journal of Gerontology* 55(6), 362–372.
- Gill C. (2001) What is the ‘social model of disability’ and why should you care? *Alert! The Newsletter of the Institute on Disability and Human Development* 12(2), 6–9.
- Goffman E. (1963) *Stigma: Notes on Management of Spoiled Identity*. Englewood Cliffs, Prentice Hall, NJ.
- Goodall C. (1995) Is disability any business of nurse education? *Nurse Education Today* 15, 323–327.
- Goodley D. (2004) Who is disabled? Exploring the scope of the social model of disability. In *Disabling Barriers Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 118–124.
- Gordon P.A., Feldman D. & Crose R. (1998) The meaning of disability: how women with chronic illness view their experiences. *Journal of Rehabilitation* 1, 5–11.
- Harrison T. (2002) Has the Americans with Disabilities Act made a difference? A policy analysis of quality of life in the post-Americans with Disabilities Act era. *Policy, Politics & Nursing Practice* 3(4), 333–347.
- Jablensky A. (2000) Handicap and disability: words versus concepts. *Disability and Rehabilitation* 22(11), 513–514.
- Jette A.M. (2006) Toward a common language for function, disability, and health. *Physical Therapy* 86(5), 726–734.
- Kitchin R. (2000) The researched opinions on research: disabled people and disability research. *Disability & Society* 15(1), 25–47.
- Lewis K. (1983) Grief in chronic illness and disability. *Journal of Rehabilitation* 1, 8–11.
- Lutz B.J. & Bowers B.J. (2003) Understanding how disability is defined and conceptualized in the literature. *Rehabilitation Nursing* 28(3), 74–78.
- Marks B.A. (2000) Jumping through hoops and walking on egg shells or discrimination, hazing, and abuse of students with disabilities? *Journal of Nursing Education* 39(5), 205–210.
- Marks B.A. (2007) Cultural competence revisited: nursing students with disabilities. *Journal of Nursing Education* 46(2), 70–74.
- Michalko R. (2002) *The Difference That Disability Makes*. Temple University Press, Philadelphia, PA.
- Mitra S. (2006) The capability approach and disability. *Journal of Disability Policy Studies* 16(4), 236–247.
- Morris J. (1992) Personal and political: a feminist perspective on researching physical disability. *Disability, Handicap and Society* 7, 157–166.
- Morris J. (1993) Gender and disability. In *Disabling Barriers-Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 85–92.
- Morris J. (2001) Impairment and disability: constructing an ethics of care that promotes human rights. *Hypatia* 16(4), 1–16.
- Myers J.K. (1965) Consequences and prognoses of disability. In *Sociology and Rehabilitation* (Sussman M.B., ed), American Sociological Association, Washington, DC, pp. 35–51.
- Noonan J.R., Barry J.R. & Davis H.C. (1968) Personality determinants in attitudes toward visible disability. *Rehabilitation Counselling Bulletin* 1, pp. 1–16.
- Northway R. (1997) Disability and oppression: some implications for nurses and nursing. *Journal of Advanced Nursing* 26, 736–743.
- Northway R. (2000) Disability, nursing research and the importance of reflexivity. *Journal of Advanced Nursing* 32(2), 391–397.
- Oliver M. (1983) *Social Work With Disabled People*. Macmillan, London.
- Oliver M. (1992) Changing the social relations of research production? *Disability, Handicap, and Society* 7, 101–114.
- Oliver M. (1993a) Disability and dependency: a creation of industrial societies? In *Disabling Barriers-Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 49–59.
- Oliver M. (1993b) Re-defining disability: a challenge to research. In *Disabling Barriers-Enabling Environments* (Swain J., Finkelstein V., French S. & Oliver M., eds), Sage, London, pp. 61–67.
- Oliver M. (1996a) *Understanding Disability. From Theory to Practice*. Macmillan, Basingstoke.
- Oliver M. (1996b) A Sociology of Disability or a Disablist Sociology? In *Disability and Society: Emerging Issues and Insights* (Barton L., ed.), Longman, London, pp. 18–42.
- Oliver M. (1997) Emancipatory Research: Realistic Goal or Impossible Dream? In *Doing Disability Research* (Barnes C. & Mercer G., eds), The Disability Press, Leeds, pp. 15–31.
- Oliver M. (1998) Theories in health care and research: theories of disability in health practice and research. *BMJ* 317, 1446–1449.
- Oliver M. (2004) If I had a hammer: the social model in action. In *Disabling Barriers-Enabling Environments* (Swain J., French S., Barnes C. & Thomas C., eds), Sage, London, pp. 7–12.
- Pohl C. M. & Winland-Brown J.E. (1992) The meaning of disability in a caring environment. *Journal of Nursing Administration* 22(6), 29–35.
- Priestley M. (2000) Adults only: disability, social policy and the life course. *Journal of Social Policy* 29(3), 421–439.
- Schroeder M., Buckley K. & Debisette A. (2001) Public policy decisions related to disability and rehabilitation: is it time for a new paradigm? *Policy, Politics and Nursing Practice* 2(4), 310–315.
- Scullion P.A. (1999a) Conceptualizing disability in nursing: some evidence from students and their teachers. *Journal of Advanced Nursing* 29(3), 648–657.
- Scullion P.A. (1999b) ‘Disability’ in a nursing curriculum. *Disability & Society* 14(4), 539–559.
- Soanes C. (2003) *The Compact Oxford English Dictionary of Current English*. Oxford University Press. Retrieved from http://www.askoxford.com/concise_oed/disability?view=uk on 21 December 2007.
- Spruill L.C. (1999) Social, legislative, and clinical influences on defining disability: implications for information management. *Topics in Health Information Management* 19(3), 10–14.
- Swain J. & French S. (2000) Towards an affirmation model of disability. *Disability & Society* 15(4), 569–582.
- Thomas C. (2004) Disability and impairment. In *Disabling Barriers-Enabling Environments* (Swain J., French S., Barnes C. & Thomas C., eds), Sage, London, pp. 21–27.

- Thorne S.E. (1993) *Negotiating Health Care: The Social Context of Chronic Illness*. Sage Publications, London.
- Thorne S. (2001) People and their parts: deconstructing the debates in theorizing nursing's clients. *Nursing Philosophy* 2, 259–262.
- Thorne S.E. & McCormick J. (1997) Deconstructing the gender neutrality of chronic illness and disability. *Health Care for Women International* 18(1), 1–16.
- Thorne S.E. & Paterson B. (1998) Shifting images of chronic illness. *Image: Journal of Nursing Scholarship* 30(2), 173–177.
- Thorne S.E. & Paterson B.L. (2000) Two decades of insider research: what we know and don't know about chronic illness experience. *Annual Review of Nursing Research* 18, 3–25.
- Thorne S., Paterson B., Acorn S., Canam C., Joachim G. & Jillings C. (2002) Chronic illness experience: insights from a metastudy. *Qualitative Health Research* 12(4), 437–452.
- Thorne S.E., Paterson B. & Russell C. (2003) The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research* 13(10), 1337–1352.
- Tighe C.A. (2001) Working at disability: a qualitative study of the meaning of health and disability for women with physical impairments. *Disability & Society* 16(4), 511–529.
- Titchkosky T. (2000) Disability studies: the old and the new. *Canadian Journal of Sociology* 25(2), 197–224.
- Vernon A. (1997) Reflexivity: the dilemmas of researching from the inside. In *Doing Disability Research* (Barnes C. & Mercer G., eds), The Disability Press, Leeds, pp. 158–176.
- Wendell S. (2001) Unhealthy disabled: treating chronic illnesses as disabilities. *Hypatia* 16(4), 17–33.
- Whittemore R. & Knafl K. (2005) The integrative review: updated methodology. *Journal of Advanced Nursing* 52(5), 546–553.
- Williams S.J. (1989) Chronic respiratory illness and disability: a critical review of the psychosocial literature. *Social Science & Medicine* 28(8), 791–803.
- Williams S.J. (1999) Is anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health and Illness* 21(6), 797–819.