

“Life is just not the same anymore” –the disability experience

Ansmarie van Erp, Toowoomba Health Services

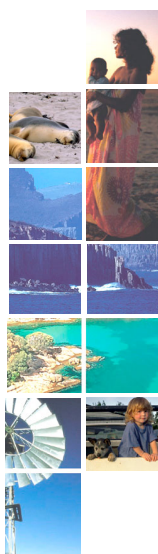
INTRODUCTION

The presence of a permanent physical impairment and subsequent disability acquired later in life significantly alters a person’s everyday life. Yet, while disability, as a medical condition, is a focus of research and discussion, this research and discussion occurs often in neglectful ignorance of the total life experience of the individual person. Most people who acquire disability later in life, encounter a multitude of physical, psychological, and social challenges that are aspects that influence the beginning of a journey, occasioned because people’s lives have been and continue to be disrupted by changing circumstances. The rehabilitation process, including the adjustment and adaptation to a multitude of losses, is often difficult and, for many, unending. To facilitate the rehabilitation process, it is imperative that health care professionals understand how people respond to change and loss, how they carry on with life in spite of – or because of – the presence of disability, and how they find ways around such adversities. Empirical data on rural communities in particular, confirm that rural people with disability experience significantly more serious physical, psychological and social problems compared with their urban counterparts (see for example Mathers 1994; Australian Institute of Health and Welfare 1998). Consequently, a study was designed to bring to the forefront the experience of disability as a phenomenon that rural people live through. Underpinning the study was the question “what is it really like to live with disability?”

This paper provides an overview of the study findings; it offers insight in the personal and situational influences of rural people living with disability and presents strategies that may influence health practice.

BACKGROUND

Management of disability and rehabilitation is well-described in the medical literature. The literature highlights the dominance of the medical model of disability, whereby medical and rehabilitative professionals tend to conceive disability as an individual physiological condition requiring the afflicted individual to be given appropriate medical care (Imrie 1997). Analysis of the literature reveals that wider social and environmental influences surrounding a state of disability are not highlighted. Lewinter and Mikklesen (1995) and Horgan and Fin (1997), for example, identified that the major focus in many disability studies has been on the patient’s functional recovery as seen by the health professionals – seldom by the patient. Whilst respecting the value of such information, this “bypass entirely the ways that experience [of disability] is constructed, and the way in which it is made to matter (more or less) in the lives of those concerned” (Radley 1999, p.27). Ideas and wishes of people with a disability, for example, are sometimes deemed as “unrealistic” or “impossible”,



perhaps because we, the health professionals, rarely consult the people who *actually* experience disability. As such, French's (1993) advice is "to become fully acquainted with disability from the perspective of the person as it helps us to adjust the social and physical world to accommodate them" (p.23).

METHOD

The setting of the study was a number of rural communities in South East Queensland.

Map 1 The Darling Downs and Queensland



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

Data was collected through in-depth interviews with rural residents who acquired a disability later in life as a result of illness or an injury. An important and defining aspect to this study was that some had experienced an acute onset, whilst others had a more slowly progressive onset. Participants included a retired butcher who had experienced a stroke; a nurse with Multiple Sclerosis; a dairy farmer with facioscapulohumeral dystrophy; a sheep farmer with a brachial plexus lesion; a grain grower with a leg amputation; a 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. The conditions discussed here are relatively common to some extent, except for the brachial plexus lesion and the facioscapulohumeral dystrophy, which are, mercifully, rare

Although each person has lived for most of, if not all their life in a rural environment, their experiences should not be considered typical of rural people elsewhere in rural

Australia – though in many respects they are similar. Many had experienced what could be described as “fairly hard lives”, typically working in the rural industry or in the agricultural sector. Despite this, they all rated their health as “reasonable”, with only an occasional visit to the GP or Specialist for a health check-up or renewal of a prescription.

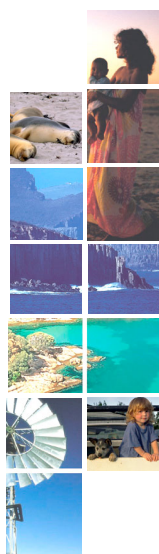
METHODOLOGY

To understand disability as a human event, van Manen’s (1990) hermeneutic phenomenology was used. This research approach places human situatedness central, based on the belief that human beings can best be understood from the experiential reality of their lifeworlds (van Manen 1990). Rather than seeking a judgement about facts or reality, the aim of phenomenology is to gain people’s understanding, opinions and expressions of feelings. Thus, rather than generating theories or general explanation, phenomenology aims to describe the experience as it exists. It is about expressing thoughts and perceptions of phenomena in the form of language in speech or writing (van Manen 1990) and offers a method for conversations and observations to be analysed so that we come to a fuller grasp of what it means to be in the world as a rural man or woman living with disability. It pursues, not the sense people make of things, but what they are making sense of. In the context of this study, what is physical disability as a phenomenon that people [living with disability] experience before they make any sense of it?

Interviews with participants were tape-recorded and transcribed into narrative, written form and imported onto the computer, using a software package Ethnograph v4.0 (Seidel, Friese and Leonard 1995) for the initial phase of data import and line numbering of each file. Microsoft Windows™ was used for textual analysis. Each interview was carefully examined to identify sentences or phrases that could be thematic of the experience. Such analysis is more than a superficial reflection of the explicit meaning of the participant’s descriptions; it is a method as a way of achieving a level of thoughtfulness that encourages the researcher to make a distinction between their first-hand impression of the participant’s stories (the text) and the essence of the experience in question. van Manen’s thematic analysis is a form of reflective inquiry that guides the uncovering of the essence or ‘... a bringing into nearness that which tends to be obscured and illusive to the first-hand superficial reflection of an experience’ (van Manen 1990, p. 31). Although each person’s reflection was different, some commonalities and similarities were threaded throughout.

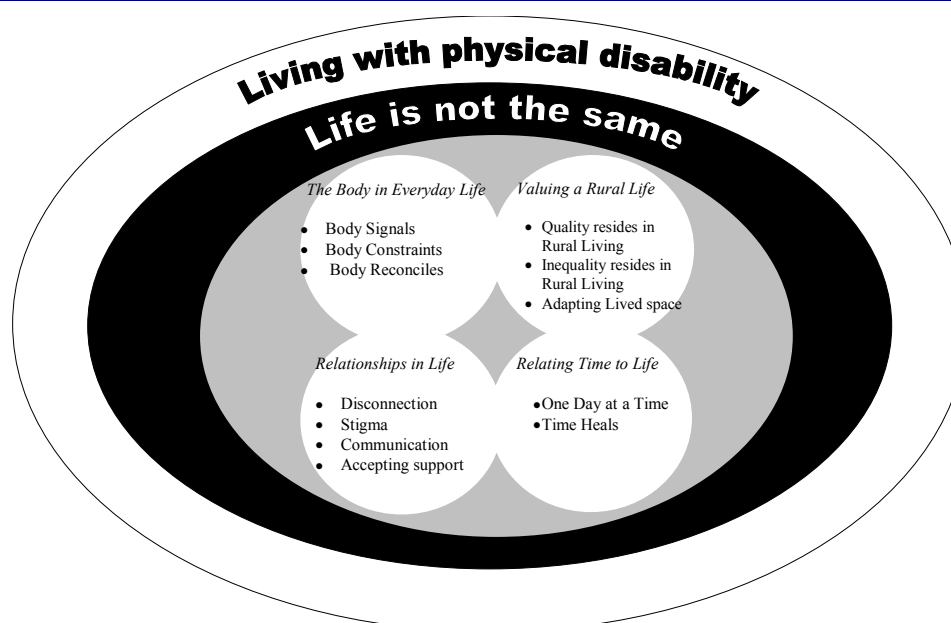
RESULTS

Thematic analysis revealed that for the participants, the lived experience of physical disability could be characterised by the expression: “life is not the same”. On further exploration, this expression referred to a complex view of life for people living with physical disability that can be described four themes. These themes represent an artificial separation of the components of living with a disability, as perceived by the participants, they occur simultaneously and are separated purely to provide clarity for the reader – in actual fact, they are all components of the one experience.



The themes and their relationships are depicted in a model of living with disability as it exists for the participants in this study (see Figure 1).

Figure 1 Themes that explicate the experience of living with disability



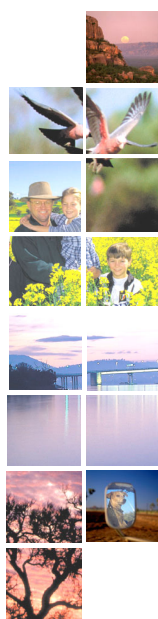
The participants described one aspect of living with disability in a number of ways. I have called it, with debt to Merleau-Ponty (1962), **“the body in everyday life”**.

First, there is recognition by the participants that disability begins when the *“body signals”*. *“Body signals”* refers to the earliest indication of bodily failure. This happened in distinctive ways. For some it was sudden, with no time to prepare; others had a much longer phase that allowed for planning and gradual time to adjust. Each person had their own account of how they experienced the onset of symptoms, seeking and receiving help from others, including health professionals. Different time spans exist from the time of onset till a diagnosis. For some it was instant and unmistakable, others experienced a much more ambiguous journey filled with obstacles. Eventually all participants learned of the diagnosis: *“you have...”* (MS, Parkinson’s Disease, Stroke etc.).

Participants repeatedly asserted that living with a physical disability meant that they no longer could perform certain everyday tasks due to bodily failure. For each person, everyday life is now experienced through a body that experienced impairment and feelings of discomfort, unsteadiness and so on. I have termed this the *“body constraints”*. This theme relates to participants’ experiences of physical and emotional constraint brought about by their physical bodies.

The *“body reconciles”* relates to the different ways in which each of the participants face up to living with his or her physical and social limits.

This study is situated within a rural environment and as such rural living reserves a special experience for the participants. The connectedness between rural space and the participants’ lives is woven throughout the data. I have termed this **“valuing a rural life”**. In this study, participants emphasise the advantages of rural life, that is, the



“quality resides in rural living”. They repeatedly comment on the connection between themselves and their sense of belonging in their lived space. For them, rural life characterises quality of life.

Participants experience disadvantages associated with rural living which I have termed *“inequality resides in rural living”*. They comment on how the geographical disadvantage impacts on everyday life and refer, for example, to the cost of living or the distance to affordable, accessible health services.

Despite the challenges associated with rural living, participants are not motivated to leave their place of residence. Instead, they expressed a strong desire to remain in their own homes and in their own community surrounded by members of that community. Participants discuss *“adapting lived space”* and explain how they have organised their everyday life space and arranged their living areas to accommodate the impairments and the physical change associated with it.

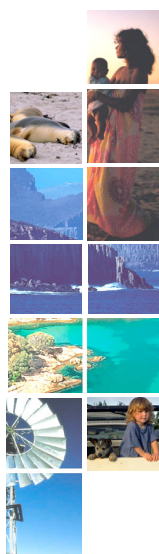
For the participants, the experience of physical disability is not personal, but it is transactional, communicative and profoundly social. The data suggest that the experience of living with a physical disability is not only about one particular individual's experience. It is also about social networks, positive and negative social situations that together form a social reality with aspects of negotiation, sharing and support that I have termed **“relationships in life”**.

Participants in this study conceptualised that living with disability leads to disengagement with others, which I have termed this *“disconnection”*. This theme incorporates various aspects of the social reality that each of the participants encountered. Lessened and impaired social contact and a sense of social isolation were frequently mentioned. This happened in two ways. For some, it was of their own accord, forced by physical reasons, such as fatigue or mobility impairment. Others experienced avoidance, or even abandonment from friends and relatives.

According to the participants, signs and symptoms associated with musculoskeletal or neurological conditions are simply not accepted by many. *“Stigma”* is thrust on the participants in this study, due to the nature of their visible physical impairment. This refers to what Williams (1993, p.111) terms an *“anathema to many of our contemporary codes of conduct”*, and *“our sense of what is deemed correct behaviour and good manners”*. For example, a man who walks with a staggering gait and often displayed uncontrollable movements of arms and legs in public, experienced negative comments and thus felt embarrassed to appear in public. This emotion was shared amongst the wheelchair-dependent participants, who confirmed that being in a wheelchair has little appeal to public sentiments.

“Accepting support” comes from personal networks and other social settings that together form an *“integral dimension of the lives lived together”* (Kleinman 1988, p.186). Many agreed that the main source of support tended to come from the family, particularly spouses and children. Support also comes from other sources, such as from support groups and health professionals. Apart from family support, participants felt reassured that they had their spirituality, a source from which strength was drawn, hope was based on and faith was given to.

“Communication” relates to the importance of interaction between health professionals and the participants in this study. Many asserted that forms of communication with



health professionals were deficient and often did not allow them to acquire knowledge of their status. Participants provided their own account of their efforts to counteract these experiences through adaptation to a changed life, coupled with a determination to get on with their lives. They did this in an effort to hold on to their lives in their own (rural) environment, so deeply valued.

Participants talked about their personal life history; their past, present and future which created an understanding of orientation to being-in-the-world, which van Manen (1990, p.104) terms "the temporal landscape". Over time, participants began to realise the impact of living with a physical disability in their lives, they began "**relating time to life**".

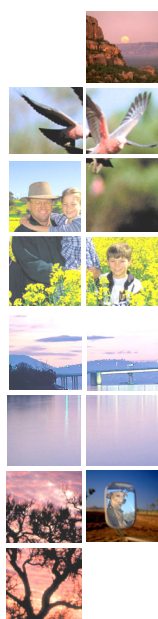
Many realised that an essential response to living with disability, is to face the reality of the situation, which began to take hold as soon as participants recognised and understood what had happened to them. Aware that they had to face adjustment of their life, participants made strategic decisions concerning the selective allocation of their (often-limited) resources to do the tasks they would like to do. This included a drastic change to what participants believed they could do in the present and the future. They were forced to reduce or modify their activities and thus structure and restructure time. The presence of a disabling condition had made lives uncertain and with that uncertainty came the enforced realisation of lost opportunities and prospects.

To focus on daily issues without being overcome by dashed hopes and unmet expectations, many adopted "*one day at a time*". This theme, with debt to Charmaz (1991), was created by the participants' need to develop some guidance for everyday functioning, whilst at the same time, having some sense of control. By concentrating on the present, they also avoided, or at least minimised, their thinking about the future. Participants tried to pull their attention into the present whilst pushing the future further away.

Whilst participants realised that there was no cure available, they admitted that "*time heals*". They discussed how the initial period following diagnosis assaulted their sense of self and how it brought about a reorganised confrontation with the reality. However, as time went on, they began to adopt an expressive and cognitive approach solely intended to (re)gain a renewed perception of the self. On the one hand, they were realistic about their limitations within their current situation and expressed concern about not being able to participate in many of their valued activities and social roles. They accepted the reality of living with a disabling condition. On the other hand, mixed with this realistic position, was an optimistically positive construction of their situation accompanied by hope. Hope is tomorrow and beyond, a time period that relates to a continuation of everyday life activities in the usual way, time, and place. For all, the hope was to remain living in their own environment, surrounded by their loved ones.

CONCLUSION

The acquisition of disability is a serious assault on a person's health and well-being. Not only can disability sneak up slowly and attack a person's health; it can also rob a person of confidence and psychological well-being. Because disability can strike openly at the physical and emotional side of his or her being, a person can be left



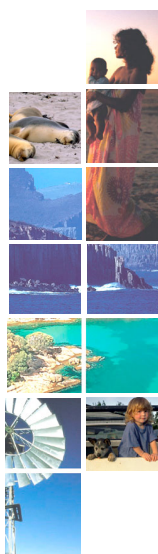
vulnerable, anxious, and insecure. People with a disability can overcome the physical loss of bodily function, but are defeated by the emotional “loss of body”. Initially they feel shocked, depressed, and in despair; and imagine that life will never be the same again. Following the state of shock and “outcry” (Horowitz 1983) people mourn as they move through countless losses: loss of functional self, loss of independent self, loss of mobile self, loss of former self. A part of the physical body is lost and with that, a part of their life. Before the impact of disability, work, including farm work, was planned from a position of strength. Afterwards, there was a role reversal and mixed feelings emerged. In general, many people living with physical disability are concerned that they have lost their independence altogether; they feel useless and envisage that they will become burdens on others in society, most notably their families. Predictably, loss becomes the theme of his or her cognitive efforts (Seymour 1989) and there is a risk of becoming trapped in such despondency.

It is during these times that health professionals should be attentive and ascertain that men and women receive not only medical attention, but are given also emotional support. Good recovery will be jeopardised if this is ignored. People may sit and brood and become increasingly isolated. The unhappiness and inertia can become self-perpetuating; and people can slip into isolation with adverse effects on physical and psychological well-being.

People with a disability demand that health professionals broaden their views on disability and start listening. Their “expert” voices are instrumental in guiding our practice. Understanding that the successful work associated with a person with disability is dependent upon the recognition and meaning of its impact upon the individual will assist health care professionals in their relationships with people living with disability. *Health professionals should extend their viewpoint about disability beyond the “disease-centred” medical model and expand their knowledge by paying attention to disability from a person-centred perspective.*

People noted that much of the disability impact does not relate merely to their physical bodies. Instead, disability is associated with social acceptance, a desire to stay in his or her own environment, and yearning to grow old in the midst of their loved ones. The results of this study show that there are gaps between such common expectations for most people and the reality for the people currently living with disability in rural areas.

It may appear that rural people with a disability manage quite well and need no assistance. Most disability management, however, takes place in and around the home, and consequently, a lot of the everyday life concerns faced by people living with disability and their families are invisible to health care providers. Yet, after spending many hours with each participant, it appeared that many of the participants worried about their health. For example their fear of falling essentially had forced them to become more sedentary. This is a concern, as it appeared that people were not seeking social or health services input. It is my firm belief that each person would have valued information about adaptations, equipment, living safely in the home, falls prevention etc. Although health needs of people could be recognised by health professionals and service providers who are in a strong position to advise people with disabilities and refer to others if necessary, it did not appear to happen as often as might be possible. Since participants mentioned that they have annual checkups by their General Practitioner, *this should be used as a means to refer those living with*



disability to a multi-disciplinary team in order to address each person's needs with as much breadth and depth as possible.

Many unhappy patient experiences began when a health professional uttered the infamous words "let's wait and see". The point is that this opportunity is actually a defining moment, as it may give rise to a successful (self) management of a lifelong condition. Pre-discussed plans, aimed at helping people to achieve a sense of mastery over future challenging situations and to gain a sense of personal control, is a useful process. The ultimate goal is to create enhanced feelings of competency, which may ease emotional distress. Future plans *can* be discussed; strategies *can* be put in place, even if the future is entirely uncertain. Having a "blue print" of the future may encourage people to become active, rather than remain passive participants; more importantly it may boost the person's confidence in addressing problems as they arise in the future. ***Health professionals should turn their attention to identifying ways of preventing further health risks associated with disability by discussing future scenarios.***

Disability was understood as a life-changing experience that entails complex time-consuming and energy-depleting processes and is defined by personal, family and social development. For the participants in this study, the lived experience of disability can be characterised by the expression: "life is not the same".

The understanding of the essential nature of this lived experience that emerged from this study has implications for health practice. The practice of disability intervention, based solely on impairment, may be inadequate to facilitate optimal health outcomes for rural people. Instead, health care professionals can assist these people in discernment of priorities, maintaining existing relationships, advocacy of rights, and finding the balance to encounter physical and societal adversity. Thus, the study suggests that health professionals need a broad conceptualisation of what constitutes legitimate knowledge for practice and a recognition that disability is an ongoing journey rather than a final destination.

REFERENCES

- Australian Institute of Health and Welfare. (1998). *Health in Rural and Remote Australia* (AIHW cat. no. PHE 6). Canberra: Australian Institute of Health and Welfare.
- Charmaz, K. (1991). *Good Days, Bad Days – The Self in Chronic Illness and Time*. New Jersey: Rutgers University Press.
- French, S. (1993). What's so great about independence. In J. Swain, V. Finkelstein, S. French. & M. Oliver (Eds.). *Disabling Barriers – Enabling Environments*. London: SAGE Publications.
- French, S. (1994). *On equal terms working with disabled people*. Oxford: Butterworth Heinemann.
- Horgan, N.M. & Fin, A.M. (1997). Motor recovery following stroke: a basis for evaluation. *Disability and Rehabilitation*, 19, 64–70.
- Horowitz, M. J. (1983). Psychological response to serious life events. In S. Breznitz (Ed.), *The Denial of Stress* (pp. 129–159). New York: International Universities Press.
- Imrie, R. (1997). Rethinking the relationships between disability, rehabilitation and society. *Disability and Rehabilitation*, 19(7), 263–271.

- Kleinman, A. (1988). *The Illness Narratives – Suffering, Healing and the Human Condition*. New York: Basic Book Inc. Publishers.
- Lewinter, M. & Mikkelsen, S. (1995). Therapists and the rehabilitation process after stroke. *Disability and Rehabilitation*, 17, 211–216.
- Mathers, C. (1994). *Health differentials among adult Australians*. Canberra: Australian Institute of Health and Welfare.
- Merleau-Ponty, M. (1962). *The phenomenology of perception* (C. Smith, Trans.). London: Routledge & Kegan Paul.
- Office of Economic and Statistical Research (2000). *Queensland Regional Profiles June 2000*. Brisbane: Queensland Government Treasury Department.
- Radley, A. (1999). Social Realms and the Quality of Illness Experience. In M. Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology* (pp. 16–30). London: SAGE Publications Ltd.
- Seidel, J., Friese, S., & Leonard, D. (1995). *The Ethnograph v4.0: A User's Guide*. Amherst, MA: Qualis Research Associates.
- Seymour, W. (1989). *Bodily Alterations: an introduction to a sociology of the body for health workers*. NSW: Allen & Unwin Australia Pty.Ltd.
- van Manen, M. (1990). *Researching Lived Experience – Human Science For An Action Sensitive Pedagogy*. Ontario: The University of Western Ontario.
- Williams, S. J. (1993). *Chronic respiratory illness*. London: Routledge.

PRESENTER

Ans van Erp is a Senior Physiotherapist within the Toowoomba Health Services District. She was born and raised in Surinam, a neighbouring country of Brazil, in South America. Ans moved to Holland where she obtained a Bachelor of Physiotherapy with First Class Honours. In the late 1980s Ans moved to Australia with her husband and two children. In early 1990, she joined the Toowoomba Health Services and worked in Outpatients. Her experience has since extended and now includes skill-development in clinical management in areas such as rehabilitation, mental health, rural practice and community health. In 2002, Ans successfully completed a PhD in rural health – a study that was facilitated by winning the 1996 Infront Outback Research Grant. As President of a large women's organisation, Ans is a dedicated campaigner for women's issues. This role requires much community involvement and consideration of a wide range of public matters, including that of advocacy and improving the health and well-being of all citizens.

