Down ... not out—the surprising evidence of disability in old age

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Introduction

Our understanding of disability has changed substantially over the past two decades. Revolutionary changes in medicine and technology now enable clinicians to understand and treat people with disabilities in ways undreamed of even a few years ago. However, arguably the most substantial change in the understanding of disability is not in the realm of clinical services, but in the growing body of research that finds that, while disability is universal, there is marked variation in how disability is interpreted.

There is an abundance of literature that based disability upon the assumption that the problems and difficulties disabled people experience are direct results of individual physical, sensory or intellectual impairments. This position is articulated most clearly in the medical model of disability. This model has led people to view disability in terms of disease process, abnormality, and personal tragedy (Oliver 1996). It is argued that this model also has limitations for the way in which we provide care, as it is not broad enough to concern itself with disability from the disabled person’s point of view—or the disabling effects of society itself. Indeed, analysis of the literature reveals that wider social and environmental influences surrounding a state of disability are not highlighted. The assumptions therefore is that incorporating the perspectives, views, attitudes, preferences and experiences of people affected with an acquired disability will illuminate the subjective ‘lived’ experience and provide a focus on new metaphors—which could make a difference to the way our culture views people with a disability and how we as health professionals provide care.

In order to raise understanding and awareness of the meaning of disability, this study returned to the person living with an acquired physical disability with the aim of answering the question “what is the experience of living with a physical disability in a rural setting and how do personal and situational influences shape the experience?”

Disability in a rural context

Labelling people as ‘rural’ infers that they should be considered as a special group apart from the mainstream. It also indicates that rural is a homogeneous group, which it is not, as each rural community is different (Humphreys and Rolley 1991; Reid & Solomon 1992; Mathers 1994; Fragar, Gray, Franklin and Petrauskas 1997). This ‘rural’ labelling however, has been a deliberate act by the researcher to highlight further the experiences of people with disability living in a rural setting. According to Australian Institute of Health and Welfare (1998) rural people with a disability experience many health disadvantages compared with their urban counterparts. Furthermore, rural people are a rather poorly understood and mythologised population (Coward
Typically, rural people are depicted whilst horseback riding, battling bushfires or crossing flooded creeks. Alternatively, we often see images of dry and drought-stricken areas to illustrate one serious challenge that many rural residents face. This representation, justified or not, can lead to the perception that, because rural people are accustomed to exposure to hardship, they are hardened and can cope with challenges and adjust to hardship as it presents.

It is not suggested that rural people, as a group, hold either one set of beliefs and attitudes to disability or that rural people hold constant and consistent views. Nor does the study suggest that the experiences are typical, or that the participants are representative of a culture. Each person’s experience is different from that of anyone else; their circumstances and situations may be comparable, yet their experiences may not. Hence, this study set out to explore the range of views held by rural people and uncover unique meanings, not generalities, and to tease out common themes and patterns about living with disability. The crucial tenet however, was to conduct research with people and invite them to participate in the development of knowledge about themselves.

**Disability**

To illustrate ‘disability’ through an interpretation of various experiences, the following hypothetical scenario is used.

A 60-year-old male farmer rolls his tractor and sustains fractured lumbar vertebrae and permanent crush-injury of the spinal cord resulting in flaccid paralysis of the muscles of the lower limbs (physical impairment—paraplegia). As a result, he cannot walk or drive his tractor (activity limitation). Absence of public transport or taxis in his living environment to accommodate his wheelchair deprives him from working and other social and cultural activities (participation restriction). Subsequently he experiences a sense of social isolation accompanied by emotional distress (emotional impairment).

This scenario, although hypothetical, captures the usage of the term ‘disability’ in Australia (as it considers disability as a multi-dimensional phenomenon; a combination between physical and emotional impairment, activity limitation and participation restriction AIHW1999). It is in this context that disability will be used.

**Research design and method**

The needed recognition from health researchers is to acknowledge the crucial importance of learning from people’s personal, physical, and, especially, the social experience, to enhance our understanding of disability. As van Manen (1994. p.1) states

> … increasingly the health science professional is becoming aware that people require not only health care assistance, surgical intervention, or pharmaceutical treatment, but that the professional must be much more involved in the way that people experience and live with their problems in a different, sometimes deeply personal and unique manner.

Underpinning this philosophy is a doctrine characterised by the belief that people create their own social world—rather than merely being shaped by external social processes. Access to their social world, however, cannot be grasped until people are given a “right of voice” (French and Swain 1997, p.27). Hence, the aim is to transform their voice into a textual expression of essence, which serves to capture a true picture of the meaning and complexity of disability as understood within the context of the participants’ lives.
There is a profound need to be thoughtfully aware of how people think, feel, see things, or experience difficulty. This requires on the part of the health professional an “embodied form of knowing and of understanding patient-caring act—that enables instant caring and immediate judging when involved with patients” (van Manen 1994, p.1).

Due to the nature of my clinical role then as a physiotherapist and member of the Rural Allied Health Team (RAHT), I was able to access a number of rural communities within the geographical boundaries of the Darling Downs in south-east Queensland. The ‘Darling Downs’ is an area that fans out westwards from the crossing of the Great Dividing Range at ‘Cunninghams Gap’, southwest of Brisbane (see Map 1). This area covers 91 645 square kilometres and forms approximately 5.2% of the State of Queensland (Office of Economic and Statistical Research 2000).

Map 1 The Darling Downs and Queensland

Source: Office of Economic and Statistical Research (2000, p.5)

The estimated resident population of the ‘Darling Downs’ in 1999 was 201 446 persons, with around half of this population living in large regional cities, such as Toowoomba and Warwick (Office of Economic and Statistical Research 2000). The rest of the population is dispersed in small rural communities, with significant distances between them. It is from within these small communities that participants were recruited.
**Participants**

A total of nine people participated in the study, their experience qualifying them as informed participants (Taylor and Bogdan 1984; Morse 1991). The ages of the participants ranged from 46 to 81 years at the time of the interviews. Participants included a (retired) butcher who had experienced a stroke; a former nurse who developed Multiple Sclerosis; a dairy farmer with facioscapulohumeral dystrophy; a sheep farmer with a brachial plexus lesion; a grain grower with a leg amputation; the pig farmer with Parkinson’s Disease; a housewife with Osteoarthritis; a station hand with a spinal cord lesion, and a sawmill foreman who suffered a stroke. An important and defining aspect to this study was that some participants experienced an acute onset, whilst others had a more slowly progressive onset.

The research began with what appeared to be a simple question: what is it like to live with a physical disability? People’s experiences and their reflections were then “borrowed” (van Manen 1990, p.62) through a series of in-depth interviews. In-depth interviews were used rather than a quantitative means of measurement, analysis or replication and enabled the generation of rich data. Without participants and without the employment of unique and specific interview contexts, much of the data that was sought would have remained hidden—out of sight and beyond reach. Van Manen (1990) writes that “interviewing served as a resource for developing a richer and deeper understanding of a human phenomenon” and is also a “vehicle to develop a conversational relation with the other (interviewee) about the meaning of an experience” (p.66).

**Results**

The data revealed that for the participants, the lived experience of physical disability could be characterised by the expression: ‘life is not the same’. Indeed the experience of living with disability is one that depicts initial crisis, followed by a gradual recognition that in due course ‘life resumes’. Furthermore, recognition emerged among participants that they had to learn to ‘cope with limitations’. As a result, an acknowledgment occurred that the harmonic existence of the body has altered, and, step by step, a sense of reconciliation began to appear. “Reconcile” according to Macquarie Dictionary (1996) means “to render, no longer opposed, bring to acquiescence”. Here, voices of participants have been incorporated in the text in font ‘Arial’. For Shane (not his real name), reconciliation began when energy was invested in the continuation of life.

I knew it wasn’t going to be easy, I may have lost power but not my courage. (Shane)

For Shane and other participants, realisation set in that energies would have to be directed to rebuilding their lives. Their preparedness to work hard on assimilation of the realities of loss and adjustment to the future meant a focus on energies on the goal of what Seymour terms “remaking the body” (1998). This is typical for the participants. The experience of physical disability means, first and foremost, dealing with physical barriers. This created a complex set of new issues, situations, and circumstances over which participants had little control—leaving them in a virtual state of tentative equilibrium, from which position they dealt with whatever life would bring. Despite many undesirable changes, participants were more or less forced to devise certain solutions and deal with the mundane tasks of everyday life. For them life had resumed.
Life resumes

Resumption of life is not experienced in discrete categories but in a way that incorporates many different aspects. For some, it meant living with an altered mind-set, often preceded by acceptance. The following quote from John illustrates an aspect of acceptance that precedes resumption of life.

I've accepted that I can no longer drive. When we go to town, my wife drives via the back roads. This gives me the time and the opportunity to see what others [farming neighbours] are doing.

Many of the participants showed that in spite of their disabling conditions, they took control of their own lives to varying degrees. Some tried to learn as much as they could about their condition, while others learned how it could best be managed. Glenn for instance, has taken control by learning the latest pharmaceutical information in relation to Parkinson's Disease. He has gained knowledge through his support group peers. Empowered by this, he approached his physician.

I was always afraid to question any [health-related] decisions made by my doctor and specialist. Through the support group, I've been encouraged to ask questions. Last time, I asked about some lighter tablet. The doctor said, "OK, we can try a lighter dosage". I felt good about it; it is about me ... so I want to make decisions that concern my health.

Glenn already is the expert on Parkinson's Disease by having lived with it, but he feels reassured by obtaining additional information. Robinson et al. (1995) have found that people who feel they are in control feel empowered in life and can endure change better. By obtaining knowledge about the aetiology, diagnosis, treatment and many other aspects associated with disability, people can have many advantages and that is an obvious potential source of strength.

It is clear from the participants’ experiences that the restricted physical activity affects everyday life in terms of the ability to maintain self-sufficiency and (ultimately) the freedom to live a chosen lifestyle. Most individuals engaged in minor and major life style modifications and adopted numerous strategies, including adaptation of the lived environment. The data indicated that a surprising number of people saw their injury or disease as a challenge that could be conquered, probably because this perspective had worked in the past.

Support

Whilst it was remembered that disconnection with the outer world had occurred to a large extent—due to physical limitation—it was replaced by many positive things in participants’ lives, such as the love, care and support from the people close to them.

Participants asserted that despite much uncertainty in their lives, there was certainty about increased family closeness, together with the comfort of knowing that they were loved and would continue to experience a sense of belonging. All participants reported that their supportive relationships, whether with partners, children, extended family or friends, were a source of strength for them. This strength had a positive effect on living with disability.

In this inquiry, there is also evidence that spiritual support offered a view that was both accepting of life’s challenges and comforting in times of difficulty—now and in the future. The importance of spiritual support was emphasised by those who have experienced adverse circumstances in their life. Whilst participants testified strongly that they were strengthened by their faith, they were also
able to find meaning to their lives through the help received from support groups and other health professionals.

Many displayed a determination to get on with life. Often this was built on previous life experiences; some had battled droughts, others had battled floods or fires or other setbacks during their lives. Each time when they encountered such a disaster they were able to come back and contribute to the ‘get on with life’ mentality. They felt that those life experiences were helpful in their everyday life.

I have lived a tough life with some hardship. My house has been flooded twice and burnt once. I was told to leave the place, but I was determined to stay there and rebuild the house. And that is what I did. That is how I do things. I’m determined that this [stroke] is not going to get me. Down, but not out and determined to make the best of it and just get on with life. (Karl)

Determination, for the people in this study, has been a predominant feature that made it possible to find appreciation in everyday life. Whilst participants experience physical impairment, limited activity and restricted participation, many live a life that encourages prospect of a valued future; they are able to move on in hope.

Although living with disability involved a certain amount of hard work, it appeared that, over time, with determination and hope, emotional pleasure and fulfilment could be attained despite overwhelming odds. Although ordeals are not behind them, some participants actually feel that they have a new possibility lying ahead of them. This is certainly the case for Troy who stated:

Whilst the accident has made my life more complicated, it also made it easier by forcing me to slow down. If I didn’t have the accident, I probably would have died from a heart attack. I now focus much more on simple things, having a wine with my wife when she comes home from work or ringing my daughter to ask her how her day was. (Troy)

Troy has come to re-evaluate life and now savours the idea of having second prospects. Living with a disability tends to force individuals to “eliminate the insignificant”, and to “find and savor the important and meaningful aspects of life” (Robinson et al. 1995, p. 146).

Conclusion

Whether it was a simple twist of fate or a sudden serious accident, the accounts of the participants foreshadowed a lifetime of dealing with the limitations imposed by a physically disabling condition. Yet, in spite of this, participants were adamant that they would manage their physical changes as much as they could. The data also revealed that living with disability, is much more that dealing with the physical factors (Van Erp 2002). In fact, it the managing of emotional change that proved to be much more intricate. Determined to allay such feelings, participants took a positive attitude by redefining their lives. This was often accompanied by acceptance. By coming to terms with the situation, participants faced the reality that the current circumstances cannot be altered. Over time, they have become reconciled and have resumed their life.

Crises do not end with an obvious finish, but participants developed skills that enabled them to move beyond a survival existence to a way of life that is ‘normal, although restricted’. For some the outcome of this process is the ability to carry on with life in spite of physical limitation. Others had no choice. They were forced to give up work and re-evaluate their body in everyday life. In many cases, participants have made great efforts to manage their roles as normally as possible,
becoming skilled at functioning in everyday life despite their ever-present and often unpredictable bodies.

Although the evidence is far from conclusive, it is interesting to note that all participants passed through a similar set of physical circumstances and situations, yet their experiences differ from one another and offer a varied insight into everyday life that may give valuable clues in understanding the phenomenon of living with a disability. In moving from one phase to the next, participants experienced a sense of progression, albeit it with some regret of leaving something behind: their former identity. This transition is not smooth and is compared to a struggle that is followed by an active decision to face reality and thus accept. By accepting and adjusting to time, participants are able to act in the present and foresee a future, whilst being submitted to a force that is beyond themselves.

Resisting the reality is not about ‘giving in’ or ‘giving up’; rather it is a positive act, one that denotes strength, not weakness. The future, then, could be accepted only when participants were prepared to leave the old life behind them and disengage themselves from former familiar experiences. For some, disengagement was a liberating experience, and more easily accomplished by those with spiritual beliefs, as faith helped to give them inner strength. The task was always to balance hope and the future throughout personal crisis—a hope for better … not worse. Participants realised that whilst the actual future is beyond anyone’s control, some control can be retained by hope and faith.

**Acknowledgment**

This research was supported by the Darling Downs Health Services Foundation “Research Infront Outback Grant”.

**References**


