

Chapter 1

Introduction

What is it like to live with chronic illness? This question has some urgency for it stays with me and asks me how I should nurse. To fill gaps in understanding means I can come to 'know better', that is, to understand more about Ms Thorne and so many more people who have some similar, potentially similar, and quite different experiences. To be able to picture her life of illness and what that meant to her might well have revealed how she wanted to meet the future and how she could have been *cared* for before her life became so difficult that she concluded there was no possible help for her.

In order to address this question I have used phenomenology as a means of paying attention to and learning from people's experiences in their world. It is a perspective which throws light upon the unique and shared meanings of experience for human beings. This insight is achieved through meticulous attention to and interpretation of the ordinary everyday occurrences of the phenomenon. Kestenbaum (1982) dwells upon the connection between phenomenology and poetry. He comments on D.H. Lawrence's observation that poetry draws attention to things in a new way and therefore helps people to see the familiar world in a new light:

Like poetry, phenomenology makes a "new effort of attention" by recovering and revealing the habitual structuring of our everyday experience, experiences of art and religion, and our professional experiences. Phenomenology enables us to see everyday and other realms of experience (science, fantasy, medicine, etc.) as constitutions of subject experience (not simply "subjective" experience) (Kestenbaum 1982, p.14).

This way of researching lived experience is, van Manen (1990, p.5) contends, a way of the researcher becoming even more a part of the world. This type of engaged research is an act of caring. To care in this instance is to truly desire to understand others better. This research is driven by a desire to benefit people who have chronic illness. van Manen (1990) also states that knowing is not just a 'cognitive act' but involves a loving responsibility to find out what 'contributes to the good' of the people researched.

The generically chronically ill person does not exist. It is impossible to generate meaningful information that describes 'the experience' of all those who have a long term illness. Indeed Frank (1991, p.45) writes that 'care begins when differences are recognised'. However, chronically ill people do share a world and culture. It is in this shared world and culture that the generally held attitudes, beliefs and practices constitute the situations in which people find themselves and the ways they learn to react to them. How they respond to these situations will always be complicated. Understanding these experiences is not concerned with simplifying and making abstract generalisations. Rather, seeing them in their concrete complex situations is more likely to uncover the meaning these experiences have for people.

This existential view is not a popular one, for treating people as complicated beings is time consuming. As Frank (1991, p.45) points out, it is much easier to theorise and compartmentalise people into categories which all have their own slick solution. However solutions and treatments are not care. In order to care I need to know many things. Watson (1988, p.30) quotes Mayerhoff (1971, p.13):

To care for someone I must know many things. I must know for example who the other is, what his [sic] powers and limitations are, what his needs are, and what is conducive to his growth; I must know how to respond to his needs and what my own powers and limitations are. Such knowledge is both general and specific.

Such knowledge is not generally regarded as essential in today's technological/bureaucratic health care system. However, I would argue that such knowledge is highly desirable and the nurse who pays attention to the lived experience of people enhances the quality of what s/he does.

To understand what something means is to basically reveal what is its existence. For example, to decide *what is chronic illness* I ask, *what does it mean to be chronically ill?* It means: I have little chance of recovery; it means I go towards the future filled with pain and contending with disability; it means I have to ask other people to help me, and so on. This is an ontological question (a question concerning existence) and one that can only be answered by turning to the reality of the experience of the sufferer of chronic illness: '... as lived, reality is the experiencing of the object' (Kestenbaum 1982, p.14).

This is a study where eighteen people have helped me to recognise some of the unique and shared meanings that chronic illness has for them. These people have told me their stories of everyday occurrences. The texts of these experiences have been analysed and interpreted to reveal horizons of meaning in the lives of people with chronic illness. In this introductory chapter the terms 'chronic' and 'illness' will be

discussed in order to establish some understanding which was held before I turned to the phenomenon in question in order to understand its reality. Some of the literature relating to the field of chronic illness will be reviewed and an outline of the whole thesis will be given. It is worth explaining that this study relies heavily upon the lived experience of people to furnish understanding. The understanding generated is existential and thereby necessarily complicated. Throughout I intend to explain things as they appear in the lived world rather than as they are explained conventionally in convenient abstract and general terms. Therefore the incidence of chronic illness will not be demonstrated with statistics nor will there be a short and simple definition of the phenomenon of chronic illness.

Chronic illness

Curtin and Lubkin (1990) offer the reader a range of definitions of chronic illness dating from 1949 onwards. All the definitions have some problem or other for these authors and the definitions reflect the gradually changing attitudes towards chronic illness prevailing within health care generally. For instance, a definition written in 1949 is considered by Curtin and Lubkin (1990, p.5) to be patriarchal, medically orientated and inflexible. Frustrated with the shortcomings of available definitions they came up with this definition:

Chronic Illness is the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function and prevention of further disability (Curtin & Lubkin 1990, p.6).

I am not convinced that the people who helped with this study would be impressed with this definition for it does not adequately portray their experience. Phenomenologists do not necessarily refute definitions and theories for I can see the truth in aspects of most ideas generated. The important principle is that existential being is the basis for understanding rather than abstract theories. At a later date the understandings generated in phenomenological works can be compared to the theories and together they may be used to complement each other at a later stage.

Chronic illness is not defined in this study. The people who participated were volunteers who decided for themselves whether they considered themselves to be chronically ill. In the advertisements placed in the local newspapers, to attract people to help with the study, the term chronically ill was used and then rephrased as long-term illness. A short statement of definition serves to simplify and make general a phenomenon. In this study the intention is to define chronic illness not in a short sentence but through detailed interpretation of various experiences related to chronic

illness. The reality is that this whole thesis contributes to a definition of chronic illness. The person searching for a definition needs to read this and more to learn something extra about what chronic illness is.

The word 'chronic' derives from the Greek word *χρόνος* which means 'time'. The dictionary (*Shorter Oxford 1975*) uses these expressions to define 'chronic'—'lasting a long time, lingering, inveterate'. 'Inveterate' is a negative term for something which is—'long established; deep rooted, obstinate (now mostly of things evil)'. Colloquially, 'chronic' is often used in a derogatory way to mean something which is not enjoyable and which has lasted too long—as in 'what a chronic day'. Place (1992) found that people in her study who had a chronic illness really resented the term 'chronic'; they too felt it was a derogatory word which should not be used to describe them. In this study I did not ask any questions about the term 'chronic illness' and no one mentioned it as important. The participants in this study related more to their diagnostic group than to people with chronic illness generally.

The word 'illness' is worthy of some analysis. The intention was to find a word that conveyed the total experience of being unwell rather than a state directly attributable to certain specific symptoms related to a disease. Helman (1981, p.548) makes this point briefly—'Disease is something an organ has: illness is something a man [sic] has.' Kleinman (1988, p.3) remarks:

By invoking the term illness, I mean to conjure up the innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability.

Indeed there are some experiences of disease where illness is not a feature. Hypertension is an example of a disease that does not always correspond with an experience of illness. The focus when considering the experience of illness rather than disease is upon what Kleinman (1988, p.4) describes as the 'principal difficulties' that have to be contended with. For example, rather than being bothered by asthma per se the person experiences wheezing and embarrassment. Brody (1987) undertakes a detailed investigation of the word 'sickness' in order to understand the experiential notion of 'not being well'. He summarises the state of sickness in the following ways:

- a) To be sick is to have something wrong with oneself in a way regarded as abnormal when compared with a suitably chosen reference class.
- b) To be sick is to experience both an unpleasant sense of disruption of body and self and a threat to one's integrated personhood.

- c) To be sick is to have the sort of thing that medicine, as an evolving craft, has customarily treated.
- d) To be sick is to undergo an alteration of one's social roles and relationships in ways that will be influenced by cultural belief systems.
- e) To be sick is to participate in a disruption of an integrated hierarchy of natural systems, including one's biological subsystems, oneself as a discrete psychological entity, and the social and cultural systems of which one is a member (Brody 1987, p.22).

These statements are recognised by Brody as being short and rather general; however, he uses them as foundations from which to explore the complexity of the lived experience of sickness.

Taylor (1994a, pp.4–5) notes that illness is often regarded as the 'antithesis of wellness'. With similar results to Brody (1987) Taylor finds that the literature surrounding illness sees it as: 1) a remedialable state, that is, one that is amenable to treatment; 2) a role, one which is different to the norm and therefore has attendant rights and responsibilities; 3) illness as power, that is, the person uses the state to gain social privileges and exemptions from certain social responsibilities; and 4) a negotiated state, one in which the ill person and the health care professional work together to make decisions about the course of care and treatment.

The experience of illness is affected by the culture which constitutes ways members organise their thoughts and construe illness expectations. However, these usual cultural patterns may be altered according to social circumstances and according to the particular life history of the person involved (Kleinman 1988, p.5). These ideas are apparent in this study. I am able to find the cultural values and beliefs which impinge on all the participants, but I can appreciate the differences which relate to social circumstances of the participants and their particular histories. While illness trajectories are not, and probably never will be, predictable, it is possible to discover the source of many of the meanings people make, and share, of their predicaments.

There is a tendency to view illness in terms of acute illness, relegating chronic illness to the margins of health care interests along with the debates concerning the elderly and disabled. It is therefore necessary to consider the distinctive state of chronic illness. The matter of who qualifies as chronically ill has expanded over the years. This is because of the massive developments in the treatment of acute illnesses. The considerable successes of modern medicine have resulted in a far greater number of people joining the ranks of the chronically ill. While modern medicine is often able to hold back death, it has not been similarly successful in finding complete cures for

such diseases as heart failure, renal failure, liver failure, and so on. Frank explains the new dimension to chronic illness:

Disease used to be either critical, meaning life-threatening but quick, or chronic, meaning long-term. Disease moved to a crisis from which the patient either recovered or died, or else the patient lived as an invalid, gradually wasting away. Medical technology keeps enlarging the numbers of those living “normally” in remission; we have more and more of the “chronically critical” (1991, p.139).

While there are now many people who have survived acute illness, a proportion of them will reside in a state where the ‘difficulties’ alluded to by Kleinman (1988, p.4) can be severe. The need to have these ‘difficulties’ attended to is great, but this is often not possible in a health care system which is geared to biomedicine. However, when considering the consequences of not having treatment the person is under some pressure to be thankful and put up with her/his lot in life. In this study, Jane, who has undergone transplant surgery, is a prime example of this type of uncomfortable existence.

The incidence of chronic illness

A conventional beginning to studies regarding chronic illness is to substantiate the ‘size of the problem’. This is done with rubbery statistics which highlight the vast numbers of people loitering in compromised states of health. Figures are quoted which demonstrate the proportion of the health budget spent on caring and treating those people in our society who will not get completely well. Statistics regarding the demographics and costs of treatment and care vary according to the presenter and the aim of the project. While they are presented as proof positive of the need for careful attention to this area, as one wades through the material the realisation dawns, even though it is a message one is highly receptive to, that the ‘empirical’ data are manipulated to convey whatever the author wants. The intention is laudable for the chronically ill are a neglected group who deserve more, but the method is so worn and frankly suspect now, that it does not have the intended impact.

It is the intention in this introduction, too, to draw attention to chronically ill people. However, it will be done by directing the gaze to sufferers’ lives and presenting their situations in concrete ways rather than highlighting abstract figures as used in the introduction to most works. Even a cursory look at life around one can convey how commonly chronic illness occurs and how it affects people and those who come in contact with them. I have asthma; the neighbour to the right of me has hypertension and the one to the left has transient ischaemic attacks. His wife had cancer of the breast and is still living in the semi-chronic world of the ‘remission society’ as Frank (1991, p.139) terms it. I conjecture, by looking down my medical ward, that out of

twenty people, none will be completely cured. Instead they will go home to manage in a compromised state of health.

Literature within the field of interest

As the understandings revealed in this work will be derived from the experience of the participants¹ in the study, it is neither conventional nor is it necessary to prime the work with a comprehensive critique or review of the literature. van Manen (1990, p.47) proposes that it can be a disadvantage to read about the subject before turning to view it as it is experienced. This is because the ideas and theories contained in the literature may predispose the researcher to premature understandings which influence the interpretation unduly. Indeed, inherent to phenomenology is what Kestenbaum (1982, p.13) terms the 'habit of mind' of phenomenology; that is, phenomenologists regard lived experience before it is subject to formal theories. However, following Heidegger (1962) and Gadamer (1994), who propose that predispositions or prejudices are inevitable and form a complementary part of any interpretation, it can be argued that there are advantages to reading and remarking on some of the literature surrounding the topic of inquiry in an interpretive phenomenological study. Indeed Morse (1994, p.25) and May (1994, p.19) maintain that some knowledge of the field of inquiry is an essential prerequisite to an interest in the phenomenon to be researched and that this knowledge should be provided as a preamble to the study. The cursory review of the literature that follows serves to show how the field has been influenced by various health related disciplines and inspects some of the interpretive nursing work in the area.

As some authors explain, the literature regarding chronic illness is becoming so prolific it is proving difficult to provide a comprehensive critique (Gerhardt 1990; Gullickson 1993; Dluhy 1995). Sufferers, nurses, doctors, sociologists and psychologists have contributed to the accumulative research. The majority of the literature is concerned with distinct chronic diseases. This perspective tends to detract from the idea that there are some common shared experiences people with chronic illness have and understand. It also deters people from regarding the chronically ill as a large and important group in society.

Besides the medically dominated epidemiological projects which discern the cause and course of disease, much of the general literature is concerned with how people adapt both socially and psychologically to long term illness (Thorne & Robinson 1988a, 1988b). Over the last ten to fifteen years a new trend has appeared in the

¹In this instance I include myself as a participant in the research.

literature which, although it is small compared to the rest, is relevant to the work in this study. Both doctors and sociologists of health have become interested in the philosophically grounded interpretive perspectives. Books and papers have appeared which delve into the experience of the lived world of the ill and chronically ill (Kleinman, Eisenberg & Good 1978; Kleinman 1980, 1988; Kestenbaum 1982; Brody 1987; Sacks 1986, 1991, 1995).

Distribution of ontological and epistemological perspectives in nursing research on chronic illness

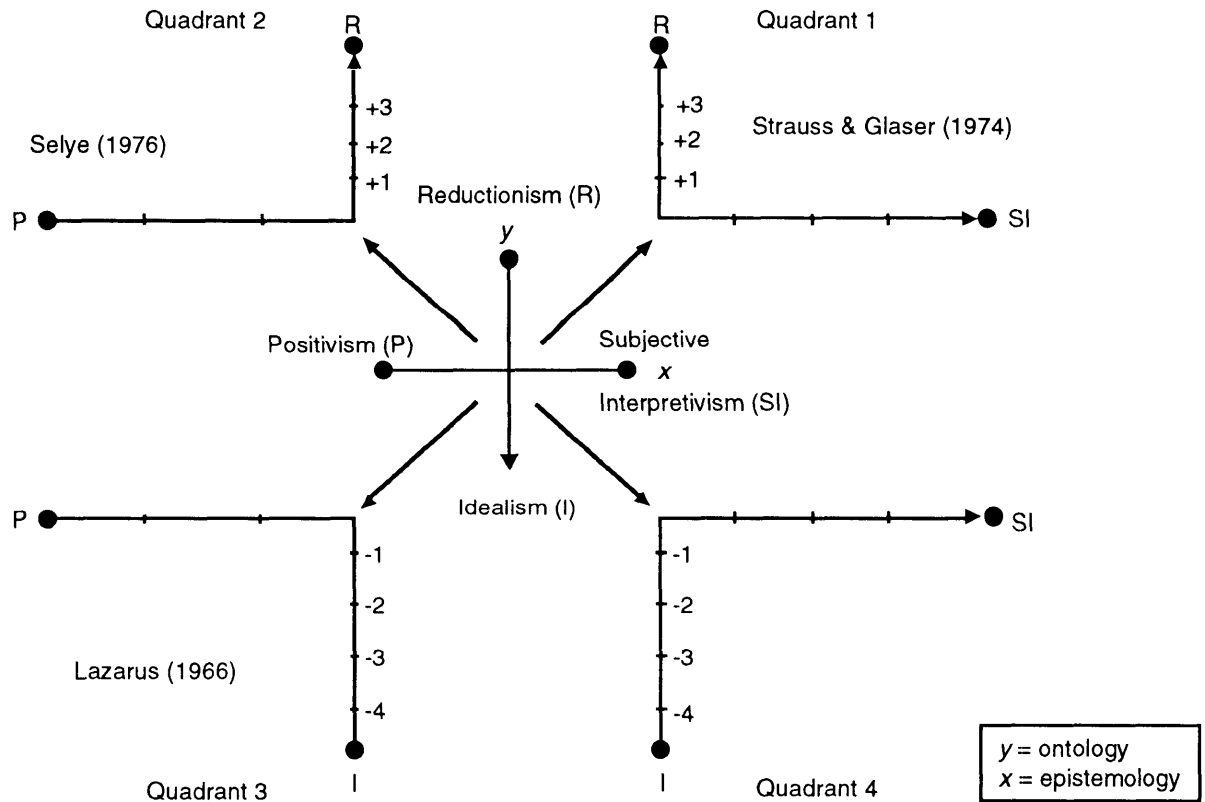
Dluhy (1995) considers the wealth of nursing literature on the subject of chronic illness and provides a useful schema of the works. She establishes the pluralistic nature of the literature and contends that the most productive approach to the pluralism is to consider how the various works can be compiled in order to reveal issues in the field. Her aim is to show that findings may complement one another and this co-operation is in the interests of good nursing practice. The onus of this project is on 'uncovering connections between perspectives, and identifying conditional states' (Dluhy 1995, p.1053). This co-operative view is a refreshing change from the usual competitive exchange in which it is presumed that other perspectives have to be discredited. She deduces the following themes/issues from the nursing literature on chronic illness:

1. Demands and challenges (fatigue; dyspnoea; pain; uncertainty; stress/adaptation).
2. Emotional and cognitive responses (defence mechanisms; control/mastery; coping/adaptation; attributions).
3. Day to day tasks of living with illness (life management/normalising symptoms).
4. Being chronically ill in the culture of a 'health' society (roles/transitions; disability; stigma; social definitions of illness).
5. Changing interactional patterns with family and health care providers (social support; relationship with health care providers).
6. Potential life outcomes (quality of life; meaning in illness; redefining the illness situation) (Dluhy 1995, p.1055).

Dluhy (1995) arranges the collected literature by locating works according to their philosophical underpinnings. She identifies perspectives related to the differing views of the person (ontological) and knowledge (epistemological). These views are arranged along two intersecting axes. The extremes range, on the ontological axis, from the idea of the person as a physical entity reducible to parts, to that of the person as an holistic autonomous self interpreting being. The range on the

epistemological axis is a view of knowledge as a means of prediction and control, to knowledge as subjective and interpretive. The intersecting axes form four quadrants in which projects can be located (see Fig 1).

Fig 1: Theoretical map for chronic illness in the nursing literature



(adapted from Dluhy 1995, p.1056)

This matrix or map is an ingenious device for emphasising some interesting contradictions or problems faced when ideologies and research methods clash. For example:

... quality of life, as discussed conceptually, appears to stress the holistic view of the person. Measurements of quality of life, however, are more frequently positivistic in nature (Dluhy 1995, p.1055).

However, in all fairness, she concedes that the authors commonly express frustration at the difficulty experienced in capturing the experiential spirit of quality. The problem here is the inadequacy of the tools available for generating knowledge rather than the philosophical approach of the researchers. In similar vein while nursing espouses an holistic approach to client care, the majority of the studies of chronic illness are found to be reductionist.

Dluhy (1995) places research studies on chronic illness in one of the four quadrants formed by the crossing axes of epistemology and ontology. This placement gives a rough idea of the underlying philosophical approaches towards the person and knowledge acquisition of the various schools of research (Fig 1).

She finds there is a collection of studies which are based in the biological and medical sciences concerned with specific diseases and the causation of physical symptoms. Dluhy (1995) places them in quadrant two. These studies tend towards positivistic science and the reductionist view of the person.

A large cluster, in quadrant three, is influenced by psychology and these studies view the person as a holistic being. However, they use positivistic research designs which lead the researcher to interpret the research participants' perceptions from an objective viewpoint. Many of these researchers are influenced by the work of Lazarus (1966) and therefore focus on coping and adaptation among the chronically ill. Researchers in these studies try to discover why some individuals and families cope and adapt to chronic illness better than others (Pollock 1986; Larkin 1987).

A small cluster of research studies are influenced by the view of the person as reducible to parts and science as an interpretive exercise (Dluhy 1995, p.1055). Dluhy (p.1056) locates the seminal work of Strauss and Glaser (1974) on chronic illness and the quality of life in this quadrant. This is right for while theory generated in grounded theory comes from the data, the process of theorising ('hypothesis-sampling' and 'categorising') is rigid and the explanations and predictions made are held to be generalisable and prescriptive (Gerhardt 1990, p.1153). Gerhardt (1990, p.1153) acclaims Strauss, Glaser and their school of researchers at the University of California's School of Nursing, as pioneers of qualitative research in the field of chronic illness. Certainly their works have been influential in the field for twenty years and they are also well known as experts on grounded theory research (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek & Wiener 1984; Strauss & Corbin 1988; Strauss & Corbin 1990). Their focus is upon the research participants' (whether they be sufferers, carers, or family) perception and definition of the situation. They see the problems associated with chronic illness as an interaction of social and physiological factors.

In the last cluster of her theoretical map Dluhy (1995, p.1055) locates 'the most holistic, existential notions of chronic illness'. The boundaries of quadrant four are knowledge as subjective/interpretive and the person as a self interpreting being. It is in this quadrant that this phenomenological study of the experience of chronically ill people belongs.

To date Dluhy (1995, p.1055) finds that there is no nursing scholar who exemplifies this quadrant in the area of chronic illness. Of more note, however, Dluhy (1995, p.1055) finds less contribution to the nursing knowledge amassed, regarding chronic illness, from this quadrant than from any of the others. So despite nursing's overall rhetorical commitment to holistic and pluralistic philosophies² the evidence is to the contrary—there is a '... continuing commitment to positivistic, mechanistic approaches' (p.1057). This is a conclusion that Conrad (1990) also reaches in a broader review of the methods and conceptual developments in the wider health related chronic illness literature.

Gerhardt (1990), in a useful paper, traces the development of qualitative research on chronic illness. Within this sphere he finds more phenomenological studies than Dluhy (1995) who confines her review to the nursing literature. While Dluhy may find that the majority of papers are positivistic and mechanistic in the nursing literature, this, I suspect, is a tide which is turning. Nursing research is following the ideals of its commitment to the holistic nature of the person and the value of new paradigm research. There is a burgeoning of nursing research into the experience of illness (Morse & Johnson 1991; Benner 1994; Munhall 1994) and it is reasonable to predict that this will be the case with chronic illness too. The works of Thorne (1993), Gullickson (1993), and Benner (1994a) are examples of interpretive studies dealing specifically with the experience of chronic illness.

Kleinman (1988) proposes that the meaning of illness is rarely pursued in the world of health care. Instead there is a '... radically materialist pursuit of the biological mechanisms of disease'. Attention is turned away from the problems caused by illness which are usually of prime concern to the chronically ill person and their family. He proposes that the relatively 'soft' view of meanings is devalued in the face of the 'hard' facts associated with biomedicine. He writes: 'This pernicious value transformation is a serious failing of modern medicine: it disables the healer and disempowers the chronically ill' (p.9).

Interpretive nursing studies

Thorne (1990, 1993) and Thorne and Robinson (1988a, 1988b, 1989) have done extensive research with chronically ill people. Thorne (1993, p.11) describes her work as: 'qualitative explorations of chronic illness experience, focused increasingly on the societal context in which that experience was shaped'. Her work demonstrates the way that experience is shaped by the social context of health care. Her book

²By this is meant that knowledge is not bound to one foundational point.

Negotiating Health Care: The Social Context of Chronic Illness is a significant contribution to the literature.

She founded the work on data that had already been collected in an earlier research study. The earlier work specifically related to health care relationships. In that work she used a grounded theory approach. Over time she added to the data which eventually consisted of three to four taped interviews with each of ninety-one people (chronically ill individuals, 60%; family members of adults, 18%; family members of children, 13%). Her rationale for using the data again was that the participants had given such rich and broad information in the interviews that there were more meanings to be gleaned from the database (Thorne 1993, p.234).

Her latest work (1993) explores the experience of chronic illness and relies heavily on her previous work, particularly in the area of relationships with health care providers. Her methodology has changed to accommodate the social construction of experience and an appreciation for shared meaning. However, she still uses the techniques of grounded theory for data analysis and the themes which have been selected impose more structure than would be found in an interpretive phenomenological study. The structure of the work includes conceptual levels (named: the individual, the social and the structural) and themes which correspond to the conceptual level. For example, at the individual level she considers onset and diagnosis, acuity and chronicity and normalcy and visibility; at the social level she considers relationships with health care providers and trust and confidence; at the structural level she considers confrontations with the health care system, politics and ideology, and response and resolution. The size of the project necessitated the use of a team of researchers who cross checked and revalidated each other's work. This was a process which demonstrated the team's commitment to validity and inter-researcher reliability rather than to the process of reflective and dialogic interaction with the texts. The latter is a process used in interpretive phenomenology in order to generate understandings concealed in the accounts of everydayness apparent in the texts (Thompson 1990).

There is general criticism of interpretive work that it does not have an obvious impact upon practice. This is because the researchers concentrate upon consciousness-raising rather than proffering solutions or suggesting strategies (Carr & Kemmis 1986; Dluhy 1995). Works like Thorne's (1993) do generate ideas to transform as well as inform practice. This is one of the benefits of the slightly more structured and mechanistic framework she employs.

Benner, Janson-Bjerklie, Ferketich and Becker (1994) conducted an interpretive phenomenological study as part of a larger study concerning the experience of living with asthma. This was a large project funded by the National Centre for Nursing Research. The narratives collected in three interviews with the ninety-five participants were related to specific questions. In the first and third interviews the participants were asked to recall an instance of asthma and to describe how they coped. In the middle interview the participants were invited to tell the story of their whole experience related to illness. The researchers investigated the participants' described relationships between themselves and their illness and offer the following categories for people: acceptance, transitional, non-acceptance and adversarial. These types of categories are clear and simple, as are most abstractions. However, there is the possibility that they distance the work from the existential nature of experience and deny its complexity. Benner et al. (1994) do give further information about the '... hidden cultural dialogue about self-reliance, falling ill, dependency, and self-respect' (p.248). However, the impression of stasis prevails and is quite different from the existential themes revealed in other more scholarly interpretive phenomenological works.

There is a marked difference between the large funded interpretive studies and the smaller scholarly works. It appears that some philosophical congruence is lost when researchers need to accommodate the funding body's appreciation of practical outcomes. The quarter given, in the interests of practicality, to the motives of funding bodies moves the works toward Dluhy's (1995) third quadrant, edging away from existentialism.

In a far smaller study, Gullickson (1993) seeks to uncover the shared practices and common meanings revealed in the experiences of twelve people with chronic illness. Unfortunately the project is only partly written up in the literature and the full study is not available (Gullickson, C. 1993, pers. comm., 4 Nov). However, she reveals an emerging pattern which she calls 'my death nearing its future'. This is not a category for people to fit into but it is an idea that is found embedded in the actions people describe in the texts. It is something that people with chronic illness understand and share with each other. She writes:

Chronic illness experience brings close what we struggle to keep afar, our own death as a possibility. It is through the act of understanding the nearness of the possibility of one's own death that new possibilities for being emerge (Gullickson 1993, p.1388).

As Dluhy (1995) says, there is great scope within the discipline for more work which fits into the fourth quadrant. Hermeneutic phenomenology and other interpretive perspectives form a powerful source of information regarding the reality of illness as

it is experienced. Kestenbaum (1982, p.viii), a medical doctor who has appreciated and used phenomenology to enhance the practice of health care professionals writes:

... phenomenology helps to uncover the human meaning of illness—the “humanity of the ill”—and in doing so locates illness within the larger context of the human condition.

In this respect, then, phenomenology makes it possible to grasp “being ill” as a distinct manner of being-in-the-world, that is, it contributes to a philosophical anthropology informed by reflection on the phenomenon of illness. Such reflection advances not only our knowledge of human nature but also our understanding of the awareness that a health professional needs if his or her practice is to convey more than simply an adequate technical comprehension of bodies and persons. To grasp the meaning of illness for humanity, the patient, and humanity of the patient is more than simply to “identify” with the patient or to feel compassion. It is to appropriate at least one of the conditions necessary for professional judgement inspired by human wisdom (Kestenbaum 1982, p.viii).

One can speculate on how much the wise nurse has to offer people who are experiencing illness and, in the case of this study, chronic illness. This kind of experiential understanding is underestimated and undervalued because it is not readily translatable into protocols or what are conventionally viewed as outcomes. However, it has the potential of enhancing the knowledge and practical artistry of any nurse who is open to the revelations contained in the studies.

The literature of personal experience

The literature relating to the personal experience of illness is evocative and emotive reading. The effects of illness are so profound that they inspire a range of people to express themselves. Four personal accounts by scholars who have analysed and reflected deeply on their experiences stand out amid the literature. They are *A Leg to Stand on* by Oliver Sacks (1984), *Living with Chronic Illness: Days of Patience and Passion* by Cheri Register (1987), *At the Will of the Body: Reflections on Illness*, by Arthur Frank (1991), and *The Life of Illness* by Carol Olson (1993). These authors write with the authenticity that only a sufferer of illness can achieve and all have the gift of being able to express themselves exquisitely. They truly achieve their aim of taking the reader near the experience and enriching their understandings of the illness experience.

Sacks (1984) is an example of a physician who was so impressed by his experience of illness that he wrote about it. After this experience he made a career of including an understanding of the experience of the people who came to him with neurological problems in his medical assessments. His concern and care for these clients shines through his work which demonstrates the potency of this perspective (Sacks 1986, 1991, 1995). Register (1987) is a woman who combines her own experience of years

of chronic ill health with those of others. In her research she interviewed fellow sufferers and analysed the data from a deeply personal position. The insights she brings in the way of humour, sadness and anger make the experiences come alive. Olson (1993) uses the philosophical framework of hermeneutics to interpret her own experience of living with renal failure and the illness experiences of her brothers and sisters:

The following question dwells in my life: "Can we understand the life of illness?" The question emerged in childhood, when my oldest brother, Eddie, and my baby sister Grace, died of kidney failure and related causes. When I was ten years old, my mother told me I had kidney failure, too. During my teen years my younger sisters, Joy and Crystal, and I were frequently in hospital as the disease progressed. Crystal died when I was in high school. The following year 1969, my older brother Arthur experienced the sudden collapse of his kidneys with Hong Kong flu and began dialysis on the artificial kidney machine. Joy and I started dialysis two years later. Our years on dialysis together ended when Joy and Arthur died in 1983. My father had died from a heart attack in 1979. Yet the meaning of their lives is not primarily that they died but how they lived (p.1).

Olson takes up a conversation with the texts of her own narrative and her sister's journal. She uses literature to convey emotions and ideas generated through her hermeneutical interpretation. Frank (1991), a medical sociologist, wrote an analysis of his experience of suffering myocardial infarction, cancer and radical chemotherapy. His work combines experience, deep personal reflection and analysis of the context of illness. His ability to write expressively means he can convey his feelings and thoughts in the most poignant way.

It is right that people who experience illness have such a profound effect on the literature which is published. They should be the ones to impress the rest of us who do not feel as they do, however much we may wish to understand. It is worth remembering though that the majority of people with chronic illness do not have the same opportunities for writing as these four exceptionally gifted people. Ordinary people need to express the meaning of illness too. Keith (1994a) has assembled the most powerful book of disabled women's literature. She is a writer who has encouraged fellow women sufferers (disabled and chronically ill) to write about their experiences. She values the company of people like herself and understands the need they have to share their feelings. As an editor she has encouraged and helped the women express themselves in a variety of the most touching work. This poem is included to demonstrate one piece of work from the collection.

The horns of my dilemma

*I seem to spend
half my time
Wishing*

*I had horns
On my head
To look the part
A rarity
Like the almost extinct
Wild bison of eastern Poland.
So children could stop and point
Look mummy that lady's got horns!
Before being hurried along by some embarrassed adult.
Horns or else flickering antennae
Which bleeped
Unmistakably alien
Or extra-terrestrial
Hooves which sent showers
Of sparks flying
Whenever they touched the ground.
Devilish, wicked, supernatural.
And a tail,
Oh yes a tail
Swishing and bushy
With fronds and tassels
In luminous green, I think. So nobody could make the usual
assumptions,
So I wouldn't have to explain
How I'm different
We'd get this fact established
Right away
Because what hurts worse
Than any pain
Is the denial.*

*The trouble is
I spend just as much time trying to explain
With increasing impatience
That in fact
I don't have horns
Or hooves,
Not even a bushy tail.*

*Trying not to frighten
People away
Reassuring anxious relatives
and friends.*

*Some things I play down
Others I censor right out
Working overtime
To bridge a widening gap.
Searching for common ground.
So as not to be labelled
Into oblivion
So I'm not written off
Before I've even had a chance.*

*Here are my tears, I say
Salty and wet like yours
Here are my hopes
Which need tending
Like anything you want to grow
And what hurts worse
Than any pain
Is the denial.*

*Why is it people
Either think I'm just like them*

*or else
Like nothing on this earth
And no part of their lives?

If I can live with this dilemma
It doesn't seem too much
To ask others
To recognise
How I'm different
But very ordinary
Ordinary and very different.*

(Maria Jastrzebska)

These books which reflect personal experiences send such a different message to both chronically ill people and their families, friends and carers from that in the self-help section of the literature. They say, 'This is how I feel, a whole range of things'—'Maybe you feel like this too'—'This is how I understand the experience'—'Join the community', 'We are worthwhile'. On the whole the self-help books are written to inspire the fighting spirit and emphasise the role of the person in controlling and managing their own disease. This is a model of care which can be motivating but also extremely wearing over a long period of time.

From the review of the nursing literature I conclude that there is room in the literature for works which take an interpretive view of chronic illness. We need to gather information about other people's experiences because this in turn allows us to become more experienced ourselves (van Manen 1990, p.62). Alongside information regarding the incidence, cause, coping mechanisms and social adaptations found in the nursing and general literature, nurses want studies that attune them to their clients' lives and allow them to become part of that world.

Summary of the thesis

Eighteen people helped with this research by recounting their ordinary everyday experiences of living with chronic illness. The information they gave is presented in terms of Heidegger's notion of time as the foundation of existence. The people reveal how their experience of illness is affected by their history with stories of how they were and how they became ill. They show how much their history influences their constructions of a self image. They also draw comparisons with the way they were, which highlight feelings of loss. The present is extrapolated through their descriptions of their actions and the situations they find themselves in—situations which graphically demonstrate the struggle involved with day to day living and the maintenance and control of their illness. The future presents the possibles which the person is reaching towards which impinge upon their present moods and partly constitute the present for them. These are possibles which are deeply affected by the

experience of illness which will be long lasting. They show fears, worries, resignation and calm.

Introduction

The introduction serves to pose the research question—*What is the experience of chronic illness?* The research question emanates from a concern in practice and the understandings generated in the research will be used to inform nurses. Phenomenology as a methodology is a means for the researcher to extrapolate the meaning of experience and is therefore a way of determining what it is ‘to be chronically ill’. The term chronic illness is explored as a human condition determined by longevity and something which is a total human experience rather than an entity. The difference between acute illness and chronic illness, it is established, is becoming blurred as the range of illnesses which can be treated change. In the literature review it is established that there is a paucity of nursing research that explores the lived experience of chronic illness. There is, however, a great deal of literature from other disciplines, especially medicine and the sociology of health, which relates to such things as epidemiology, the cause of chronic illness, the treatment of symptoms, and the coping and adaptation mechanisms adopted in chronic illness.

The context

In chapter two I explore the background to the study; that is, Australia, the Australian health care system and the setting of the study in two cities in rural New South Wales. This is a useful chapter because it gives clues to the origin of some of the culturally constituted values, beliefs and attitudes held by participants and which combine to influence their experiences of illness.

The participants in the study are all either connected to education, farming or the local small industries. They are all concerned for the economic decline in rural areas of Australia. This is a problem which has been exacerbated by the worst drought this century. The rural Australians are used to hardship. On the Tablelands they live in difficult country which, although it is spacious, has thin, poor soil and the weather conditions can be baneful. Rural Australians impose standards on themselves: they expect to work hard and be uncomplaining. They are self-reliant and generally only look to people outside the family for support in times of disaster. Their day to day hardships tend to be of the chronic kind with which they are expected to cope inside the family. Some of these attitudes apply to the chronic nature of illness.

A significant proportion of the Australian taxpayer’s money goes into funding the Medicare system and towards pensions of varying types. There is a general concern

that some people are over using the system. This type of prejudice pressurises users and beneficiaries to justify their needs. This is particularly stressful for people who can foresee that they will require years of medical resources and who find it difficult to demonstrate their illness. The extreme case of this type of stress is exemplified in this study by Paul, who has backpain.

Space or distances in rural Australia are vast. The space can seem larger and more difficult to traverse when a person struggles with chronic illness. Most of the medical specialists operate in the large cities, which means people make long, expensive and difficult trips several times a year.

Methodology

Chapter three is a long chapter in which I explore the philosophical underpinnings of the research approach, which is interpretive phenomenology. The chapter begins with a critique of traditional science in which a case is made for the acceptance of different ways of knowing. This is particularly important for professions like nursing in which the knowledge gained through experience is such a source of wisdom for practitioners.

There are brief introductions to both phenomenology and hermeneutics. Although 'phenomenology' is a term used quite loosely in some nursing literature, it is by no means a generic word. The differences between Husserlian and Heideggerian phenomenology are defined because these are important concerns which have an impact on the method chosen for the process of the study.

This study is informed by the philosophical works of both Heidegger (1962) and Gadamer (1994). Heidegger set the scene for an existential phenomenology; that is, a pursuit of understandings revealed in everyday occurrences. I consider his existential analysis of: Being-in-the-world, care as the fundamental way of being, time, temporality, and space. Gadamer's work is used to understand the notion of hermeneutic interpretation. Gadamer's philosophy is in harmony with Heidegger's; however, he extends the notion of interpretation and gives more details. Like Heidegger, he values tradition and history, both of which constitute people's world view and prejudices. He reclaims prejudice as a natural and essential way of being human and he proclaims it is the unexamined prejudices which are problematic. The place of the researcher in the interpretive exercise is alongside the participants. The aim is that through conversations between the researcher and the research participants' texts the two perspectives can merge to form a wider horizon of understandings. The understandings gathered together and represented are a result of what Gadamer (1994) terms the 'fusion of horizons'. The fusion of horizons is a

complement of both worldviews: those of the chronically ill and of the researcher/nurse.

Interpretive phenomenology is being studied by nurses who wish to reveal knowledge which is embedded in everyday activities and situations. In the last section of the chapter I briefly consider the number of nurse researchers who have used phenomenology. Finally, I concentrate on the work of Patricia Benner who has made a mark in nursing research with interpretive phenomenology underpinned by the philosophical works of Heidegger and Gadamer.

Method

This chapter contains the details of the process of inquiry. I outline the preparation for the fieldwork. This includes ethical approval for the study which, although it was granted without difficulty, proved to be more complicated than at first anticipated. Issues of confidentiality had to be revisited a number of times during the study and I was faced with some difficult dilemmas. The participants were volunteers attracted by newspaper advertisements and one local radio interview.

The fieldwork lasted approximately six months, during which time I made initial contact with people and usually did two tape recordings of their stories of chronic illness. I usually visited again to discuss what had been said and to formally finish the research relationship. I kept in contact with some of the participants up until the time I left Australia to return to England.

The tape recordings were transcribed and entered into the computer program NUD*IST. Details of the hermeneutical analysis are recorded in the chapter. It took some time to decide upon the process of interpretation as both Gadamer and Heidegger are against the formulation of method and the resulting constraints it imposes. However, for the sake of practicality some method was required. I endeavour in the study to be true to the hermeneutical cycle in terms of relating continuously to the whole story and then to the parts, and to the notion of the fusion of horizons.

Case studies

Six of the participants are introduced in this chapter. The picture is drawn from their texts and from the fieldnotes I kept during the study. This compilation of their stories is the first stage in the interpretation of the texts. They represent individual whole lives and the ways particular participants are living with chronic illness. This is where we start on the hermeneutic cycle, with examples of wholes. At the end of the chapter

important concepts are revealed and highlighted. These ideas serve to guide the subsequent conversations and questions developed with the texts.

Histories

In this chapter the past is revealed to display its impact upon the present lives and aspirations of the people with chronic illness. The way people were and what they achieved is an important part of the person they still are. It was a fundamental starting point to the researcher/participant relationship that I should appreciate who the people were still constituted how they wanted to be portrayed.

The people also detailed how they became ill and how they procured a medical diagnosis and treatment. The relationship with medical practitioners began to emerge as highly significant in terms of feelings of self respect and confidence. It was at this point that I began to feel the stark absence of nursing in the lives of these people. This was a feeling which developed throughout the three horizons of time: the past, the present, and the future.

Lives

People's present is revealed through asking the texts, *What it was the people did*. It is possible through the examination of actions and situations to construct ideas of what it means to live with chronic illness. The feeling that prevails is one of struggle—struggle to contribute to a life of illness, to control the disease, to work and to socialise. This struggle to live with chronic illness is set against the backdrop of their ordinary lives. Most people have to deal with other complications and problems in their lives, because being ill for a long time does not excuse one from these types of worries. There are many expressions of pain and extreme fatigue. The other side of the coin is the reception of help, in terms of medical treatment, including receiving medicines, social benefits from the state and less formal support from friends and family. Seeking help may be a demeaning exercise and one which can make the sick person feel they are a lesser being.

Futures

The future is particularly poignant for the chronically ill because by the nature of chronicity the future holds the prospect of more illness. The person with chronic illness faces a future with more hardships, loneliness, struggle, pain and worry. However, some people describe a calm or peace which can be achieved through the depths of suffering. Possible physical dependence appears to be more worrying for people than impending death. Indeed, death is not discussed by the participants whose illnesses are not life threatening.

Conclusion

In this chapter I review the understandings generated from the texts and speculate on what they might mean for nurses in practice. I discuss the absence of nursing in the texts and make a suggestion that chronically ill people are missing out on professional care because they do not refer to, or they are not referred to, nurses. I consider how I could have nursed the people in this study. In an attempt to review the process of the interpretation and estimate its worth, I consider the methodological principles suggested by Madison (1990, pp.28–29). These principles are:

- a) coherence
- b) comprehensiveness
- c) penetration
- d) thoroughness
- e) appropriateness
- f) contextuality
- g) agreement (1)
- h) agreement (2)
- i) suggestiveness
- j) potential (pp.29–30).

The aims and intentions of the researcher

I intend that this thesis will be a work of both science and art. I hope to generate understandings and be able to emotively convey them through this written script. Watson (1988, p.67), writing about art in the context of transpersonal caring, says the following:

The activity of art is based on the fact that a person receiving another person's expression of feeling, through hearing, sight, or even intuition, is capable of experiencing the emotion that moved the other to express it. To use the simplest example: one person laughs, and another who hears becomes merry ... A person suffers, manifesting his suffering by groans and spasms, and this suffering transmits itself to other people ...

It is on this capacity of one human being to receive another human being's expression of feeling and to experience those feelings for oneself that the artistic activity of nursing and caring is based.

Phenomenology, van Manen (1990) stipulates, is a literary art. It is through the process of writing and rewriting this manuscript that the understandings have revealed themselves. I wish to touch readers with the experience of chronic illness so that they may feel some of the experiences described and thereby come to be closer to people with chronic illness; that is, to know them better in order to understand them and to care for them.

Primarily this is a work for nurses. It may be of interest to others, but in the main I want to envelop nurses in the experience of chronic illness in its everydayness. I hope nurses may use this research to see the lives of people who are chronically ill in new ways. This is in order that they may extend their understanding of the lived world of the patients/clients with whom they work and express their new views through heightened care of patients/clients. They may even decide to offer nursing assistance to people who do not commonly get help because they are seen to be 'coping'.

Besides the understanding of the experience of chronic illness I have attended to the philosophical underpinnings of interpretive phenomenology. After Kestenbaum (1982, p.7), I see nurses adopting a phenomenological 'habit of mind'. 'Habits of mind' are the attitudes and approaches to the world as generated, in this instance, by our professional culture. I would like to see us adopt and appreciate the interpretive turn towards the patients' narratives and stories of their everyday lives. I mean a turn which throws attention upon the person's experience and lights the nurse's way to care. Paterson and Zderad (1988), Watson (1988), Benner (1994a) and Taylor (1994b) have already made the connection between nursing and interpretive phenomenology and I hope to continue to encourage nurses to develop this phenomenological 'habit of mind'.

Chapter 2

The Study Background

*I shall leave my home, and forthward wander stoutly to the northward
Till I come by chance across it, and I'll straightway settle down,
For there can't be any hurry, nor the slightest cause for worry
Where the telegraph don't reach you nor the railways run to town.*

*And one's letters and exchanges come by chance across the ranges,
Where a wiry young Australian leads a pack horse once a week,
And the good news grows by keeping, and you're spared the pain of weeping
Over bad news when the mailman drops the letters in the creek.*

(Banjo Paterson)

Introduction

In line with the methodology chosen for this study, and described in detail in the next chapter, it is appropriate to draw a picture of the milieu in which the study took place. A description of the area and a superficial analysis of the health care system in Australia may serve to locate and facilitate understanding of the participants' experience of chronic illness. This description may throw light on some common ideas, myths, rhetoric, customs and ideals which surround this area. These all contribute to the profile of the people who participated in this study. Indeed they constitute, or at least influence, the experience of the study participants and are a part of the formulation of their views.

All the people who helped with this study live in, or within a one hundred kilometre radius of the rural cities of Armidale and Tamworth in the New England region of New South Wales. This area is classified as 'rural Australia' and should not be confused with 'remote Australia'. The remote areas of Australia are the far flung places from which it can take days of motor travel to reach a town with modern amenities and where neighbours are thin on the ground. In contrast, the New England region is relatively well populated and most people live within a couple of hours of a town. It is classified as 'rural' for a number of reasons, for example farming is the primary industry, the populations of the towns are relatively small compared to the capital cities and the distance to Sydney is well over five hundred kilometres (a six or seven hour drive from Armidale). Rural dwellers are the minority in Australia. The vast majority of the population (85%) live in either the capital cities or the major urban centres. What is more, the most populous area forms a triangle in the south east of Australia incorporating

Brisbane, Sydney and Melbourne, leaving vast areas either unpopulated or very sparsely populated. The New England region is on the borders of the Brisbane, Sydney, Melbourne triangle.

As a visitor and researcher I have taken a keen note of all new experiences and I have appreciated Australia very much. Coming to live in a rural part of New South Wales from Melbourne has enabled me to appreciate some of the contrasts between city and rural living. I have experienced the vastness of the continent, the wonder of the huge horizons arched by high vaulted skies, felt the power of the elements, the inconvenience of rural supplies and the loneliness created by the great distance from family and friends. There are technological 'advances' which are used to overcome what some Australians refer to as 'the tyranny of distance'. A distance from major cities which is, at the same time as it is decried and overcome, relished and chosen by many as it offers a preferred lifestyle.

This introduction to the 'life-world' of the participants in the study is important. It is through the repetitive study of the background (whole-world) and figures (the personalised experiences and perceptions of people regarding their chronic illness) that an understanding or interpretation of what it means to have chronic illness may emerge and be re-presented. An understanding of the communal world of the participants gives one clues to the influence that shared experiences and meanings in a culture have upon individuals' construction of their particular understanding of their situation. While the individual may not agree or hold with the prevailing ideas current in the community s/he is still affected by them. This is because the ideas influence other people and affect the ways they behave.

Madjar (1991, p.111) explains the importance, in a phenomenological study, of a balance between the study of figure (chronic illness) and ground (the experience of living in the world with chronic illness). On the one hand, too much concentration upon figure serves to decontextualise it. This makes it difficult to extrapolate what it means *to live* with chronic illness. On the other hand, too much concentration upon ground may mean that an inadequate understanding of the phenomena of chronic illness is expressed. This makes it difficult for the researcher to find and write about the common views (shared meanings) which relate to the experience of chronic illness. The background in this instance is the surroundings in which the people who helped me, live. These surroundings are made up of a number of things such as the countryside, the politics, the culture, traditions, history and language shared by the community.

The constant shift between figure and ground creates a tension which is inevitable. It is a tension between the individual's egocentric, illness-centred, particular accounts and the communal understandings of ill people who are human beings, Australians and rural

Australians. Some of these attributes show a person as being particular and others are attributes which are assigned to a community generally. Both views are bred of the common experiences they have over time and in a place. The special meanings made because of personal history, particular needs and experience, and the meanings shared because they were learnt in the same world. Both vistas are important and portray only a partial presentation alone. In tandem they reveal a richer scene from which to understand the experience of chronically ill people who live in Australia and, more particularly, New South Wales. Allwood (1989, p.306) explains that Gadamer uses this tension between the unique experiencing individual and their broader situation to generate understandings. He appreciates the unique experience as a phenomenon of great interest but as one which is a result of the tradition/situation the person belongs too. The result of this type of circumspection is a scenic panorama of life from which it is possible to appreciate those features of a situation which might contribute to the experience of all chronically ill people and those which might contribute to only one individual who helped to create this particular study of chronic illness.

Parse (1992, p.38) writes of 'living paradox' as an inevitable way of being and becoming in the world. She suggests that living with paradox enriches the human perspective of life; contradictions should be acknowledged and accommodated rather than regarded as vicious oppositions or poles which have to be resolved. In this study all the people involved have distinctive subjective experiences which appear to relate only to themselves and which colour the way they understand their situation. However, at the same time they share understandings within their community—cultural, historical and social meanings, which are an integral part of their constructions of reality. Lawson (1985, p.23) reminds the reader that Nietzsche, Heidegger and Derrida all endorsed paradoxes as unavoidable elements of life. The circular and accumulative nature of the study of both individual views and their shared derivations (developed through language) are at the sources of hermeneutical interpretation (Gadamer 1975; Gelven 1989; Hekman 1986, 1990; Thompson 1990). In this case the understanding of the 'lived-world' of chronically ill people is one in which paradox is viewed as inevitable and as something to be 'lived-with' rather than as a problem to be resolved.

It is rare in this chapter for the individual people involved with the study to be referred to. This is because I am trying to create a picture of their 'life-world'. The world they share with other people in Australia and, more specifically, their local community in the New England region of New South Wales. In chapter five I will introduce some of the individuals who helped with this work, by presenting their personal narratives. The broad picture portrayed in this chapter will hopefully enrich the reader's interpretation and

understanding of the individual perspectives given later in the work, as indeed the later biographies should add meaning to the broad picture presented in this chapter.

An Australian identity

The generation of an identity born of shared history and location is considered by Ward (1966, p.1) in his book, *The Australian Legend*, where he explains the idea of the Australian 'national character'. While these characteristics are not purely myth, neither are they naturally inherited nor universal, he proposes. The idea of 'national character' is related to reality in two ways: firstly it is created from a people's history and experiences and, secondly, it affects how they think they should behave typically:

According to the myth the 'typical Australian' is a practical man, rough and ready in his manners and quick to decry any appearance of affectation in others. He is a great improviser, ever willing 'to have a go' at anything, but willing too to be content with a task done in a way that is 'near enough'. Though capable of great exertion in an emergency, he normally feels no impulse to work hard without good cause. He swears hard and consistently, he is the 'world's best confidence man', he is usually taciturn rather than talkative, one who endures stoically rather than one who acts busily. He is a 'hard case', sceptical about the value of religion and of intellectual and cultural pursuits generally. He believes that Jack is not only as good as his master but, at least in principle, probably a good deal better, and so he is a great 'knocker' of eminent people unless, as in the case of his sporting heroes, they are distinguished by physical prowess. He is a fiercely independent person who hates officiousness and authority, especially when these qualities are embodied in military officers and policemen. Yet he is very hospitable and, above all, will stick to his mates through thick and thin, even if he thinks they may be in the wrong (Ward 1966, pp.1-2).

This is an exaggerated and idealistic notion of the rural Australian. It is based on the bushman of the last century and rather typically ignores females. While it is not an 'identikit' of any one of the people with chronic illness in this study, some characteristics are evident in these people and are certainly found in the community. Conversely some of these characteristics are thrown into sharp relief by participants who do not have them and describe how they feel different in some situations. An example of this is Sarah, who more than once emphasised that she was not like Australians. She explained that unlike 'Australians' she would talk and complain about her plight and hassle people for what help she was entitled to. Her family, friends and the state (fdnt:1.19-21) all received her vociferous opinions and assertive demands, even though she felt her 'un-Aussie' behaviour made her unpopular in some quarters. Although Australians are used to people from many cultures settling here, there is an intolerance, from many, for people from other nations who do not conform to 'Australian ways'.

This intolerance is contrary to the notion of the Australian as intrinsically fair to others. Theophanous (1993, pp.26-27) demonstrates the paradox between the Australian

characteristic of fairness and the injustices that do occur in Australian society today. First he cites Mendelsohn (1982) in order to make a case for the Australian tendency towards social justice:

The original Australian settlers (apart from the convicts who were the victims in the cruel British class war) had the impulse to emigrate from the British Isles and from Europe in order to escape economic and political tyranny and to adventure into a new land promising freedom and prosperity. The ideas of mateship and mutual support come from the need to survive in harsh conditions (1993, p.27).

However he then highlights the two significant inequalities in Australian society which would seem to contradict Mendelsohn's ideal: 'a. a sustained gap between the rich and the poor, with continuous pressure for the gap to widen [and] b. significant discriminations based on race, culture and gender' (Theophanous 1993, pp.27–28).

Perhaps there is a mateship for people within the immediate group, but it may also be the case that the heritage of hard times and the need 'to survive' creates a tendency towards defensive behaviour. This is more likely to be so if Australians feel, either rightly or wrongly, that their access to prosperity is threatened. Taylor (1991, p.4) describes a creeping individualism in Western society which he terms one of society's present 'malaises'. He proposes that people are tending to concentrate on their own (or their nuclear family's) needs. This means they lose the broader vision and concern for others in society. While the idealistic notion of the Australian paints one picture perhaps the reality is different; perhaps it is one that merits exploration and, as Taylor (1991, p.33) proposes, an ethical dialogue.

Rural women are becoming more noticeable in the literature (James 1989; Poiner 1990; Dempsey 1992; Franklin, Short & Teather 1994) and in local politics. This attention for Australian women comes after years of marginalisation and neglect in public spheres as evidenced in Ward's description of the 'typical Australian' which exclusively refers to Australians as men (1966, pp.1–2). Hogan points out that, even now, women tend to be appreciated in times of hardship '... when it means sharing the failures and the difficulties rather than the successes' (1994, p.31). Like the men, Australian women are portrayed as tough and capable, but also as the ones who hold the family together in good and hard times. Magilvy, Congdon and Martinez (1994, p.23) describe the rural tendency to value people's 'hardiness, ability to work, self-reliance, and practicality'.

When they are superimposed on people with chronic illness, these rather 'robust' national characteristics have various effects. They can cause distress and lead chronically ill people to presume they are, and/or that others view them, as inferior beings.

Australia

Australia is an ancient land whose first nation of people were the Aborigines and Torres Strait Islanders. There is evidence to show that the continent of Australia was inhabited thirty thousand years ago (Clarke 1986, p.9). The Aborigines were a tribal race which, spread thinly across the continent, did not reach large numbers. They lived primitive lives in harmony with the land, surviving for centuries using the earth's natural resources and their intuitive and practical wisdom. Their cultural heritage is tenuously preserved in the twentieth century by their ties to the earth, their legends and their dreamtimes. These are customs to which I, as a non-Aboriginal, could never do justice by describing, nor indeed can I understand completely, but which I respect deeply.

In 1788 a retired, English army officer was appointed Governor-in-Chief of New South Wales and the European colonisation of Australia began in earnest. In the two centuries since the British government assumed control and government of Australia there has been a continual rise in the numbers of the non-Aboriginal population. However this increase, as in most other Western countries, is slowing. The 1991 census revealed the number of people living in Australia to be over seventeen million (17 486 300) (Australian Bureau of Statistics 1992). Even now the density of the population in Australia (2.2 inhabitants per square kilometre) is well below the world average, which is thirty-nine inhabitants per square kilometre (Australian Bureau of Statistics 1992).

Immigration has gone through the following well known phases: the first newcomers were mainly convicts and then settlers from all parts of the United Kingdom and Ireland; then immigration from Western Europe and later Eastern Europe which peaked after World War II; and the last phase, since the eighties, has seen an increasing number of immigrants arriving from Asia to settle in Australia. The changing mix of cultures in Australia, which is so evident in the capital cities, is barely noticeable in the agricultural rural areas. Initially new immigrants tend to settle in large cities so most of the non-Aboriginal Australians in the New England region are of European origin.

While the country is now termed multicultural, the British influence abounds, particularly in the political and administrative structure of the country, the legal system, the language and some of the customs. The introduction of European farming practices and animals—sheep, horses, rabbits, foxes and pigs and so on (to serve European taste buds and leisure pursuits)—has had a devastating effect upon the environment. Environmental groups in Australia are burgeoning; they hope to halt the progressive destruction of the fragile environment. 'Greenies', as they are termed, are often unpopular with rural people. Their manifestos are seen to be critical of land management practices and their policies are often construed as threatening to the rural lifestyle.

Along with their land the Aboriginal people have suffered. Their original lifestyle has all but disappeared. They have migrated to towns where unemployment is rife and health problems, which are associated with poverty and poor social conditions, abound for them. Donovan (1994, p.28) assesses that the average life expectancy of an Aboriginal boy born in 1990 is over eighteen years (18.2) shorter than a non-Aboriginal Australian boy; the discrepancy between Aboriginal and non-Aboriginal girls is nearly twenty years (19.8). These figures are somewhat distorted because of the higher infant mortality rate amongst the Aboriginal community; however they adequately portray a difference in the health status of Aboriginal and non-Aboriginal Australians.

When I invited people with chronic illness to help with this study it was an open invitation to any adults in the community. However, I expected that there would be little response from within the Aboriginal community and when no Aboriginal people answered my invitation this hunch proved correct. Indeed I am neither skillful nor knowledgeable enough to re-present their stories. Stories are important to the Aboriginal culture and should be treated with special care. Chronic illness is as prevalent, if not more so, among the Aboriginal community and I hope that their experiences will be re-presented, in their own way, some day. In the meantime they may find that some of the experiences of the people in this study do strike a cord with them too.

The Federal government has had a Labor Party (social democratic) in power since early 1983 and the last general election was held in 1992. New South Wales has a conservative (Liberal/National coalition) State government¹ and the New England region returns a National (ultra conservative) Party member. Rural areas are traditionally more conservative in their politics than the metropolitan areas tend to be. Indeed the National Party used to be called the Country Party and it retains most of its popularity in rural districts. However proportional political representation ensures that rural people in Australia have only a minority influence in government.

The economic structure of the country is capitalist but this is underpinned by a welfare system; a welfare system which is under considerable strain (Malko 1992, p.33). Despite their other differences all the political parties are committed, albeit to differing degrees, to a welfare state, or at least a welfare safety net. No matter what the commitment, however, it is becoming increasingly costly and difficult to manage.

Australia has prospered economically since colonisation and, as most rural Australians are quick to remind others, the success of Australia traditionally had a rural base (Humphreys & Rolley 1991, p.1). Wealth is brought by farmers (sheep, cattle, cereals and

¹In March 1995 New South Wales voters returned the Australian Labor Party to government, with the slimmest of majorities.

fruit), miners of mineral resources, foresters and their associated refining industries. This is an anomaly as Australia is one of the most urbanised countries in the world. Approximately sixty-five per cent of Australians live in capital cities and a further twenty per cent live in major provincial cities, leaving only fifteen per cent living in rural areas (Reid & Solomon 1992, p.11).

The structure of the health services

The Australian health care system is fragmented and complicated. This is partly because it is controlled and organised at three different levels—the Commonwealth government, State and Territories governments, and Local governments, and partly because the country is so large and the needs of people in differing regions are quite distinctive and difficult to accommodate fairly.

The responsibilities for health at the Commonwealth level have gradually expanded since the institution of a Department of Health in 1921. In the early days the main charge of this Department was quarantine (Donovan 1994, p.116). Now responsibilities range from health programs (eg health promotion, prevention of AIDS, aged care services, control of drug and alcohol abuse) and benefit schemes such as Medicare and pharmaceutical provision. As with most health organisations the Department has undergone many changes recently which involve the re-allocation of funds and functions within the Department. The Department has been called the Department of Human Services and Health (DHS&H) since late 1993.

In effect the Commonwealth determines the health policy directions for the whole of Australia, while the states provide and administer the services. The constitutional arrangements in Australia allocate the legitimate powers with respect to health between the Commonwealth and the State governments. This allocation of powers means that the Commonwealth can only fund, through the states, rather than provide service. However the Commonwealth is prescriptive and the states are bound to certain health projects. This power is held because the Commonwealth government controls the largest proportion of the health budget. The Commonwealth has the money because the states conceded the revenue from Income Tax to them in 1942 when they faced bankruptcy. Despite the ability of the Commonwealth government to prescribe health policy the State governments are quite distinctive and their particular political persuasions make a considerable difference to the organisation of the health services in each state or territory (Donovan 1994).

The State government authorities are responsible for provision of the following health services:

- hospital services
- mental health programs
- dental health services
- systems of extended care
- child, adolescent and family health services
- women's health programs
- health promotion
- rehabilitation systems
- regulation, inspection, licensing and monitoring of premises, institutions and personnel (Donovan 1994, p.117).

The State government in New South Wales has central agencies and departments which '... are concerned mainly with the determination of policy, budgeting and financial control, planning, standards of performance and their measurement, program and budget reviews, industrial and personnel matters and major capital works ...' for the above list of services (Donovan 1994, p.117). Regional authorities are responsible to the state authorities for service provision and standards of care. Local government is responsible for environmental health.

Australia spends roughly the same as other developed nations on health. In 1992–3 health expenditure, according to the Australian Bureau of Statistics (1992) reported by Donovan (1994, p.122, p.281), was over eight per cent (8.5%) of the gross domestic product. This sum represented an increase of less than one per cent (0.8%) over the previous year. Approximately the total amount spent (\$34 338 billion) was contributed in the following ways:

Commonwealth government	\$15.1 billion
State and Local governments	\$8.1 billion
Private sector	\$11.1 billion

This spending compares well with the other countries in the Organisation for Economic Co-operation and Development (OECD) (Donovan 1994, p.129). Health indicators, such as life expectancy and infant mortality rate, equate well with other Western nations (Palmer & Short 1994, p.16). However, these positive statistics do not necessarily correlate to spending on health services. The major contributors to improved health are environmental or public health measures and social/economic factors, such as improved housing and standard of living, rather than health service provision per se (Malko 1992, p.33; Palmer & Short 1994, p.243). Clinton and Nelson (1995, p.12) observe that despite the generally good statistics for health spending and health status indicators, the health of the Aboriginal community is around the level of developing countries. This level is well

below the standards of most non-Aboriginal Australians. Inequality such as this is a problem in Australia and one that the government is committed to address in terms of the social indicators mentioned above (Theophanous 1993).

Rather than improving health generally, some might suggest that the ever expanding range of medical treatments for diseases is creating more chronic illness in the population. Examples are people with heart failure and renal failure. (I am not putting forward an argument against medical intervention, nor would any of the people in the study. What I suggest is that once it is recognised that so much of medical treatment *creates* chronic illness there may be more commitment to provide treatment and care which is appropriate for the long term well being of people with long-lasting illness.)

A proportion of the revenue for the public health sector (medical services and the public hospital system) is raised by the 'Medicare' levy. This universal insurance scheme was introduced to Australia in 1984. Part of the Medicare fund is raised by a levy (1.25%) on all taxable income (Clinton & Nelson 1995, p.30) and the remainder from general government revenue. Contrary to popular belief the income levy only pays a partial contribution to the whole health budget.

Treatment in the public hospitals for Medicare patients is free at the point of delivery, but this is not the case with the majority of outpatient medical consultations. A visit to the doctor has a range of prices and methods of payment. Medicare has set a schedule fee for medical consultations. The patient pays in the doctor's surgery and can redeem eighty-five per cent of the set fee from the Medicare office in town (note this might be quite a trek for some people). Doctors are not obliged to keep to the schedule fee and most charge more—a supplement which the patient pays for on top of the fifteen per cent not accounted for by the Medicare rebate. There are some GP practices which do not charge extra and they bulk bill Medicare (accepting 85% of the schedule fee). In these cases no money changes hands in the surgery and the service is free at the point of delivery.

Medical care other than that in hospitals is mainly provided by general practitioners, the majority of whom are in private practice. In the cities it is possible to find a practice where the doctors will directly bill Medicare rather than charge the patient². However the large majority of doctors in Australia charge more than the Medicare rate for consultation and are not prepared to cut their income in this way. Practices where bulk billing occurs are rare in rural towns. Informally, allegations of cartels abound. Bond (1993, p.23) reports '... when one case of bulk billing was offered in a rural town, the other doctors threatened to boycott him'. There is an interesting paradox here, for on the one hand there is a general feeling that doctors overcharge and therefore exploit the public. On the other

²This practice is commonly known as bulk billing.

hand doctors are revered for their knowledge and expertise and are a service people value (Humphreys & Weinand 1991, p.54).

In tandem with the public health system there is a major private health care sector in Australia. This service comes in the form of private hospitals, ancillary services (laboratories, radiology, etc) and private practitioners. While the public service is available for all citizens, those who are able to insure themselves for private care are encouraged to do so. This general policy is an attempt to alleviate the strain on the public health sector and to reverse the trend away from private insurance which took a dip when the Medicare levy was introduced.

The Commonwealth government introduced the Pharmaceutical Benefits Scheme in order to ensure that individuals were not excluded from having certain drugs because of financial constraint. At the same time they ensured, through the scheme, that part of the cost was borne by the purchaser. In the majority of cases the client pays the first sixteen dollars of the price of any item approved by the scheme. After spending four hundred dollars, in any one year, the client is entitled to a concessional rate of two dollars sixty cents per item. Holders of Pensioner Health Benefit Cards (people who are unemployed or on supplementary income from the state) are given the concessionary rate at the beginning of the year. The scheme does not cover the increased price of non-generic drugs and some new drugs. There are no automatic concessions for people with long standing diseases, such as diabetes, hypertension or epilepsy. To complicate matters further, no payment is made in return for pharmaceuticals received by public patients from hospital pharmacies. People who are chronically ill can be prescribed a panoply of medications and quite quickly reach the four hundred dollar benchmark in the year (Donovan 1994, p.120; Clinton & Nelson 1995, p.36).

The Australian Medicare system provides a safety net for those who cannot afford health insurance and guarantees that any Australian who requires medical treatment is cared for despite an inability to pay for the service. It represents a 're-distribution' policy that will ensure people with lower incomes are subsidised by higher income earners. However, this health care system does not offer equity of service to the population. Although everyone is guaranteed care and treatment a 'better' service can be bought.

Direct taxation is considered high in Australia and there is a feeling of resentment among many people against those who do not 'fend for themselves' (Palmer & Short 1994, p.25). Alternatively there is a backlash feeling that one might as well get one's money's worth out of the Medicare system after contributing to it, especially as other people do.

In fact health services are free to only a small minority. The Medicare levy, cost of pharmaceuticals and private charges can add up to a significant proportion of a user's income per year. While the amounts paid each year by people who are chronically ill are not usually ruinous, they do extend family budgets and affect people's standard of living. For the chronically ill, health care requirements are likely to increase as the years go by. People who have 'existing conditions' may have difficulty in obtaining private health insurance or their condition may be excluded by the policy. Resentment can well up if health care costs affect a family's standard of living (Frank 1991, p.117). There are examples of families who are severely affected when a chronically ill member requires nursing home care. Payment for this type of extended care is means tested and in these cases the middle income earners fare poorly. There are a few examples from the people in this study where the cost of medicines causes resentment. However none of them require, or indeed envisage requiring, long term institutional care. On the whole there was a feeling amongst the participants that too much complaining about the cost of the health service would be unfair.

In the New South Wales Government Budget Statement, Phillips (1993b), the then Minister for Health, reassured the electorate that, in co-operation with the other states, New South Wales would develop a National Health Policy in relation to budgetary allocation. He outlined a continued commitment to Medicare and national goals. The national goals were directed at improving the general health of the nation and focus on the following areas: cardiovascular disease, cancer, ageing and mental health (Phillips 1993b, p.9). Nowhere in the Statement (Phillips 1993b) are people with chronic illness specifically mentioned; nowhere is there a consideration of the view that one of the reasons for chronic illness is medical treatment. The conundrum presented by Illich (1976) persists—the more medical services New South Wales invests in, the more chronically ill people there are likely to be. At one stage in the report examples are given of what health service can be provided for seventy-five thousand dollars:

- 90% of one liver transplant including the cost of treatment in the first post operative year
- one heart transplant including the cost of treatment in the first post operative year
- neonatal intensive care for one premature baby weighing 1 000g or less
- hospital dialysis for 1.5 renal patients for one year
- 7.5 coronary artery by-passes
- 10.5 hip replacements
- 250 quit smoking courses (Phillips 1993b, p.8).

The most expensive of these procedures (the first five) will involve the client in ongoing chronic illness. When these types of 'value for money' comparisons are made, contingency is seldom, if ever, included for long term ongoing care and treatment.

The Issues Paper No.1, of the National Health Strategy published by the then Department of Health, Housing and Community Services (1991, p.16), acknowledges the increase of chronic illness as a significant trend in Australia and the following statement is made:

To deal with these chronic needs of the old and young, health services must increasingly have the capacity to take an ongoing interest in a person's well-being, and to develop knowledge of, and contact with, the total range of services which the person needs. This often runs counter to the organisational and financial arrangements of health services which are tilted towards short-term, acute interventions of a specialised nature, rather than ongoing and integrated treatment and care (National Health Strategy 1991, p.17).

This is an insightful statement, which offers no practical solutions. The chronically ill in the community are not recognised as a group in real terms, even though they are referred to as such in this paper. In effect, they are subsumed in such categories as 'the elderly' or 'the disabled', or included with others with the same medical diagnosis (ie diabetes, arthritis, cardiovascular). This dispersion means they are not dealt with as a distinct set, and their problems associated with the special nature of long term illness are concealed.

In Australia anyone who receives a state allowance of any sort (unemployment, sickness, old age, etc), is called 'a pensioner'. Rumours of 'bludgers'³ living off the state are rife. These rumours are given credibility by media reports, which are perjorative. They highlight such things as people living off unemployment on the Gold Coast⁴ and single mothers who can bring up several children supported by the state for years (Dunlevy 1995, p.1). In the *Australian*, Crews (1995, p.12) counters that this is a harmful and reactionary view but his voice represents a minority view. All the people who participated in this study were concerned about other people's opinions regarding their health status and they wanted to establish and, thereby, convince me that they were genuinely ill. I believe such anxiety is partly a result of this prevailing attitude.

Neither the cost of the health service nor indeed government strategies was an issue that dominated conversations between myself and the participants in this study. What was striking was the number of people who were on pensions who did believe that they got worse care and were stigmatised (Ia:431–439). This is a point which is reconfirmed by the participants who changed to private care and noted an improved service (La:99–115, 146–154). There were some participants who made no judgemental comments but I found they received inferior treatment. I could not help drawing a comparison between the different attention (eg the range of diagnostic tests and specialist consultation) given to two people with chronic fatigue syndrome. One is a self-employed 'odd jobber' drawing

³Bludger is a peculiarly Australian word for people who are seen to '... evade their responsibilities and impose upon others' (*Macquarie Dictionary* 1991).

⁴The Gold Coast is a beautiful part of the Southern Queensland coast with clement weather all year around. It is a haven for pensioners.

a sickness pension and the other person, who has paid medical insurance, is middle class and married to a prominent person in town. One participant, Elizabeth, told me she noted a difference in doctors' attitudes when she became a pensioner. This is just one of her examples:

*... by the time I got in for my appointment I was feeling so ill I could hardly sit there. And I thought well I have come all the way from **** [name of town] I have got to see him ...[pause]... and he was talking to me—and again I had filled out my forms and he saw that I had an invalid pension—and I have never had this experience until I went on this invalid pension, with doctors ...[pause]... and I felt he was more concerned about whether he was going to get paid than [about] me, and why I was there—because he said, 'You should have come through the clinic to see me.' But there is a three month wait! [The specialist had not noticed that despite drawing an invalid pension Elizabeth had chosen to pay for private insurance and that this was a private consultation.] And then he wanted to know what my husband did ...[pause]... and all the time I'm feeling so ill.*

(Ia:427–438)

Those participants who were able to afford private insurance and choose their specialist, even when it meant travelling large distances to see her or him, considered themselves privileged. There are media messages to the public to encourage the view that the private health system will deliver a better service to the individual and their family. These messages are endorsed by the medical profession, who wish to generate income, the governments who wish to contain the cost of the Medicare system, the insurance companies who want to increase business, and people with high incomes who pay for private medical insurance and want their Medicare contributions to be static. These messages are being resisted on the whole, as the *Australian* newspaper reports private health insurance is continuing to fall (Blue 1995, p.3). It tends to be the section of the public who are generally healthy, who are choosing to opt out of insurance schemes. I suspect that people who use the health service regularly, as do the chronically ill, would appreciate the cocoon of private health insurance but, as expressed earlier in the chapter, private health insurance is more complicated for chronically ill people. In many cases they will have to rely on the Medicare service—they do not have a choice.

Rural Australia—the New England region of New South Wales

*South of my days' circle, part of my blood's country,
rises that tableland, high delicate outline
of bony slopes wincing under the winter;
low trees blue-leaved and olive; outcropping granite—
clean, lean, hungry country. The creek's leaf-silenced,
willow-choked, the slope a tangle of medlar and crab-apple,
branching over and under, blotched with a green lichen;
and the old cottage lurches in for shelter.*

(Judith Wright)

It is relatively difficult to define 'rural Australia' (Humphreys & Rolley 1993, p.7; Johnson 1994, p.12). In 1989, the Commonwealth Department of Community Services and Health offered the following classification based on local statistics:

- capital cities
- other major urban (combined population exceeding 80 000)
- rural major (population over 20 000 in NSW and Victoria, 1 800 in Queensland, 14 000 in other states, or half these figures but density of population greater than 30 people per square kilometre)
- rural other
- remote major (areas which are more than a few hundred kilometres from a major urban area, or are separated by a major natural barrier)
- remote other
- other off shore areas and migratory (National Rural Health Strategy Committee 1991, p.45 cited in Humphreys & Rolley 1993, p.8).

The rural areas of Australia are disparate and anyone making general comments should do so with caution. Reid and Solomon (1992, p.26) object to the use of local statistics to classify areas. They maintain that topographical criteria for rural identification, such as population density, population size, and distance from urban areas, are limited because so many local variables (ie price of fuel, condition of roads, mode of transport, climate, and dominant occupation of the community) have a significant bearing upon the experience of remoteness or isolation felt by people in various parts of the country. In existential terms, a rich grazier with a light aircraft may be a great deal nearer to a city than someone living closer in kilometres but who travels on dirt roads, depends on the broken down 'ute' (utility truck) and has to budget carefully for funds to cover the cost of the fuel.

Humphreys and Rolley (1993, p.7) describe the following types of Australian rural areas:

In Australia, the pattern of rural settlement varies greatly between closer settled agricultural districts (characterised by horticulture and dairying), and areas of extensive agriculture and pastoral activity such as typify the remote inland regions and sparselands. Rural Australia also includes large regional centres, as well as declining service towns, monofunctional mining towns and dispersed farming families.

Tamworth is what Humphreys and Rolley would refer to as a 'regional centre'. The countryside on the Tablelands between Tamworth and Armidale is sparse and unattractive, the soil is not particularly rich, the grass is thin and brown, the scrub has been cleared and many of the gum trees which remain are badly affected by 'dieback'⁵. Armidale is a service town. It fares relatively well in these hard times because it is a regional educational centre with several boarding schools and a university. These institutions are an important source of income for many of the people in the town.

Despite the various definitions of rural, Cloke (1985) advises that the qualification of rural depends on the purpose of the researcher. In this case I am interested in the experience of people with chronic illness who happen to live in a rural area. The nature of rural living is brought home through the experiential accounts of the people who helped with the study. I have heard graphic accounts of the experience of rural living associated with chronic illness; accounts which include the problems of travelling long distances, isolation and fear when alone on 'out of town' properties, and difficulties finding the 'best' doctor. However there are also accounts which include the benefits of the beautiful *vistas*, the peace and quiet and the feeling of being at home with the land. The latter is a typically rural Australian characteristic noted by Humphreys and Rolley (1991, p.20). Perhaps a snippet from Sky's story will illustrate this point. The incident occurred as she was driving in fairly isolated country:

... and I was feeling terribly sad and—and sort of really depressed and thinking about all this sort of stuff [her problems]. And I looked out at the land; I was looking at all this land and it was just bare. It...it had been literally raped, that land, you know. The trees had just been ripped off it and I was thinking about this land and I was thinking about my own body and the things that had happened to me and ...[pause]... I just suddenly felt this complete affinity with the land ... I wasn't just alone, I was part of something greater. And that was extraordinary—that was just a really extraordinary experience.

(Ua:408–427)

The New England region stretches up along the part of the Great Dividing Range in the north of the state, from Tamworth in the south to the Queensland border in the north. It is an inland part of the country about two hundred kilometres from the coast. From the Pacific Highway⁶ there are only a few bitumen roads that wind up the steep escarpment of the New England mountain range to the Tablelands.

⁵Dieback is a condition which has several causes, including excessive clearing of bush and it results in trees becoming progressively lifeless. Australian plains are starkly dotted with the skeletons of affected trees.

⁶The Pacific Highway is part of the National Coastal Highway and links Sydney to Brisbane.

As mentioned before, the people who helped with this study all live in the New England region. The people come from small holdings outside towns and from the cities of Armidale and Tamworth and the towns of Uralla and Guyra. While Tamworth and Armidale are relatively large cities with populations of approximately forty thousand and twenty-two thousand respectively, Uralla and Guyra are small towns with populations of approximately two thousand. I have experienced the size of these towns in the following ways. Tamworth is relatively large with a Myers department store, a shopping plaza, an airport and a base hospital⁷ and it is well known throughout Australia as the ‘Country and Western Music Capital of Australia’—there is a large festival each year which culminates on January 26, Australia Day. Armidale is smaller; it has two sets of traffic lights, a small district hospital with an emergency department plus 80 beds, three food supermarkets and no cinema. Uralla has a post office and a main street lined with small stores, two hotels (the ‘top pub’ and the ‘bottom pub’) but no supermarket or hospital. Guyra is similar to Uralla with approximately the same amenities, with the exception of a hospital which is linked to Armidale Hospital and provides a service for local people requiring long term or emergency care.

Unlike the major cities, in rural areas private hospitals providing acute care are scarce. The New England region has one small acute private hospital. Private and charitable nursing homes for the care of the elderly and chronically ill are common, however. This provision of mainly extended care facilities is a feature of rural communities. Indeed some of the beds in the smaller public hospitals have been converted to extended care facilities. Acutely ill people tend to be transferred to the nearest base hospital for ‘high tech’ treatment which is not possible to provide in the smaller towns. On the whole, the reason for the participants in this study being admitted to hospitals far away from their homes was because that was where their specialist had admitting rights. In this study most participants were hospitalised in Sydney. Except in the case of a person who had transplant surgery, the location was related to the specialist physician’s admitting rights and attendance rather than a lack of local facilities. (By ‘local’ I refer to Tamworth, which is within a two and a half hour drive from all the participants’ homes.)

In the last three years Australia has been gripped by the worst drought in memory. The effect on the landscape and the rural population has been impressive in terms of its pervasive rancour. New England has been affected badly. The land is parched, dams are empty, creeks are dry, revealing only cracked mud beds, and the sheep and cattle are pathetically lean. They graze along the roadside—the ‘long yard’—searching for a last morsel of fodder, making hazards of themselves for passing motorists at twilight. On the

⁷A base hospital is the traditional New South Wales name for the larger hospital situated in rural towns. Nowadays the best equipped base hospitals are in the regional centres of Wagga Wagga, Tamworth and Dubbo.

outskirts of towns the kangaroos and native animals are more visible than usual. They come in from the bush to look for water and grass; their carcasses line the roads. Although farms are the most directly affected, businesses in urban centres are also feeling the pinch; days of rain are universally welcomed—no one ever complains of wet weather. There is a national concern for the rural plight. Appeals to help graziers caught in the drought are generously supported and news of the drought situation is a regular feature on the national media networks.

Australians are used to cycles of drought but this one has been particularly harsh and long. It is the worst one experienced this century. It has ruined the smallholders and newholders who tend to have debt and no years of plenty to bolster them through these lean times. It has sobered the graziers with the largest properties, who can probably last out until the drought breaks, but whose incomes are reduced. The graziers' hardship has the spin offs of reduced local employment and lower spending in the rural urban centres. The predicament folds a familiar feeling of worry around the entire community.

The drought has become the scapegoat for the 'rural plight'. Many graziers, mostly the family farmers, will never recover, even if the weather improves and rains are plentiful. Their weather problems are compounded by the falls in commodity prices and rises in the cost of farming equipment and supplies. In the 1980s the graziers were advised to 'get big or get out'. Many families borrowed money and bought extra acres which became millstones around their necks when the interest rates rocketed. Seventy per cent of agriculture production is from the really big land holders: it is these companies who have a future and will continue to expand. The days of the 'family farm', as it is known now, are nearing an end. It is a threat which will not be halted by a good rainfall. As the saying goes: times are tough for farming communities—but then they always have been (Wahlquist 1995, p.13).

To add to the problems brought about by the drought, in January 1994 New South Wales had bush fires which destroyed a major part of the state's natural bushland. The infernos killed people and animals, leaving ruined lives, homes and towns in their wake. The ability of the land to regenerate after such natural devastation is likened to the tenacity of the Australian rural community, which has the ability, so myth has it, to survive and recuperate after recurrent hardship. Most rural people I know would say there is little choice when times are hard. The people in this study often mentioned that life is hard in the country anyway and being ill makes it harder. But then almost everyone is hard up; they do not, on the whole, expect special help from the community. Healthsharing Women (1994, p.97), a group of women writers who provide health information for women, make the point, when discussing family violence, that rural communities are well known for neighbourly support in times of 'community emergency'. However, the same

effort is lacking when the emergency is of a personal and family nature, as in violence or, I would suggest, chronic illness. This is also the experience of people in the study.

Many of the people in hard hit rural areas are heading for the cities where they can hopefully find work and, sadly, this is particularly so with the younger generation. The average age of the farmer is rising, as few children wish to take over the burdensome responsibilities of modern farming. This migration depletes the rural areas of population which makes it difficult to maintain community life and weakens the arguments for maintaining public services.

Rural people can be defensive when 'townies' and 'greenies' criticise their land management practices, expecting them to conserve and preserve but, at the same time, to produce more and more. There is a feeling that they are being controlled by people who have no experience of real rural survival and who do not understand their way of life. The people with whom I came into contact were well aware of the fragile environment. The soil on large parts of the Tablelands is shallow and although the bush has been cleared ruthlessly, the land is not really suitable for grazing cloven-hoofed stock. Sheep rip out the grass by its roots and both sheep and cattle pummel the dry ground with their hooves until it becomes as hard as rock. Farming practices are changing but, as incomes are at stake, progress takes a slow forward course.

The rural Australians are quick to note inequalities between the cities and rural Australia. They wryly remark that NSW stands for Newcastle, Sydney and Wollongong. This 'joke' serves to highlight what is seen as an unfair concentration of interest and government resources on city dwellers. Jane, one of the participants, remarked:

... I don't think that the doctors realised that there's [a] part of the state north of Hornsby.⁸ They don't realise, you know, that people come from further away than that ...

(Vb:329–332)

Time and space are experienced quite differently by people in the countryside. Rural people are used to wide open spaces, large skies and fresh air. They laugh when I consider one hundred kilometres from town is a long way. And yet they are careful to plan trips to town because forgotten items or chores cannot be returned for easily. Distance from town is not measured in kilometres but rather by how long the round trip is, what kind of car you have and the cost of the petrol. Driving on dirt roads for miles⁹ is uncomfortable but the discomfort is magnified when the person is in pain or feels

⁸Hornsby is a northern suburb of Sydney.

⁹Although Australia uses the metric system many people still refer to miles especially if they want to convey how far they have travelled.

nauseated. A trip to town can mean a grazier loses a day's work. A trip to the city can mean days away from work.

It was interesting to note the different experiences of the participants in the study when travelling to Sydney to see a specialist or to have hospital care as there were some harrowing experiences. Experiences included extreme physical discomfort (pain and nausea while travelling, sitting waiting for appointments, staying in basic accommodation and using public transport), loneliness, fear and worry. Some participants fly to Sydney; however flights are expensive which usually means that a partner cannot afford to accompany them. It also means that they do not have private transport in the city—rural people are not used to travelling on public transport, nor indeed the vagaries of metropolitan systems. If they travel down by car or coach, a day is required either side of the appointment to travel and accommodation is needed for two nights. I am told that the stiffness created by sitting for several hours is excruciating when you have arthritis and the nausea induced by the monotonous motion and exacerbated by analgesics is almost unbearable.

It is these kinds of experiences that give meaning to the space between New England and Sydney rather than criteria such as measurements of cost and kilometres. An appreciation of these experiences can only be extrapolated by hearing accounts from chronically ill people who have to make these journeys 'for their health'.

Australian rural health issues

The various Australian governments are aware of the well founded accusations of inequalities in health service provision throughout the country. This is in Aboriginal health, in the health of people with non-English speaking backgrounds, those in lower socio-economic groups and the health of people living in the rural areas of Australia. The subject of rural health services is now a recurrent topic of national concern, in both rhetorical and concrete terms. However as Malko (1993, pp.3–4) points out, since the current recession rural communities no longer command a strong economic position in Australia and consequently the status and power the people once had in the country is diminished.

In terms of health care services (access to hospitals, doctors and specialist treatment) rural communities are disadvantaged compared to city dwellers. In the capital cities people have ready access to a wide range of health services (Humphreys 1988; Humphreys & Rolley 1991, 1993; Moss & McMichael 1990; Malko 1992; Palmer & Short 1994). However it is doubtful whether introducing, or in some cases re-introducing, services that equal those available in the cities would significantly improve the health of rural people.

Investigations are under way to assess and plan health services for the rural and remote areas of Australia according to the population needs (Humphreys & Rolley 1991, 1993). However when examining the experience of chronically ill people, it should be noted that compared to their counterparts in the city, rural people with chronic illness have considerable problems. The main problems appear to be accessing their doctors, choosing a specialist and making long, expensive and usually uncomfortable journeys to the city if they wish to consult the specialist of their choice. The current trend for policy makers to focus upon health promotion further disadvantages people who are already ill and face years of needing medical attention. It is unlikely that any extra resources given to the rural areas for health services will be spent on improving specialist medical services to anywhere near the city standards.

The problems referred to above which rural chronically ill people encounter are compounded if these people are from the lower socio-economic groups. There is a scheme to pay for travel to the cities (the isolated patient travel and accommodation assistance scheme) but this is paid out on a discretionary basis and usually reserved for acute episodes and hospital admission. A copy of the details supplied by the Social Work Department of the New England Tablelands Health Service is attached as Appendix 1. It is obvious from the form that chronically ill people will not benefit much by the scheme and the amount of administration is probably not worth the remuneration in some instances; for example, note that an escort must be 'medically' necessary (p.2). Travelling alone when constantly feeling ill and tired is extremely difficult and most of the people I was with would not consider the journey to Sydney without a companion. Assistance with air travel is only awarded for a 'life or death' situation (p.2). Amongst the people who helped me with this study, only one of them drawing a pension benefited from the scheme (Elizabeth was given assistance with two journeys a year to Sydney by train); two other pensioners, Peggy and Jim, were referred to specialists in the local town. In the case of Paul, he reluctantly decided to pay for a private consultation and surgery, and therefore had to pay for his own transport to Sydney for surgery despite being unemployed for two years. To pay for this treatment he had to borrow four thousand dollars from a friend—he was unable to raise a loan from any of the banks. Interestingly, Pam, who is physically disabled, has no trouble getting free transport.

In response to the evidence and the commitment of the Australian governments to social justice (Theophanous 1993), several initiatives were set up to address rural health problems in the late 1980s. One of these initiatives was the Rural Health Alliance, consisting of a range of health professionals and some consumer representatives, which was inaugurated in order to develop a National Rural Health Strategy. The areas to be addressed were identified in an overview of the National Rural Health Strategy presented

at the 1st National Rural Health Conference held in Toowoomba in February 1991. They were:

- identifying the needs of rural and remote communities
- meeting the health needs of particular groups
- improving education, training and career development in rural practice
- overcoming disincentives to rural practice
- improving resource allocation mechanisms and rural infrastructure (Mara 1991, p.31).

It is laudable that the strategy focus is upon planning according to the needs of the community; needs which are based on the experience of people in the community rather than health service deficiencies. However this approach does bring with it enormous problems. A rural community is not an homogenous group so it is likely that the needs of individuals in the community vary widely. People who make decisions regarding needs have to balance an appreciation for the popular demand and a sensitivity to the requirements of minorities who are not particularly successful at forming groups or articulating their requirements.

The chronically ill were referred to in an overview of the first Rural Health Strategy which was presented to the National Rural Health Conference, Toowoomba in 1991. They were subsumed into the theme of 'Meeting Health Needs of Particular Groups' (National Rural Health Strategy Committee 1991, p.22). However the chronically ill are not referred to in the *National Rural Health Strategy* which was finally published three years later (Australian Health Ministers' Conference, 1994). Colmer (1992), when introducing this theme at the National Rural Health Conference in Toowoomba, identified a group of people with particular health problems. These people, he claimed, required a range of services from physiotherapy, speech pathology, diabetes education, genetic counselling, counselling, day care service and so on (1992, p.38). These services are available in both Tamworth and Armidale, although they were not used by many of the people in this study. Uptake of services is measurably lower in rural areas compared to urban areas (National Rural Health Strategy Committee 1991, p.16). The major problem experienced by the people in this study, caused by rural dwelling, is access to and choice of specialist doctors to direct their medical treatment and specialist services such as diagnostic equipment and specialist surgery.

In 1993 Ron Phillips, the then New South Wales Minister for Health, reported to the Rural Health Conference that the State government was spending eight hundred and seventy million dollars (\$870 000 000) on rural health; this figure represented a real increase of sixteen per cent since 1988 (Phillips 1993a, p.8). However he also warned that there could be no further increases in the near future, although in fact infrastructural

support to rural areas did increase after this time. In 1994 he reiterated his 1993 message. It would appear that for the time being rhetoric will have to suffice because there will not be enough revenue, in the foreseeable future, to create a health service in rural Australia which is on a par with the main cities. Indeed it would be difficult to justify such expenditure and yet these are the services that the chronically ill tend to require and have to travel to the cities to get.

Faced with an imperative to contain health care costs, the overall policies of the government in New South Wales over the past seven years of conservative power have been to introduce reforms based on privatisation, rationalisation, centralisation and to encourage a user-pays orientation. This has had dramatic effects on health services in rural New South Wales, meaning that existing services and personnel have undergone times of extreme change and re-orientation. It appears that when cost cutting exercises are undertaken rural areas are likely to fare badly because they cannot compete with the densely populated areas in terms of need for service or uptake of services. It could also be suggested that as rural areas have largely been safe conservative seats they have missed out on some of the resources that various governments offer as carrots around election time.

The closure of hospital beds (a rational cost cutting exercise), no matter what the reason, always sounds like 'the knell of passing days' for small towns and is resisted locally. People tend to equate rationalisation with hospital closures (or bed closures at the least) and reduction of services. All are seen as symbols of the decline of rural Australia and the insensitivity of the majority of the country to their concerns and difficulties.

Humphreys and Rolley (1993) found that rural people in their study valued their local hospital along with their GP most highly amongst health services, but they quote Copp's remark that (1976, p.32), 'People may demand hospitals when they really require preventive medicine, environmental protection, and improved nutrition'. The current focus on preventive medicine, however, is not particularly helpful for those people who are already ill and who face years of struggling with their illness. It is unlikely that we will begin to understand the needs of this group of people until they are given an opportunity to express what it is like to live with chronic illness and until the community as a whole view them and their experience of illness as valuable and as something that could befall any one of us in the future.

Conclusion

There is an interesting media message to the public in Australia which I think impinges upon the lives of people with chronic illness. There is a form of demographical nightmare

which is described repeatedly. The 'greying' of Australia is a term bandied about and the repercussions of this are reported in the following way: the labour workforce will shrink; larger proportions of the community will be dependent and the welfare system will not be able to cope on current funding. This picture of an increasingly dependent population has a 'knock-on' effect for the chronically ill as they are seen to swell the numbers of dependent people. The onus of policies are to care for the elderly (read also chronically ill dependent) people in homes (preferably their own) in the community. This means increased lay and family commitment to care. While people are reluctant to discriminate blatantly against the people who use the welfare system there is a mild hysteria about people bludging off the system. Besides feeling 'un-Australian' if they cannot beat it (their disease) people are made to feel that they are imposing a strain on a system which is barely coping.

The rural lifestyle on the Tablelands is seen to have many advantages and many of the inhabitants chose to set up home here. The climate is considered superior to inland areas where the heat can be intense, or the coast which is unpleasantly humid at times. There is little crime, no overcrowding, less competition, reasonable public services (schools and health care) and access to cities, either by air or bitumen road. The distance from the major cities does make life more difficult for people who are chronically ill. This is predominantly because access to services and doctors is seen as more difficult than in the towns.