Disability and Illness: The Perspectives of People Living with a Long-term Condition

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Overview
- Ways of looking at impairment, disability and illness
- Why a long-term condition can be perceived as both an illness and a disability
- The invisibility of disabilities
- Disability and the self
- Disability as both sickness and health

Demographic changes are certain to mean that there will continue to be an increase in the total number of people with long-term conditions and disabilities in the UK (Office for National Statistics, 2009; Shakespeare and Watson, 2002). Translated into actual numbers, the Office for Disability Issues (2008) estimated that there were nearly 10 million disabled adults in the UK, with around 5 million of these people being over state pension age. The definition of disability used in the collection of these figures was ‘having a longstanding illness, disability or infirmity, and having a significant difficulty with day-to-day activities’. This definition implies a link or overlap between illness and disability, which can be further understood through examining the experiences of people with certain long-term
conditions. Using research reports of people with Multiple Sclerosis (MS) as well as my own experience of this condition, this chapter will explore how these blurred boundaries can lead to a range of challenging experiences when receiving health and social care. The box, ‘Margo’s story’ puts you in the picture with regards my own experience of having a long-term condition and disability:

Margo’s story

For around 15 years, I made repeated visits to a series of general practitioners, complaining of severe fatigue. On each occasion, I was met with platitudes like ‘But everyone gets tired’. It seemed impossible to explain that this wasn’t normal tiredness - I knew what that felt like and this wasn’t it! Sometimes I was offered anti-depressants, but with a previous history of major depression, I knew that was not the problem at that time.

It was only in 2003, when my health broke down completely, that my GP began to do investigations. I began to have severe dizziness and pass out, my fatigue was now overwhelming, and within a few months I needed a wheelchair to go more than a hundred yards.

The investigations took nearly two years. The uncertainty during this period only added to the stress of having a major and progressive condition. I was imagining myself to have every condition from Motor Neurone Disease to a brain tumour. Finally, in March 2005, I was diagnosed as having Multiple Sclerosis (MS), a condition that is made worse by stress. As I was able to identify relapse-like episodes dating back at least 15 years, the neurologist diagnosed me immediately as having the secondary progressive type. I had an illness (or rather a long-term condition) and I was also disabled.

By this time, I was having to use a power wheelchair whenever I left home, and was being visited by carers every morning. While using a wheelchair undoubtedly gives me more independence physically, I do feel frustrated by inaccessible premises and events. I am also made angry by insensitive and thoughtless comments from those who presumably have no experience of disability.

I get frustrated when I ‘fall into the gaps’ of care: for instance when there is a break in a prescription between the initial supply from a hospital doctor and the repeat supply from my GP. It is frustrating, too, when health care professionals will not listen to my knowledge of how my condition affects me, and try to apply a one-size-fits-all remedy. A physiotherapist refused to believe that I was having cognitive (thinking) problems ‘because you’re studying for a PhD’. This was annoying beyond belief.

The ‘invisible’ symptoms of my disability remain the most difficult for others to understand. Lack of mobility is easy to comprehend; fatigue and pain not so. As subjective experiences, they are hard to communicate, and as everyday words, everyone has their own definition and experience of them. I have a number of (Continued)
ongoing symptoms or ‘illnesses’, such as frequent infections, but fatigue is my biggest enemy. I have used the Spoon Theory (Miserandino, 2010), to explain severe fatigue to people, and know many others who have done the same. My social life now mainly revolves around other people with MS and a few others who are able to understand that I may need to cancel things at very short notice if I have a ‘bad day’.

I don’t know what the future holds. All I know is that my condition will progress: I don’t know how fast, or how far. This uncertainty is one of the hallmarks of MS, and one of the most difficult things to deal with.

My experiences, briefly outlined above, specifically highlighted the lack of a clear distinction between illness and a disability, as well as the invisibility of disability, the juxtaposition of health and illness in disability and the role of professional attitudes in the experience of disability. These were also constant themes in my research with people with MS, discussed here in relation to recent literature and highlighting the implications for health and social care practice.

Illness or disability?

The International Classification of Functioning, Disability and Health, known more commonly as ICF (WHO, 2002), is an official classification of health and health-related domains. These domains are classified by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual’s functioning and disability occurs in a context, the ICF also includes a list of environmental factors. In this classification body functions are defined in a very narrow, medicalized way, but domains of activity include a wide range of self-care, social, spiritual and political activities. Environmental factors include physical and social barriers, support and relationships, attitudes, and policies. In spite of the inclusion of these factors, this classification is usually considered to represent one of the medical models of disability.

From the late 1960s onwards, many disabled people have campaigned for more of a role for themselves when disability is defined. For example in 1976 the Union of the Physically Impaired Against Segregation (UPIAS) proposed this definition for the social model of disability:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily
isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

Thus we define impairment as lacking part or all of a limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical impairment is therefore a particular form of social oppression. (UPIAS, 1976: 14)

Within this definition, disability becomes oppression placed by society on people with impairments. Impairment is a prerequisite of disability (Finkelstein, 2001), but disability does not necessarily follow from impairment. In this chapter, however, I will continue to use the term ‘disability’ in its everyday sense, to include physical impairments.

The distinction between impairment and disability is important to many disabled people because it removes the ‘blame’ for their oppressed position in society. Many of the structures of bureaucracy seem designed to make the disabled person aware of how they fail to meet the ‘norm’. For example, claimants for Disability Living Allowance, which aims to provide finance for people with mobility and personal care needs, have to describe themselves using negative terminology, as an incapable person rather than in positive terms (Reeve, 2002). It is my contention here that when health care professionals are working with people with disabilities and long-term conditions, using the social model and emphasizing positive aspects of their lives is not just a theoretical position, but a vital part of understanding.

Illness is what is perceived by the person living with it, as opposed to disease, which is a condition diagnosed and treated by doctors (Eisenberg, 1977). Many disabilities are disabilities only – the individuals concerned remain in good health, with no ‘illness’ present. One participant in my research, who has cerebral palsy, is offended if anyone refers to him as ‘ill’, as he does not consider himself to be so. In other situations, an individual may be considered to be ‘ill’ but not ‘disabled’, for instance by asymptomatic conditions such as the early stages of type 2 diabetes.

Some conditions may lead to both illness and disability, as in the case of MS. Multiple sclerosis is a debilitating condition in which the body’s own immune system begins to destroy the protective sheath covering some of the nerves. This interferes with communication between the brain and the rest of the body. Ultimately, this may result in damage to the nerves themselves. Multiple sclerosis can occur at any age, but is most commonly diagnosed between the ages of 20 and 40. Women are about twice as likely to develop it as men. White people, particularly those of Northern European descent, are at highest risk of developing multiple sclerosis; people of Asian,
African and Native American descent are at lowest risk (Mayo Clinic Staff, 2009).

The symptoms of MS can vary widely and can be perceived as either part of the illness itself or can lead to disability, or both, depending on the amount and location of damage. The symptoms may include numbness or weakness in one or more limbs, partial or complete loss of vision, double vision or blurring of vision, tingling or pain, tremor, or dizziness (Mayo Clinic Staff, 2009). Extreme fatigue is probably the most common symptom of multiple sclerosis (Bakshi, 2003; Multiple Sclerosis Encyclopaedia, 2008; Kos et al., 2008; Smith and Hale, 2007). Along with a high prevalence of depression (Chwastiak et al., 2002; Patten et al., 2003; Siegert and Abernethy, 2005) and general malaise, this often leads to MS being perceived by those with it as an illness as much as a disability. People with multiple sclerosis often have very frequent contact with health care professionals for such things as catheter and bowel care or treatment of infections (Hennessey et al., 1999), reinforcing the perception of MS as an illness as well as a disability.

My own experience gives a good example of MS as both an illness and disability; as I mention in my story above, I have a number of ongoing symptoms or ‘illnesses’ which force me into frequent contact with health practitioners, underlining the blurred boundaries between illness and being a disabled person with a long-term condition. Having multiple long-term conditions almost always means that health and social care is required from a range of specialties. Furthermore individuals with one long-term condition often have to visit a number of different specialists: I myself am currently under the care of a neurologist, an MS specialist nurse, a continence specialist nurse, a urologist, a gastroenterologist, wheelchair services, a physiotherapist and an occupational therapist, as well of course as my GP and practice nurse. I also have daily visits from carers. This can lead to fragmentation of care and frequently to frustration due to lack of co-ordination between the different services involved.

Many people with MS have noticeable decrements in health-related quality of life and research has indicated that individuals with more than one long-term condition may experience an even poorer quality of life (Sprangers et al., 2000). The effect of disability on daily living is thought to be greater in MS than in many other long-term conditions (Devins et al., 1993). Other common features include anxiety, depression, and cognitive impairment (Feinstein, 2004; Patti, 2009). There is increasing recognition that these issues form a vital component of people’s health-related quality of life, distinct from physical disability alone (Mitchell et al., 2005). However not all people with MS have both illness and disability; some may have mobility problems, for instance, without any of the ‘illness’ symptoms such as fatigue and pain. Many others, particularly in the early stages, have
only ‘illness’ symptoms and no obvious disability. People can move between categories at different stages of their condition.

The invisibility of disability

Many symptoms of multiple sclerosis are invisible, and can be hard for others to appreciate and accept. There can be a perception that disabilities have to be visible to be ‘taken seriously’ (Stone, 2005). I have myself encountered professional care staff who held (and expressed) the opinion that I am not ‘really’ disabled because I am able to walk short distances – ignoring the reality of the pain and fatigue this causes me. It is particularly hard for people with MS to explain to others the all-pervading, crippling fatigue that many of us experience. It is often easiest to use an analogy, such as The Spoon Theory, in which Christine Miserandino, an American woman with a long-term condition called ‘lupus’, uses a bundle of teaspoons to describe the restrictions of long-term conditions (Miserandino, 2010).

Miserandino wanted to convey how people with a long-term condition often have a limited amount of energy with which to tackle everyday life. Each expenditure of energy, or each activity undertaken, leads to less available energy for any subsequent activities. She likened each energy expenditure to a spoon; with a limited number of spoons in the bundle it is important to be aware of the effects of each activity. One could ‘borrow’ a spoon from the next day’s supply but that simply meant you would have less to use tomorrow and what if that day you become ill; ‘…you do not want to run low on spoons, because you never know when you will truly need them’ (Miserandino, 2010).

I am aware anecdotally of many people with MS who have used The Spoon Theory to explain MS fatigue to family and friends, with some success. It could also increase understanding during consultations, and underlines the importance of health and social care practitioners listening to service users’ own explanations of their symptoms and experiences. Miserandino’s use of spoons as a metaphor for energy also mirrors other uses of metaphor in writings on health, most memorably perhaps by the American literary theorist Susan Sontag, who drew out the similarities between public perspectives on cancer and tuberculosis, and how both had become associated with particular psychological traits (Sontag, 1978).

Disability and the self

Research indicates that people with visible disabilities are likely to report poorer adjustment and self-concept than people with invisible disabilities:
for instance Goldberg found that children with a visible disability (facial burns) had lower levels of adjustment than children with an invisible disability (heart disease) (Goldberg, 1974). Tam and colleagues, working with Hong Kong Chinese adults, found that those with visible disabilities scored significantly lower in self-concept than did either the non-disabled control group or the group with disabilities that were not visible (Tam et al., 2003). However in the case of multiple sclerosis, it seems that invisible, illness-related symptoms such as pain and depression may cause more distress than visible ones such as problems with mobility (White et al., 2008). This may be because of the unpredictability of MS, and the subsequent difficulties in planning day to day life (Charmaz, 1991). As a female participant in my research said: ‘My condition is different day to day, week to week’.

Some people with long-term conditions may hold a specific ideology about living with such conditions, with residuals, for instance, of the Protestant work ethic. These ideologies are predicated on values of hard work, independence and individual responsibility. Maintaining a ‘normal’ life or returning to one as soon as possible becomes a symbol of a valued self. People living with long-term conditions may view physical dependency as negative, and often blame themselves for it (Charmaz, 1983). In my own research three women I interviewed discussed their fear of dependency in the following ways:

‘Becoming totally dependent with a terminal illness is something I am dreading.’
‘I could not bear to live a completely dependent life.’
‘I worry about becoming incapable of looking after myself.’

However another woman with MS took a more critical approach:

‘I do question the fear of dependency. Is this a fear of the standard of care, and the loss of dignity and respect? – if so, this needs to be addressed in our society.’

Susan Wendell, an academic with myalgic encephalitis/chronic fatigue and immune dysfunction syndrome (ME/CFIDS), clearly resents every relapse:

At the beginning of a relapse, I cannot help noticing that I am more easily exhausted every day, but I still resist giving in to being sick. The increasing fatigue feels like a progressive humiliation of my will and ego as it forces me to cancel my plans and retreat to my bed. (Wendell, 2008: 209)

I can empathize with Wendell: as someone with MS, I am regularly told to ‘listen to my body’, to rest when I need to. This makes it no easier to cancel social activities at the last minute or put off important deadlines. It is important for health care practitioners to listen to their clients, for instance
if they say they have important commitments that cannot be put off. As my own story shows, health care practitioners can make assumptions about the effects of disability or illness that may or may not be true in terms of individual experience.

Having a serious long-term illness threatens the integrity of the self by disturbing previous assumptions about the relation between the body and the self. It undermines the self and identity (Charmaz, 1995), and can leave the individual with an over-riding stigmatized identity (Goffman, 1963). With progressive conditions, this process is continually repeated as the individual tries to re-establish the integrity of the self. It may be, therefore, that people with MS are more likely to report distress from invisible symptoms than visible ones, in contrast to the other research reported above, because MS causes more ‘illness’ symptoms than the other conditions researched. With its uncertain, variably progressive course, it forces the individual through an iterative process of self-definition.

**Disability as both sickness and health**

Strict dichotomous classifications such as well/unwell or health/illness are often inappropriate, especially when it comes to long-term conditions. Aaron Antonovsky, an Israeli American sociologist who worked on the relationship between stress, health and healing, proposed a continuum model, which sees each of us at any given point of time somewhere along a ‘health-ease-dis-ease’ continuum. This moves away both from medicine’s traditional focus on those in need of a cure, and from health promotion’s tendency to focus on avoiding risk factors for disease (Antonovsky, 1996). Individuals with long-term conditions may place themselves at a range of different points on this continuum, however many people with MS find themselves towards the ‘dis-ease’ end of the continuum, as did the three participants in my research who described their physical symptoms of MS in the following terms:

‘My MS makes me feel fatigued. As soon as I wake up I am tired.’

‘It [...] produces pain all the time. I guess that is always part of your thoughts so it will affect your life in everything you do.’

‘Any physical activity especially tires me quickly and causes pain.’

Other research participants with MS spoke in terms of their condition ‘getting worse’ over time and the implications of this for their future health and well-being. As one woman said,

‘I worry about becoming incapable of looking after myself which I can barely do now and need lots of help.’
However another research participant, who was born with a progressive condition, challenged these ideas of the worsening of her condition:

‘Worse, that’s an interesting concept, isn’t it? Because I mean, I use terms like that, and I just say it, and I think what have I just said? I mean I have a progressive condition and my body will change, I do talk occasionally about getting worse, but actually I don’t … if I, if I think about it properly I don’t think about it as getting worse, I think about it as my physical state changing … and yet, society’s terminology has become so inside me that you just trot it out.’

People such as those who took part in my research may move back and forwards along Antonovsky’s continuum, depending on the stage of their condition, whether or not they are having a relapse, and whether they are having a good or bad day. An important message for health and social care practitioners is the need to remember that clients will not necessarily always be experiencing the same symptoms of either illness or disability.

Despite the often negative experiences of having a long-term condition, many individuals consider themselves to be in good health, despite disease. This dimension of health was one of nine identified by Mildred Blaxter (1990), one of the most influential writers in the health and social care field. Her research findings have been mirrored in government surveys. For example in one report, of all men and women over 65 in the UK reporting a long-term illness that limits their daily activities, just over 10% considered themselves to be in good health and another 45% reported themselves as being in fairly good health (OPCS, 2005).

Summary

This chapter has considered the relationship between the terms ‘illness’ and ‘disability’, and has used the experiences of people with MS, including my own, to illustrate how illness and disability may sometimes be at odds with each other but may at other times overlap or reinforce one another. My own experiences and those of the people I have met through my research have often been similar. MS can be perceived or experienced as both an illness and a disability and this can depend on where the individual with the condition is at any point in time on the health–dis-ease continuum. Many disabilities are ‘invisible’, however regardless of the visibility of long-term conditions they may still impact on the individual’s sense of self or self-worth. The impact of long-term conditions such as MS can be difficult for those without the disease to appreciate, particularly at times of invisibility or apparent health/absence of sickness. This has important implications
for the delivery of health and social care, especially given these changes in health status and the need for service-user focused care.

Further reading

MS Society website: www.mssociety.org.uk

References