

# Chapter 9

## Conclusion

*and this is the way the worlds end  
after space, after sense:  
not by the tin bowl, nor the Bomb  
But by Significance.*

(Les Murray)

### Introduction

A conclusion to an interpretive phenomenological study is a strange concept, for interpretations are forever susceptible to further interpretation. It is an evolutionary process which gradually draws in emerging ideas from an increasing range of perspectives. In the case of this study the interpretation is for the purpose of enriching the field of chronic illness. It would be pretentious and rather sad to suggest that conclusive points have been arrived at in this work. Rather, I see the meanings that the participants have revealed as contributions to the continuing search for better understandings of the experience of chronic illness. Then, in preference to a conclusion, this chapter is a junction—a place to join with other perspectives of chronic illness—a tributary flowing into the larger developing picture of the phenomenon. This study marks but an early stage in my continuing fascination and concern for people who have chronic illnesses.

From a practical standpoint, however, the thesis needs to draw to a close and morally there should be some practical point to the whole exercise. I told the people who participated in the study that I would use their stories to stimulate interest in chronic illness and perhaps improve their future illness experiences. In order to do that there needs to be some summary of the understandings generated so far in the study and some reflection upon them.

As this is a nursing study it was disappointing to find that nursing does not feature strongly in any of the participants' stories. In response to this dearth I will introduce my perspective to the vista and comment upon how I might have nursed the people who helped me with this work. Lastly, some evaluation of the interpretive process is necessary. This is in order to demonstrate my commitment to the responsibilities of a researcher by accounting for my research actions.

## **The significance of these understandings of chronic illness**

In line with interpretive phenomenology the everyday experiences of the people in the study have been examined and presented both in terms of unique individual stories and in terms of more general socially and culturally constituted situations which present themselves to all the people who share the predicament of chronic illness in this context. These are situations which, while they may hold similar meanings for people, may be responded to in quite different ways. The example which springs to mind is Sarah, because she understands the Australian tendency towards stoicism—which means that generally people are applauded for ‘suffering in silence’ or at the very least ‘not making a fuss’—however she chooses steadfastly to refuse to accept her predicament in this way and voices her difficulties whenever she feels it is necessary. She understands that this reaction at times causes her to be viewed as unusual and difficult by her family, friends and the caring professions.

The participants in this study were enthusiastic storytellers. They appreciated my time and attention. It occurred to me that they revelled in the chance to express themselves and to make an impression upon a listener. The participants’ narratives were, in general, descriptions and analyses of their lives and, in particular, of the experiences they had during the course of becoming and being ill. I was most struck by the need they all had to be reassured about their legitimate right to be considered chronically ill. The histories were peppered with stories which substantiated the severity of their symptoms and the changes in their lives. It appeared as if these symptoms and changes were quite likely to be doubted.

In a final process of making sense of the meanings generated from the texts *in this study* I have chosen to discuss the overriding impressions I gained when writing chapters five (case studies), six (histories), seven (lives) and eight (futures). This discussion reveals important messages about the ways in which people experience chronic illness. These messages could inform changes in the health care system and indeed in the approaches of health professionals that could improve the way in which chronic illness is experienced. This course is chosen rather than one of summarising and reiterating the points already made in the sequence of each chapter. This process represents another trawl of the texts (by now text includes the chapters in this thesis as well as the transcriptions and fieldnotes) and re-presentation of the interpretation of the experiences of chronic illness. It is a continuation of the dialogue with the texts that has already taken place; a dialogue which is essential to hermeneutical interpretation. The questions now relate to the notion of significance or, in other words, how might this relate to the understanding of chronic illness and the ways the people who experience life with chronic illness might be helped?

## **People's stories**

The value of people's stories cannot be over estimated. The health professional who is prepared to listen to a person's history will learn a great deal from him or her. I believe that the storytelling can be therapeutic for the person, it helps to order thoughts and establish what it is that matters to them. Several of the participants in the study commented upon how helpful it was to recount what had and what was happening to them. I remember Pam remarking how exhausted she felt after the first recording and how that feeling was tempered with a degree of satisfaction at being able to impress someone (fdnte:1.42).

Retelling a history helps people to impress the listener with who they are. It also gives the listener a clearer view of the significance of the illness upon people's lives in terms of the changes that have occurred and what has been lost or missed in their lives as a result of illness. Descriptions and stories of what they do and the situations in which they find themselves give the listener an idea of the personal struggle each person endures, how much the person is able to still contribute in life and where s/he is receiving help. Reflections upon the future in people's narratives demonstrate what worries them and where they might find some peace with their illness.

These stories are the most important way that someone can really get to know another. These accounts could be appreciated more by health care professionals generally. There are other ways of gathering these details besides sitting down for hours with a tape recorder. One of the advantages of chronic illness is that there is time for professional relationships to develop at a comfortable pace. The stories can be gathered in a range of different ways. What is important is that their significance is understood and appreciated.

## **Professional care and professional treatment**

Medical professionals may choose not to become involved with problems which were not directly associated with the diagnosis or treatment of the disease process. However these problems often caused people the most distress. There was a dearth of care given to these people by health professionals. One important difference between care given by friends and family and that given by professionals is that professional care does not have to be reciprocated in the same way that is considered the norm in relationships with friends and family. It provides an opportunity for the person to receive care without having to feel beholden or guilty (demeaned). Considering the amount of worry the participants had about becoming a burden or a nuisance to other people, it would appear that care that was given without the need to reciprocate would be most welcome.

The point is, treatment without care is poor and in some instances ineffective. This was particularly evident in the instances where participants suffered with depression and were

only treated with anti-depressants. By 'care' I mean professional concern *for* the person which incorporates a desire to help the person by understanding what it is that matters in his/her life. Care is for the entire person (rather than relating it to specific signs or symptoms of the illness) and involves knowing and understanding the person's predicament and all the problems which serve to make his/her life difficult. From the stories the participants gave of their experiences it is noticeable how other problems, such as ones concerning work, self-esteem or relationships, serve to make them just as uncomfortable as the symptoms of the illness. Treating only physical problems is not an efficient way to help people who are chronically ill.

Often there is not the opportunity to discuss these problems in the doctor's surgery. In some cases I wished that the health professionals could see the participants at home, as I did. Considering people's problems in context is very revealing. Peggy did not receive visits from health professionals at home and yet she desperately needed people to understand and appreciate her and particularly the problems she encountered at home.

### **Travel to consultations**

The significance of this problem is accentuated for rural people who have such large distances to travel to the major cities to keep appointments with their specialists. However to some degree it is pertinent to city people living in the suburbs needing to consult specialists too. This is especially so as transportation in the cities becomes problematic.

On the one hand, the participants in this study appreciated the services of the specialist of their choice, but on the other they did find the resulting journeys for consultations arduous. While some specialists do fly up to the rural cities, they are not a large enough number that the patients have the type of choice their counterparts in the city have or that they would prefer. Most chronically ill people would benefit from better organisation and consideration by staff in the consulting rooms and some could be helped with monetary benefits which cover the cost of travel for them and a companion. It does not appear to be within the working remit of the general practitioners in this study to inquire after the experiences patients have when travelling to see consultants in the main cities or indeed to ensure a smooth journey for the patient.

### **Attention and interest**

It appears that the participants needed to impress their families, friends and the medical profession in order to receive sympathy or help to cope with the everyday struggles associated with being chronically ill. This is in contrast to people who are acutely ill for they do not have to solicit attention nor do they find it difficult to maintain other people's attention. People with long term illness tend to be aware that they become boring as the

condition endures so far past its first impact. Each of them appreciated time to tell their story to someone who was genuinely interested in them. Listening to people who have chronic illness and being interested in what they have to say is a courtesy which makes a difference to their lives. Health professionals, friends and family would do well to consider this idea.

### **Continuity of professional health care**

It was striking that the best relationships between doctors and patients were the ones that had endured over time. It was apparent how important it was that the participants were known and appreciated as worthy people who had an interesting story to tell. Their complaints and symptoms are often complex and are best understood against the background of their whole lives and histories. I believe that these relationships are worth equal amounts of effort on the part of the patient and the doctor. There were examples in the study of doctors remaining with patients (eg Elizabeth's general practitioner) and patients remaining with doctors (eg Zoe with her general practitioner). This type of effort pays dividends in terms of helping to build the working relationship between the doctor and the patient.

### **Nursing**

There are only three instances where participants talk about nurses. Alan refers to the nurses worrying about his condition when he was admitted to hospital with cardiac failure (La:284–291). Peggy notes how over the years nurses have shown no particular care for her (Nc:15–22). Lastly, Sarah comments in a negative way about some nurses' attitudes towards pain control and their reluctance to temporarily relieve her of the responsibility of controlling her own illness (Xa:402–410). These comments relate to the times when she is in hospital and demonstrably tired of the struggle associated with being ill for a long time (Xa:504–507).

As already intimated, people with chronic illness require professional health care as well as professional health treatment. Throughout the texts the participants constantly refer to medical opinions and expertise. They relish the doctor's time and attention and remember and recount things that doctors have said to them verbatim. They still acknowledge members of the medical profession as the experts (although this respect can wear thin on occasions) and pin their hopes for improvements, or even cure, upon them. The participants were most appreciative of doctors who showed them humane concern and care in conjunction with medical expertise.

Although it is not quite as clear cut as presented here, generally, the participants require two things from doctors. These are medical acumen and humane qualities. When they

talk about the doctors whom they *appreciate*, mainly for their medical acumen, they are able to describe their medical skills in terms of their knowledge and ability to make a correct diagnosis and contain the course of each person's disease process (the exemplar here is Alan and his consultant cardiologist, Jimmy). It has already been established how important it is to have a medical diagnosis in order to understand the impact of the illness. When the participants describe doctors whom they *like*, mainly for their humane qualities, they talk about a range of things: the doctor's manner with them; the relationships they have formed; the reciprocity (Elizabeth makes patchwork quilts to help with fund raising on her consultant's unit); the communication, shared emotions, tears, humour and worries; the respect they feel for each other as human beings and the ability of the doctor to understand how they feel (Elizabeth's general practitioner comes closest to the portrait of a likeable doctor) (Ia:626–647). These are not totally distinct categories because whether doctors are appreciated for their medical skills or not is, to a certain extent, dependent upon their humane skills and vice versa. What does come across in the texts is the importance placed upon medical help. The value that is placed upon medical attention accentuates the disappointment chronically ill people tend to feel when they are let down by the medical profession.

Most of the people had a relationship with at least two doctors, one a general practitioner and one a specialist. If between them these doctors could meet the criteria for appreciation of medical skill and likeability then the person could rub along quite well in terms of medical relationships. Certainly Colin has found this combination with his general practitioner and specialist (fldnte:1.98). What was interesting was that they were unlikely to like and criticise their doctor at the same time. As was often the case, Sky was the exception to this rule. She sees the doctors as fallible human beings. She often said derogatory things about the doctors' social skills and their medical acuity but she was still capable of appreciating them when they did the right thing for her. She could also see that sometimes when her general practitioner was affable it was not necessarily a good thing for her health (Ua:340–345). She picked up the impression in these cases that she and the doctor were just two friends bumbling along together in the dark. This is a situation that is not particularly reassuring.

The problem is that the caring side of the medical service is ad hoc. Whether the doctor demonstrates caring concern for the patient or not is dependent on the individual doctor's make-up rather than on a professional commitment to caring as an integral part of therapy (as it is in nursing) (Watson 1985, 1988; Walters 1994c; McMahon & Pearson 1991). Professional *care* is not the main thrust of either the general practitioner's or the specialist's service. Indeed the structure of their service is not geared to offering care beyond the hurried and fairly superficial level of social niceness. Even in Elizabeth's

case, her general practitioner's genuine friendship, care and concern is not therapeutic in terms of addressing and helping her work through her problems. Medical appointments, set in surgeries or consulting rooms, are hardly conducive to getting to know the person. Home visits are extremely rare and yet they have the potential to inform professionals about the person and their life. It is likely that people feel more comfortable in their home surroundings and may be more likely to express their problems and needs. Such familiarity is a pre-requisite to care over a long period of time. Besides the strange environment, medical consultations are usually as brief as possible and charged for in cash. The brevity and location of consultations, with the focus of medical attention upon the disease process, combine to make communication and a resulting therapeutic caring relationship more difficult.

From my perspective I believe there are gross gaps in professional care for the people I talked to in this study. For instance, Colin does not describe any attempt which has been made by a health professional to ascertain how he is coping generally or how he has been personally affected by the onset of Parkinson's disease (this is even after he has been recognised as depressed and commenced on anti-depressant medication). His medical care might be deemed reasonable—he has been started upon and stabilised with anti-Parkinsonian drugs and is improving physically. Certainly Colin is not complaining, but maybe this is because he does not know what other things could be done to help him.

It would be reasonable to suggest that these people's initial diagnoses are in a predominantly medical domain and indeed that their subsequent treatment trajectories are dealt with best by the specialist consultant physicians. These experts are the people who know the most about particular diseases and the latest treatments. Above all their service is regarded as important by the people in this study who have chronic illness. However, looking at the arrangements of medical care from a nursing perspective, I would question the effectiveness of many of the general practitioners who are generalists and who rely upon and are guided by the specialist medical expertise of consultant physicians and surgeons. They follow these experts' instructions but fail on the whole to care for the person in terms of their general and holistic wellbeing. Either the general practitioners need to extend their services and change their working practices to incorporate professional care alongside their professional medical treatment or perhaps nurse practitioners could work with people with chronic illness in collaboration with the specialists, thus providing an 'all round' caring and treatment oriented service to clients and their families.

I was deeply moved by all the participants in this study. All of them were generous with their time and told rich stories about their illness experiences. I was initially surprised how involved I became with them and how much I worried and cogitated about some of

them for long periods after I had visited them. This lingering concern was far greater than I remember experiencing for patients I had nursed in various areas of general hospitals throughout my career. This former comparative peace of mind was despite a commitment to listening to patients in hospital and providing continuity of care within a primary nursing system. I began to realise that the depth of involvement with the research participants came about because of the amount of time I spent listening to them intently (even though I encouraged people on the wards to express themselves, it was rare that I could listen for over three hours to them) and by visiting them at home and becoming involved with their families in their own surroundings.

As a researcher I was behaving in ways that Ersser (1991, p.54) described nurses do as therapists. However I had the added luxury of having plenty of time and was able then to give my best attention, particularly in the ways I presented myself to the participants, the ways I stayed with them listening attentively and some of the things I did to help them (information giver, listener, comforter). It appeared to me that the participants who worried and concerned me required more help than they were getting and that there were gaps in the health service which meant they were being neglected. One of the reasons they stayed with me (metaphorically) and worried me was that I was not in a position to help them as much as I would have liked. I was not there officially to nurse them and as I was only with them for a limited time, care had to be taken not to set up a service which would disappoint people when I withdrew. I will give just some examples of participants who might have benefited from professional or nursing care.

### **Linda**

Superficially Linda made little of her problems and yet her untreated epilepsy was serious. I suspect that she telephoned me in response to the newspaper advertisement because she needed to share her concerns with someone. I was shocked at how she could have slipped through the medical net in this way. She had escaped treatment for epilepsy, and thereby the need to make difficult adjustments to her life, for twenty years. She is now beginning to pay the price in terms of more frequent grand mal fits and the dawning realisation that she may have to accept medication and give up her driving licence. She is beginning to understand how she has jeopardised her health and maybe even her life. These are extremely difficult things to come to terms with and the decisions she is now making are crucial. She should be able to turn to professionals for help without feeling that control will be wrested from her or that she might be judged harshly for her behaviour. She could be helped to examine her life and reflect how various events, people and situations affected her and influenced the responses she has made to her health problems. Most painfully she might consider how through her own behaviour she has, and is still, harming herself. She needs to be able to discuss the various options which are



available which may make it possible for her to be treated for epilepsy with the least amount of disruption possible to her own and her family's life. She needs to be able to face the future realistically.

I am not sure Linda would have told me so much if I had been visiting as a nurse. She told me what she did because I had assured her that what she said was confidential. I have an inkling that Linda may be one of the exceptions (most of the participants would readily accept some nursing input to their care) as she would have avoided a therapeutic relationship with any health professional precisely because they may have been able to uncover her secrets by showing care—her strategy has always been to avoid therapy and to date she has been successful. Even so, her need to talk to someone was strong.

### **Elizabeth**

Elizabeth gets some care from her general practitioner and the specialist who have now to contemplate the possibility that she also has Crohn's disease besides rheumatoid arthritis and coeliac disease. However while the doctors pick up new diagnoses to explain her new symptoms she has problems which are not being considered. Her depression is not being dealt with in any way apart from medications. There are several problems from the past that she is dealing with and she certainly has fears about her future which she needs to be helped to work with. Her pain is not controlled, nor is it obvious exactly which disease, or combination of diseases, is causing the most discomfort. The medications she takes, which do not control the pain, are a mixture of analgesics, anaesthetic blocks, steroids and muscle relaxants. This medical cocktail with methotrexate means she is probably right that she is poisoning herself. It compounds her depression, nausea, and vomiting, makes her overweight and affects her complexion and skin, generally. As has already been discussed Elizabeth is difficult to help. She is just the sort of complicated and challenging person who needs to be worked with gently, with no rush. In classical medical terms she would be termed a 'poor historian'. For the research she told wonderfully detailed stories about her life and illness but this amount of detail is not the best way to impress doctors and get through to them what is wanted. As a nurse, I could have helped her to sort out her ideas and rehearse the best way to re-present herself in order to get what she needed when visiting the doctor.

### **Peter**

Peter was another of the participants who worried me. It was not difficult to get him to talk about his misery and yet it appeared that no professionals were helping him. I suspect his sexual frustrations, when expressed, make him an unpopular patient. This is not an uncommon problem among men with multiple sclerosis and he should have been referred for specialist help. He is too young and able to have secreted himself away as miserably as he has done without some offer of support and company. It is not only his own life

which is difficult because of his problems but also that of his mother. By his own admission he is often irritable with her (Kb:286–291).

### **Peggy**

My heart went out to Peggy. She could have done with so much help and her plight has been consistently ignored over the years. The only problems she is helped with are the physical symptoms associated with asthma and even these are not always responded to. She has complex problems which need to be dealt with altogether. I believe that to understand Peggy and her predicament she needs to be visited at home. She has to feel comfortable with the person and then she will tell them all that has gone on. It is only when a professional has heard her story and seen how she lives that they may have the insight to know how best to help her.

She learns quickly and enjoyed recounting to me tales of her newly learnt assertiveness with the general practitioner. I think that she could be taught more about peak flow recordings and the use of the nebulisers and steroids. At the moment she is wary of knowing too much because she sees it as another excuse for doctors to leave her to her own devices. Peggy requires some professional support when she is making decisions about changing her medications.

She is often frightened on her own and it does not appear that health care professionals are aware of this problem. This is a realistic fear as she lives out of town with only her young son for company. Some nights she struggles for hours with wheezing which is barely improved by the use of nebulised steroids and ventolin. When she is unwell in the winter she needs a nurse to visit her at home and help her to sort out her practical problems which she just cannot manage. She needs to make contingency plans for when she is unwell because those are the times she cannot muster the strength to help herself or arrange for help.

### **Paul**

Paul's backpain is improving. However, when he tells the story of his experience of backpain it is apparent that he has many unresolved problems which have perpetuated, stemming from the time he worked in the boys' prison. I believe that the recording sessions in this research and my unjudgemental manner were helpful to him. He is learning to express the hurt and guilt associated with those days. He would be likely to benefit if he decided to have counselling.

### **Ruth**

Ruth worried me too. She has a deep sadness which she chose not to share with me. She also has to contend with a life which is becoming progressively more difficult to manage

and she is painfully aware that she is losing a grip on it. She has some tussles with her children and has chosen to deal with them firmly. She does not appear to recognise her own emotional lability and blames the children for all the altercations. She has reduced the home help although whenever I looked around the house there was a lot of work that could be done. I did not get to know her well enough to decide how I might have helped her, but in the first place, as her nurse, I would have maintained contact and demonstrated my regard for her and acknowledged her difficult position. I would have tried to learn more about her and understand her, her problems and the family dynamics. I am sure that her life could be lightened to some degree if only someone would stay with her and in due cause help her to work through some of her problems.

### **Dr Craig**

Dr Craig needed a nurse, someone he could talk to about his uncontrolled blood sugar levels and diminishing eyesight. At the moment the fear of having to start insulin is really bothering him. He does not share his fears with his general practitioner because he knows this is the doctor who will make the decision about the insulin therapy. He needs to talk realistically about his future—at the moment he is concerned that he will become dependent and require either his wife or family to nurse him. These fears could be allayed to some extent with sensible and straight information.

### **Summary**

While it is true that I spent more time with these people than most nurses would be able to, I knew them and got to know them over a relatively short period of time. A nurse who worked consistently with a number of people with chronic illness would learn their stories over a longer period of time and could be just as effective in coming to know them. Indeed, the time available means that it is possible for professionals to develop a therapeutic and caring relationship. The participants in this study required *attention, time and continuity of health care service*. They were not receiving this care from doctors no matter how nice or caring they appeared to be.

## **Evaluation of the research process**

The method cannot transcend the talent or the moral character of the interpreter but when the canons of textual evidence and consensual validation and dialogue are followed, a citizenry of critical readers and practitioners can discern better and worse interpretive accounts and better and worse ways of articulating common everyday taken-for-granted understandings. Practice then will have gained a way to influence and shape theory more directly and effectively (Benner 1994b, p.124).

Benner sums up well the imperative for the interpretive phenomenologist to balance the need to be creative and spontaneous and the need to produce an interpretation which is

plausible and which can be judged to be a 'good' or 'better' interpretation. In similar vein I have chosen tentatively to review and evaluate the research process using Madison's (1990, p.28) normative process of evaluation for interpretive research. By use of the concept 'normative' he introduces a note of rationality and reasonableness into the process. He writes:

... if by method we mean a system whose purpose it is to orient action. Method in this second sense can be defined as a rational discipline which formulates the norms for a certain procedure. Or, again, it is a norm-governed way of doing something (in distinction from arbitrary, whimsical behavior) (Madison 1990, p.29).

Relying heavily upon Gadamer's (1994) text in *Truth and Method*, Madison (1990, p.29) proffers some 'methodological principles' to guide the evaluation of a piece of interpretive research.

### **Coherence**

*The details and parts of the interpretation should be in harmony with the total picture depicted in the texts.*

Throughout the work, reference has been made to the exact place in the text where ideas have been revealed in order to demonstrate how understandings are generated from the everyday worlds and actions of the people involved in the study. Through the technique of oscillating between the part and whole there is a regular referral to the total picture of life as it is experienced by the participants.

### **Comprehensiveness**

*The general gist of the interpretation should be in harmony with the total picture depicted in the texts.*

This principle is similar to the preceding one, but relates to interpretation as a whole. Adherence to this principle was maintained by constantly standing back from the emerging interpretation and referring to developmental ideas, intuitions and 'gut feelings' expressed in the fieldnotes.

### **Penetration**

*The degree to which the author or researcher is able to reveal understanding about the phenomenon under inquiry. That is, the interpretation does what the researcher initially sets out to do.*

The research question posed at the beginning of this thesis was concerned with the question *What is it like to live with chronic illness? or What does it mean to live with chronic illness?* Chapters five, six, seven and eight directly relate to the texts in which the participants offered their descriptions of life with chronic illness. The ensuing

interpretations represent the lives of the participants and demonstrate the struggles involved in coping with illness over a long period of time.

In order to maintain the ontological and existential nature of the work, I have avoided general statements or themes which may have satisfied this principle more completely. I chose to keep the work as near to the concrete experience as possible and traded this advantage with that of neat and precise answers. The concluding chapter of this thesis does not give a summary of the answer to the research question. The answer resides in the text of the last five chapters.

### **Thoroughness**

*This principle relates to the hermeneutical dialogue that the interpreter has with the texts and the degree to which the questions posed in the dialogue are answered.*

Throughout the thesis I have written down the questions that stimulated further investigation of the texts. As an interpretation can always be developed further there are certainly more questions and avenues of inquiry which could be productively perused with these texts.

### **Appropriateness**

*The degree to which the questions that are posed in the dialogue are stimulated by the participants' experiences rather than the researcher's own agenda.*

From chapter five, where the case studies are written and presented, lines for further inquiry were generated from the experiences of the participants. However it should be admitted that the researcher's own bias does creep in. The question *Where does nursing feature in the everyday experience of people with chronic illness?* was directly connected with my own prejudice. However I believe that this question was withheld until a late stage in the research and did not obscure or relegate the important meanings which were of most significance to the participants in the study.

### **Contextuality**

*This refers to the degree to which the context and situation of the participants is accommodated as a contribution to their total makeup and forms part of any understanding.*

The context and situatedness of the participants in this study is discussed in detail in chapter two. As a newcomer to the Australian way of life I was aware of some aspects of the culture that Australians may have taken for granted. The detailed histories that people gave me of their lives, which are re-presented in the case studies written up for all the participants, ensured that their backgrounds were an integral part of the interpretation of their texts.

## **Agreement (1)**

*The interpretation does not manipulate the meaning of the text.*

As much as was practically possible in the space of this thesis I have included direct quotes from the participants. This was done in order to substantiate and bring life to the meanings I was extrapolating from conversations with the texts. I was aware that once they were lifted out of their context the quotes could have been manipulated to mean things that suited my purpose. Careful coding of all the excerpts from the transcripts ensures that they may be audited.

## **Agreement (2)**

*The participants should agree with the interpretation.*

I have modified this principle slightly because Madison (1990, p.30) refers to the interpretation of literary texts rather than to research with living participants. Some of the meanings I have found in the texts were not overt and some of the participants were slightly surprised by my revelations. I was, however, always prepared to re-look at my work if they disagreed with it or had different ideas of their own. This was the case with Sarah's story in chapter eight. While I would not term this work a hermeneutics of suspicion, where the interpreter looks for concealed meaning in every line of the text, some of the delving behind overt statements was most constructive.

## **Suggestiveness**

*The degree to which the interpretation stimulates future work.*

Concrete recommendations are not an important part of this research because the main aim of interpretive work is to raise people's awareness of a particular phenomenon. However the improved understanding that I have of the world of chronically ill people has ensured that I am full of ideas for further research and changes which could be made in the field. These ideas are touched upon in this last chapter.

## **Potential**

The ultimate "validation" of an interpretation lies in the future. A given interpretation can be judged to be "true" if, in addition to meeting the above requirements, it (like a good metaphor or model) is capable of being extended and if in the process the implications it contains unfold themselves harmoniously (Madison 1990, p.30).

I am excited by this interpretation. I do believe that there is further research to be done in the area and certainly there are changes that I will incorporate into my nursing practice.

## **Conclusion**

Since doing this work with the people who helped me with the study, I have a better understanding of the nature of the experience of chronic illness. I can conjure up, through

remembering people's stories, how difficult the whole of their lives can be. I no longer wonder at how Ms Thorne got into the predicament she did because I can see both her part in it and that of the health care professionals involved, and I understand the implications of her social and cultural context in the manufacture of her state. I do have some ideas for preventing that kind of neglect and improving the lives of people with chronic illness. Hopefully, through the dissemination of this work, I may draw attention to the cause of the chronically ill and raise nurses' awareness of the experience of chronic illness, thereby alerting them to the gaps in professional care to the chronically ill and the exciting challenges they present to nurses.

These gaps relate to the care that chronically ill people receive from health care professionals. There is, amongst some chronically ill people, a craving for more time and attention and from my perspective I see a need for a service which provides continuity, that is, the patient has the same practitioner to help them over the years. Continuity of care ensures that partnerships between chronically ill people and either nurses or doctors can develop at a reasonable pace and that the knowledge they amass over time can be used to address problems together. I would have liked to have stayed and nursed each one of the participants in this study for there was a great deal of work we could have done together.

Finally, the important evaluative question which needs to be posed is, *Besides the author and participants, can the experiences interpreted and re-presented in this thesis be appreciated by its readers?* It has been my intention throughout the thesis to write as evocatively as possible (in van Manen's (1990, p.27) words '... to resonate with our sense of lived life'). The answer to this question is with its readers.

## References

- Allwood, C. 1989, Hermeneutics and interpretation in anthropology, *Cultural Dynamics*, 2(3), pp.304–322.
- Auden, W. 1966, If I could tell you, in *Collected Shorter Poems 1927–1957*, Faber & Faber, London, p.201.
- Australian Bureau of Statistics 1992, *Australian Demographic Statistics*, No.3101.0, AGPS, Canberra.
- Benner, P. 1984a, *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*, Addison-Wesley, Menlo Park.
- Benner, P. 1984b, *Stress and Satisfaction on the Job: Work Meanings and Coping of Mid-Career Men*, Addison-Wesley, Reading, MA.
- Benner, P. 1990, Response to hermeneutic inquiry, in *Advancing Nursing Science Through Research*, ed. L. Moody, Sage Publications, Newbury Park, pp.281–286.
- Benner, P. (ed.) 1994a, *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, Sage Publications, Thousand Oaks.
- Benner, P. 1994b, The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.99–129.
- Benner, P., Janson-Bjerklie, S., Ferketich, S. & Becker, G. 1994, Moral dimensions of living with a chronic illness, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.225–254.
- Benner, P. & Wrubel, J. 1989, *The Primacy of Caring: Stress and Coping in Health and Illness*, Addison-Wesley, Menlo Park.
- Blue, T. 1995, Health funds in 'critical' condition, *Australian*, 6 April, p.3.
- Bond, A. 1993, Consumer concerns, *Proceedings of the 2nd National Rural Health Conference*, University of New England, National Rural Health Alliance, Armidale, pp.21–24.
- Boyne, R. 1988, Interview with Hans-Georg Gadamer, *Theory, Culture and Society*, 5, pp.25–34.
- Brody, H. 1987, *Stories of Sickness*, Book Crafters Inc., Michigan.
- Bury, M. 1982, Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4, pp.167–182.
- Bury, M. 1991, The sociology of chronic illness: A review of research and prospects, *Sociology of Health and Illness*, 13(4), pp.451–468.



- Capra, F. 1983, *The Turning Point: Science, Society and the Rising Culture*, Fontana Paperbacks, London.
- Carr, W. & Kemmis, S. 1986, *Becoming Critical: Knowing Through Action Research*, 2nd edn, Deakin University Press, Geelong.
- Clarke, M. 1986, *A Short History of Australia*, illustrated edn, Penguin Books Australia Ltd, Sydney.
- Clinton, M. & Nelson, S. 1995, An overview of the Australian health care system, in *Management in the Australian Health Care Industry*, eds M. Clinton & D. Scheiwe, Harper Educational Publishers, Maryborough, Victoria, pp.1–52.
- Cloke, P. 1985, Whither rural studies, *Rural Studies*, 1, pp.1–9.
- Cohen, M. 1987, A historical overview of the phenomenologic movement, *IMAGE: Journal of Nursing Scholarship*, 19(1), pp.31–34.
- Cohen, M. & Omery, A. 1994, Schools of phenomenology: Implications for research, in *Critical Issues in Qualitative Research Methods*, ed. J. Morse, Sage Publications, Thousand Oaks, pp.136–156.
- Colaizzi, P. 1978, Psychological research as the phenomenologist views it, in *Existential-Phenomenological Alternatives for Psychology*, eds R. Valle & M. King, Oxford University Press, London, pp.48–71.
- Coleridge, Samuel T. 1950, The rhyme of the ancient mariner, in *My Favourite English Poems*, ed. J. Masefield, Heinemann, Melbourne.
- Colmer, P. 1992, Meeting health needs of particular groups, *Proceedings of the National Rural Health Conference: A Fair Go for Rural Health*, Toowoomba, Department of Health, Housing & Community Services, Canberra, pp.36–41.
- Concise Oxford Dictionary of English Etymology* 1986, Oxford University Press, Oxford.
- Conrad, P. 1990, Qualitative research on chronic illness: A commentary on methods and conceptual development, *Social Science and Medicine*, 30, pp.1257–1263.
- Copp, J. 1976, Diversity of rural society and health needs, in *Rural Health Services: Organisation, Delivery and Use*, eds E. Hassinger & L. Whiting, Iowa State University Press, Ames, pp.26–37.
- Corbin, J. & Strauss, A. 1987, Accompaniments of chronic illness: Changes in body, self, biography, and biographical time, in *Research in the Sociology of Health Care: A Research Annual*, eds J. Roth & P. Conrad, JAI Press Inc, London, pp.249–283.
- Cousins, N. 1983, *The Healing Heart: Antidotes to Panic and Helplessness*, W.W. Norton, New York.
- Crews, B. 1995, A selective safety net, *Australian*, 28 June, p.12.
- Curtin, L. 1990, Maria's choice, *Nursing Management*, 21(11), pp.7–8.
- Curtin, M. & Lubkin, I. 1990, What is chronicity, in *Chronic Illness: Impact and Interventions*, ed. I. Lubkin, Jones & Bartlett Publishers, Boston, pp.2–20.
- Dass, R. & Gorman, P. 1985, *How Can I Help*, Alfred A. Knopf, Inc., New York.

- Davis, A. 1973, The phenomenological approach in nursing research, in *Doctoral Preparation for Nurses*, ed. E. Garrison, University of California, San Francisco, pp.313–324.
- Dempsey, K. 1992, *A Man's Town: Inequality Between Women and Men in Rural Australia*, Oxford University Press, Melbourne.
- Denzin, N. & Lincoln, Y. (eds) 1994, *Handbook of Qualitative Research*, Sage Publications, Thousand Oaks.
- Descartes, R. 1962 (1637), *Discourse on Method*, trans. J. Veitch, Open Court Publishing Company, La Salle, Illinois.
- Diekelmann, N. 1990, Nursing education: Caring, dialogue, and practice, *Journal of Nursing Education*, 29(7), pp.300–305.
- Diekelmann, N. 1992, Learning-as-testing: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in nursing, *Advances in Nursing Science*, 14(3), pp.72–83.
- Diekelmann, N. & Allen, D. 1989, *A Hermeneutic Analysis of the NLN's Criteria for the Appraisal of the Baccalaureate Program*, National League for Nursing, New York.
- Diekelmann, N., Schuster, R. & Lam, S. 1994, MARTIN, a computer software program: On listening to what the text says, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.129–141.
- Dluhy, N. 1995, Mapping knowledge in chronic illness, *Journal of Advanced Nursing*, 21, pp.1051–1058.
- Donovan, J. (ed.) 1994, *Australia's Health 1994*, Australian Government Publishing Service, Canberra.
- Dreher, M. 1994, Dialogue: The democracy of interpretation, in *Critical Issues in Qualitative Research Methods*, ed. J. Morse, Sage Publications, Thousand Oaks, pp.44–45.
- Dreyfus, H. 1991, *Being-in-the-World: A Commentary on Heidegger's Being and Time, Division I*, Massachusetts Institute of Technology Press, London.
- Dreyfus, H. 1994, Preface, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.vii–xi.
- Dunlevy, S. 1995, The childcare sting, *Daily Telegraph Mirror*, 4 April, p.1.
- Dunlop, M. 1994, Is a science of caring possible?, in *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.27–43.
- Dyson, F. 1995, The scientist as rebel, *Australian*, 7 June, p.27–28.
- Ersser, S. 1991, A search for the therapeutic dimensions of nurse-patient interaction, in *Nursing as Therapy*, eds R. McMahon & A. Pearson, Chapman & Hall, London, pp.26–43.
- Faulconer, J. & Williams, R. 1985, Temporality in human action: An alternative to positivism and historicism, *American Psychologist*, 40(11), pp.1179–1188.

- FitzGerald, M. 1990, Autonomy for practising nurses, *Surgical Nurse*, (Dec), pp.24–26.
- FitzGerald, M. 1991a, Change in the ward, making things happen, *Nursing Times*, 87(30), pp.25–27.
- FitzGerald, M. 1991b, Educational preparation for primary nursing, in *Primary Nursing in Perspective*, eds S. Ersser & E. Tuttor, Scutari Press, Harrow, pp.49–61.
- FitzGerald, M. 1994, Lecturer practitioners: Creating the environment, in *Unifying Nursing Theory and Practice*, eds J. Lathlean & B. Vaughan, Butterworth Heinemann, Oxford, pp.55–70.
- FitzGerald, M. (in press), The practical implications of a critique of traditional science, *International Journal of Nursing Practice*, 1(1), pp.62–71.
- Fjelland, R. & Gjengedal, E. 1994, A theoretical foundation for nursing as a science, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.3–27.
- Frank, A. 1991, *At the Will of the Body: Reflections on Illness*, Houghton Mifflin Company, Boston.
- Frankl, V. 1985, *Man's Search for Meaning*, Washington Square Press, New York.
- Franklin, M., Short, L. & Teather, E. (eds) 1994, *Country Women at the Crossroads: Perspectives on the Lives of Rural Australian Women in the 1990s*, University of New England Press, Armidale.
- Gadamer, H. 1975, Hermeneutics and social science, *Cultural Hermeneutics*, 2, pp.307–316.
- Gadamer, H. 1987, Hermeneutics as practical philosophy, in *After Philosophy: End or Transformation?*, eds K. Baynes, J. Bohman & T. McCarthy, MIT Press, Cambridge, pp.325–338.
- Gadamer, H. 1994 (1960), *Truth and Method*, 2nd revised edn, trans. J. Weinsheimer & D. Marshall, Continuum, New York.
- Gelven, M. 1989, *A Commentary on Heidegger's Being and Time*, 2nd edn, Northern Illinois University Press, Illinois.
- Gerhardt, U. 1990, Qualitative research on chronic illness: The issue and the story, *Social Science and Medicine*, 11(30), pp.1149–1159.
- Giorgi, A. (ed.) 1985, *Phenomenology and Psychological Research*, Duquesne University Press, Pittsburgh.
- Giorgi, A., Fischer, C. & Murray, E. 1975, *Duquesne Studies in Phenomenological Psychology*, Duquesne University Press, Pittsburgh.
- Gordon, D. 1994, The ethics of ambiguity and concealment around cancer: Interpretations through a local Italian world, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.279–317.
- Guba, E. & Lincoln, Y. 1989, *Fourth Generation Evaluation*, Sage Publications, Newbury Park.

- Gullickson, C. 1993, My death nearing its future: A Heideggerian hermeneutical analysis of the lived experience of persons with chronic illness, *Journal of Advanced Nursing*, 18, pp.1386–1392.
- Healthsharing Women 1994, Women, health and the rural decline in Victoria, in *Country Women at the Crossroads: Perspectives on the Lives of Rural Australian Women in the 1990s*, eds M. Franklin, L. Short & E. Teather, University of New England Press, Armidale, pp.92–99.
- Heidegger, M. 1962 (1927), *Being and Time*, trans. J. Macquarrie & E. Robinson, Blackwell, Oxford.
- Heidegger, M. 1993, Letters from Heidegger to Marcuse, in *The Heidegger Controversy*, ed. R. Wolin, trans. R. Wolin, MIT Press, Cambridge, pp.160–164.
- Hekman, S. 1983, From epistemology to ontology: Gadamer's hermeneutics and Wittgensteinian social science, *Human Studies*, 6(3), pp.205–224.
- Hekman, S. 1984, Action as text: Gadamer's hermeneutics and the social scientific analysis of action, *Journal for the Theory of Social Behaviour*, 14(Oct), pp.333–354.
- Hekman, S. 1986, *Hermeneutics and the Sociology of Knowledge*, Polity Press, Oxford.
- Hekman, S. 1990, *Gender and Knowledge: Elements of a Postmodern Feminism*, Polity Press, Oxford.
- Helman, C. 1981, Disease versus illness in general practice, *Journal of Royal College General Practice*, 31, pp.544–552.
- Hinchman, L. & Hinchman, S. 1984, In Heidegger's shadow: Hannah Arendt's phenomenological humanism, *The Review of Politics*, 46(2), pp.183–211.
- Hoffman, R. 1993, *Tired All the Time: How to Regain Your Lost Energy*, Bookman Press, Melbourne.
- Hogan, E. 1994, Making women visible: Reflection on working with women in agriculture in Victoria, in *Country Women at the Crossroads: Perspectives on the Lives of Rural Women in the 1990s*, eds M. Franklin, L. Short & E. Teather, University of New England Press, Armidale, pp.31–37.
- Holden, M. 1994, Along the lane, in *Mustn't Grumble*, ed. L. Keith, The Women's Press, London, p.60.
- Holmes, C. 1991, Theory: Where are we going?, in *Towards a Discipline of Nursing*, eds G. Gray & R. Pratt, Churchill Livingstone, Melbourne, pp.435–460.
- Hood, T. 1972, I remember, I remember, in *The New Oxford Book of English Verse*, ed. H. Gardner, Clarendon Press, Oxford, p.619.
- Humphreys, J. 1988, Social provision and service delivery: Problems of equity, health and health care, *Geoforum*, 19(30), pp.323–338.
- Humphreys, J. & Rolley, F. 1991, *Health and Health Care in Rural Australia*, University of New England, Armidale.
- Humphreys, J. & Rolley, F. 1993, *Health Care Behaviour and Service Provision in Rural Australia*, University of New England, Armidale.
- Humphreys, J. & Weinand, C. 1991, Evaluating consumer preferences for health care services in rural Australia, *Australian Geographer*, 22(1), pp.44–56.

- Hunnex, M. 1961, *Chronological and Thematic Charts of Philosophies and Philosophers*, Academic Books, Michigan.
- Husserl, E. 1981, Phenomenology, in *Husserl, Shorter Works*, eds P. McCormick & F. Elliston, trans. E. Palmer, University of Notre Dame Press, Indiana, pp.21–36.
- Hutchinson, S. & Wilson, H. 1994, Research and therapeutic interviews: A poststructuralist perspective, in *Critical Issues in Qualitative Research Methods*, ed. J. Morse, Sage Publications, Thousand Oaks, pp.300–315.
- Illich, I. 1976, *Limits to Medicine*, Marion Boyars, London.
- James, K. (ed.) 1989, *Women in Rural Australia*, University of Queensland Press, St Lucia.
- Jastrzebska, M. 1994a, Friends, in *Mustn't Grumble*, ed. L. Keith, The Women's Press, London, p.131.
- Jastrzebska, M. 1994b, Letters between the editor and Maria Jastrzebska, in *Mustn't Grumble*, ed. L. Keith, The Women's Press, London, pp.198–205.
- Jastrzebska, M. 1994c, The horns of my dilemma, in *Mustn't Grumble*, ed. L. Keith, The Women's Press, London, pp.151–153.
- Jennings, J. 1986, Husserl revisited: The forgotten distinction between psychology and phenomenology, *American Psychologist*, 41(11), pp.1231–1240.
- Johnson, T. 1994, Rural people's experiences of critical illness involving interhospital transportation: A phenomenological study, Masters thesis, University of New England, Armidale.
- Jones, C. 1990, *The Search For Meaning: Book Two*, ABC Enterprises, Crows Nest.
- Keith, L. (ed.) 1994a, *Mustn't Grumble*, The Women's Press, London.
- Keith, L. 1994b, This week I've been rushed off my wheels, in *Mustn't Grumble*, (ed.) L. Keith, The Women's Press, London, pp.61–72.
- Kestenbaum, V. 1982, *The Humanity of the Ill*, University of Tennessee Press, Knoxville.
- Kleinman, A. 1980, *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine and Psychiatry*, University of California Press, Berkeley.
- Kleinman, A. 1988, *Illness Narratives: Suffering, Healing and the Human Condition*, Basic Books, New York.
- Kleinman, A., Eisenberg, L. & Good, B. 1978, Culture, illness and care: Clinical lessons from anthropologic and cross cultural research, *Annals of Internal Medicine*, 88, pp.251–258.
- Knaack, P. 1984, Phenomenological research, *Western Journal of Nursing Research*, 6(1), pp.107–123.
- Koch, T. 1994, Establishing rigour in qualitative research: The decision trail, *Journal of Advanced Nursing*, 19, pp.976–986.
- Koch, T. 1995, Interpretive approaches in nursing research: The influence of Husserl and Heidegger, *Journal of Advanced Nursing*, 21(5), pp.827–836.

- Kuhn, T. 1970, *The Structure of Scientific Revolutions*, University of Chicago Press, London.
- Kuhn, T. 1991, The natural and the human sciences, in *The Interpretive Turn*, eds D. Hiley, J. Bohman & R. Shusterman, Cornell University Press, Ithaca, pp.17–24.
- Lamb, C. 1962, The convalescent, in *Essays of Elia and Last Essays of Elia*, ed. C. Lamb, Dutton, New York, p.216.
- Larkin, J. 1987, Factors influencing one's ability to adapt to chronic illness, *Nursing Clinics of North America*, 22, pp.535–542.
- Lather, P. 1991, *Getting Smart*, Routledge, New York.
- Lawson, H. 1985, *Reflexivity: The Post-modern Predicament*, Hutchinson, London.
- Lazarus, R. 1966, *Psychological Stress and the Coping Process*, McGraw-Hill, New York.
- Lennon, J. & McCartney, P. 1967, A Little Help From My Friends, Northern Songs Limited, London.
- Leonard, V. 1989, A Heideggerian phenomenologic perspective on the concept of the person, *Advances in Nursing Science*, 11(4), pp.40–55.
- Leonard, V. 1994, A Heideggerian phenomenologic perspective on the concept of the person, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.43–65.
- Lim, A. 1995, Still riding the gale, *Sydney Morning Herald*, 29–30 April, p.12.
- Lincoln, Y. & Guba, E. 1985, *Naturalistic Inquiry*, Sage Publications, Beverly Hills.
- Macquarie Dictionary* 1991, 2nd edn, Macquarie Library Pty Ltd, Sydney.
- Madison, G. 1990, *The Hermeneutics of Postmodernity*, Indiana University Press, Bloomington.
- Madjar, I. 1991, Pain as embodied experience: A phenomenological study of clinically inflicted pain in adult patients, PhD thesis, Massey University, New Zealand.
- Magilvy, J., Congdon, J. & Martinez, R. 1994, Circles of care: Home care and community support for rural older adults, *Advances in Nursing Science*, 16(3), pp.22–33.
- Malko, K. 1992, Policy development in rural health, *Proceedings of the 1st National Conference of the Association for Australian Rural Nurses*, University of New England, Association for Australian Rural Nurses, Armidale, pp.33–40.
- Malko, K. 1993, Editor's introduction, *Proceedings of the 2nd National Rural Health Conference*, University of New England, National Rural Health Alliance, Armidale, pp.3–4.
- Mara, P. 1991, Presentation of the National Rural Health Strategy: Overview, *Proceedings of the National Rural Health Conference: A Fair Go for Rural Health*, Toowoomba, Department of Health, Housing & Community Services, Canberra, pp.31–32.

- May, K. 1994, Abstract knowing: The case for magic in method, in *Critical Issues in Qualitative Research Methods*, ed. J. Morse, Sage Publications, Thousand Oaks, pp.10–22.
- Mayerhoff, M. 1971, *On Caring*, Harper Row Publishers, New York.
- McDonald, M. 1992, *Put Your Whole Self In*, Penguin, Ringwood, Victoria.
- McMahon, R. & Pearson, A. (eds) 1991, *Nursing as Therapy*, Chapman & Hall, London.
- Mendelsohn, R. 1982, *Fair Go: Welfare Issues in Australia*, Penguin, Ringwood.
- Merleau-Ponty, M. 1956, What is phenomenology, *Cross Currents*, 16, pp.59–70.
- Milton, J. 1990, On his blindness, in *On Nursing: A Literary Celebration*, eds M. Styles & P. Moccia, National League for Nursing, New York, pp.66–67.
- Moccia, P. 1988, A critique of compromise: Beyond the methods debate, *Advances in Nursing Science*, 10(4), pp.1–9.
- Morowitz, H. 1981, Rediscovering the mind, in *The Mind's I*, eds D. Hofstadter & D. Dennett, Basic Books, New York, p.39.
- Morse, J. 1994, 'Emerging from the data': The cognitive processes of analysis in qualitative inquiry, in *Critical Issues in Qualitative Research Methods*, ed. J. Morse, Sage Publications, Thousand Oaks, pp.23–44.
- Morse, J. & Johnson, J. 1991, *The Illness Experience: Dimensions of Suffering*, Sage Publications, Newbury Park.
- Moss, J. & McMichael, A. 1990, Inequalities in health: The epidemiological evidence and the gap, in *A Textbook of Preventive Medicine*, eds J. McNeill, R. King, G. Jennings & J. Powles, Hodder & Stoughton, Melbourne, pp.253–268.
- Munhall, P. 1993a, Epistemology in Nursing, in *Nursing Research: A Qualitative Perspective*, eds P. Munhall & C. Oiler Boyd, 2nd edn, National League for Nursing, New York, pp.39–65.
- Munhall, P. 1993b, Language and nursing research, in *Nursing Research: A Qualitative Perspective*, eds P. Munhall & C. Oiler Boyd, 2nd edn, National League for Nursing, New York, pp.5–38.
- Munhall, P. 1994, *Revisioning Phenomenology: Nursing and Health Science Research*, National League for Nursing, New York.
- Murray, L. 1994, A skirl for outsets, in *Collected Poems*, ed. L. Murray, Heinemann, Melbourne, p.150.
- National Health Strategy 1991, *The Australian Health Jigsaw: Integration of Health Care Delivery*, No.1 Issues paper, Department of Health, Housing & Community Services, Canberra.
- National Rural Health Strategy Committee 1991, *A National Rural Health Strategy: A Discussion Paper for the Conference*, Department of Health, Housing & Community Services, Canberra.
- Newman, M., Sime, M. & Perry, S. 1991, The focus of the discipline of nursing, *Advances in Nursing Science*, 14(1), pp.1–6.

- O'Sullivan, E. 1994, Letter to Lois Keith, in *Mustn't Grumble*, ed. L. Keith, The Women's Press, London, pp.208–210.
- Oakley, A. 1993, Interviewing women: A contradiction in terms, in *Essays on Women, Medicine and Health*, ed. A. Oakley, Edinburgh University Press, Edinburgh, pp.221–243.
- Oiler, C. 1982, The phenomenological approach in nursing research, *Nursing Research*, 31(3), pp.178–181.
- Oiler, C. 1986, Qualitative methods: Phenomenology, in *New Approaches to Theory Development*, ed. P. Moccia, National League for Nursing, New York.
- Oiler Boyd, C. 1989, Clarifying the issues, *Nursing Science Quarterly*, 2(1), pp.16–18.
- Olson, C. 1993, *The Life of Illness*, State University of New York Press, Albany.
- Omery, A. 1983, The phenomenological approach in nursing, *Nursing Research*, 31(3), pp.178–181.
- Orminston, G. & Schrift, A. (eds) 1990, *The Hermeneutic Tradition: From Ast to Ricoeur*, State University of New York Press, Albany.
- Outhwaite, W. 1985, Hans-Georg Gadamer, in *The Return of Grand Theory in the Human Sciences*, ed. Q. Skinner, Cambridge University Press, Cambridge, pp.23–39.
- Packer, M. 1985, Hermeneutic inquiry in the study of human conduct, *American Psychologist*, 40(10), pp.1081–1093.
- Packer, M. & Addison, R. (eds) 1989, *Entering the Circle: Hermeneutic Investigation in Psychology*, State University of New York Press, Albany.
- Palmer, D. 1994, *Looking at Philosophy: The Unbearable Heaviness of Philosophy Made Lighter*, 2nd edn, Mayfield Publishing Company, London.
- Palmer, G. & Short, S. 1994, *Health Care and Public Policy: An Australian Analysis*, 2nd edn, Macmillan Education Australia Pty Ltd, Melbourne.
- Parker, J. 1991, Being and nature: An interpretation of person and environment, in *Towards a Discipline of Nursing*, eds G. Gray & R. Pratt, Churchill Livingstone, Melbourne, pp.285–308.
- Parse, R. 1981, *Man-Living-Health: A Theory of Nursing*, John Wiley & Sons, New York.
- Parse, R. 1987, *Nursing Science: Major Paradigms, Theories and Critiques*, W.B. Saunders Company, Philadelphia.
- Parse, R. 1992, Human becoming: Parse's theory of nursing, *Nursing Science Quarterly*, 5(1), pp.35–42.
- Paterson, B. 1891, Come-by-chance, in *Banjo's Waltzing Matilda and Verse Selections*, ed. A. Mahoney, Lansdowne Publishing Pty Ltd, Sydney, pp.20–21.
- Paterson, J. & Zderad, L. 1988, *Humanistic Nursing*, National League for Nursing, New York.
- Pearson, A. 1983, *The Clinical Nursing Unit*, Heinemann, London.



- Pearson, A. 1992, *Nursing at Burford: A Story of Change*, Scutari Press, Peterborough.
- Phillips, K. 1985, Song, in *The Oxford Book of Short Poems*, eds P. Kavanagh & J. Michie, Oxford University Press, Oxford, p.75.
- Phillips, R. 1993a, Keynote Address, *Proceedings of the 2nd National Rural Health Conference*, University of New England, National Rural Health Alliance, Armidale, pp.7–10.
- Phillips, R. 1993b, *Priorities 93–94, Commonsense for Today and Tomorrow*, No.(PA) 93–105, NSW Health Department, Sydney.
- Place, B. 1992, Living with chronic illness, *Proceedings of Extending Independence Conference*, Armidale, April 22–24, University of New England Press, pp.145–151.
- Poiner, G. 1990, *The Good Old Rule: Gender and Other Power Relationships in a Rural Community*, Sydney University Press, Sydney.
- Pollock, S. 1986, Human responses to chronic illness: Physiologic and psychosocial adaptation, *Nursing Research*, 35(2), pp.90–95.
- Ray, M. 1994, The richness of phenomenology: Philosophic, theoretic, and methodologic concerns, in *Critical Issues in Qualitative Research Methods*, ed. J. Morse, Sage Publications, Thousand Oaks, pp.117–133.
- Reason, P. & Rowan, J. (eds) 1981, *Human Inquiry: A Sourcebook of New Paradigm Research*, John Wiley & Sons, Chichester.
- Reeder, F. 1988, Hermeneutics, in *Paths to Knowledge: Innovative Research Methods for Nursing*, ed. B. Sarter, National League for Nursing, New York, pp.193–238.
- Register, C. 1987, *Living with Chronic Illness: Days of Patience and Passion*, The Free Press, New York.
- Reid, M. & Solomon, S. 1992, *Improving Australia's Rural Health and Aged Care Services*, No.11 Background Paper, National Health Strategy Unit, Canberra.
- Richards, T., Richards, L., McGalliard, J. & Sharrock, B. 1992, *NUD\*IST User Manual*, Replee Pty Ltd, Bundoora.
- Ricoeur, P. 1977, The model of the text: Meaningful action considered as a text, in *Understanding in Social Inquiry*, eds F. Dallmayr & T. McCarthy, Notre Dame University Press, Notre Dame, pp.316–334.
- Romanyshyn, R. 1992, The human body as historical matter and cultural symptom, in *Giving the Body its Due*, ed. M. Sheets-Johnstone, State University of New York Press, Albany, pp.159–179.
- Rorty, R. 1991, Inquiry as recontextualization: An anti-dualist account of interpretation, in *The Interpretive Turn*, eds D. Hiley, J. Bohman & R. Shusterman, Cornell University Press, Ithaca, pp.59–81.
- Sacks, O. 1984, *A Leg to Stand On*, Picador, London.
- Sacks, O. 1986, *The Man Who Mistook His Wife For a Hat*, Picador, London.
- Sacks, O. 1991, *Awakenings*, rev. edn, Picador, London.

- Sacks, O. 1995, *An Anthropologist on Mars*, Picador, London.
- Scambler, G. & Hopkins, A. 1986, Being epileptic: Coming to terms with stigma, *Sociology of Health and Illness*, 8, pp.26–43.
- Schumacher, K. & Gortner, S. 1992, (Mis)conceptions and reconceptions about traditional science, *Advances in Nursing Science*, 13(4), pp.1–11.
- Schutz, A. 1972, *The Phenomenology of the Social World*, Heinemann, London.
- Shorter Oxford Dictionary*, 1975, 3rd edn, Oxford University Press, London.
- Silverman, H. (ed.) 1991, *Gadamer and Hermeneutics*, Routledge, New York.
- Smith, G. 1991, Heidegger, technology and postmodernity, *Social Science Journal*, 28(3), pp.369–389.
- Sontag, S. 1979, *Illness as Metaphor*, Allen Lane, London.
- Spiegelberg, H. 1960, Phenomenology and existentialism, *Journal of Philosophy*, LVII(2), pp.62–74.
- Spiegelberg, H. 1982, *The Phenomenological Movement*, Martinus Nijhoff Publishers, London.
- Strauss, A. & Corbin, J. 1988, *Shaping a New Health Care System: The Explosion of Chronic Illness as a Catalyst for Change*, Jossey-Bass, San Francisco.
- Strauss, A. & Corbin, J. 1990, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Sage Publications, Newbury Park.
- Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B., Maines, D., Sucek, B. & Wiener, C. 1984, *Chronic Illness and the Quality of Life*, 2nd edn, C.V. Mosby, St Louis.
- Strauss, A. & Glaser, B. 1974, *Chronic Illness and the Quality of Life*, C.V. Mosby, St Louis.
- Stumpf, S. 1994, *Philosophy: History and Problems*, 5th edn, McGraw-Hill, New York.
- Taylor, B. 1992a, From helper to human: A reconceptualization of the nurse as person, *Journal of Advanced Nursing*, 17, pp.1042–1049.
- Taylor, B. 1992b, The phenomena of ordinariness in nursing, PhD thesis, Deakin University, Geelong.
- Taylor, B. 1994a, *Learning from the Client's Perspective*, University of New England Press, Armidale.
- Taylor, B. 1994b, *Being Human: Ordinariness in Nursing*, Churchill Livingstone, Melbourne.
- Taylor, B. 1994c, *Researching Human Health Through Interpretation*, University of New England Press, Armidale.
- Taylor, C. 1982, Interpretation and the sciences of man, in *Knowledge and Values in Social and Educational Research*, eds E. Bredo & W. Feinberg, Temple University Press, Philadelphia, pp.154–186.
- Taylor, C. 1989, *Sources of the Self: The Making of the Modern Identity*, Cambridge University Press, Cambridge.

- Taylor, C. 1991, *The Ethics of Authenticity*, Harvard University Press, Cambridge, Massachusetts.
- Thaniwattananon, P. 1995, The experiences of nurses in providing care for patients with AIDS in Thailand: A phenomenological approach, PhD thesis, University of New England, Armidale.
- Theophanous, A. 1993, *Understanding Social Justice: An Australian Perspective*, Elikia Books, Melbourne.
- Thomasma, D. 1994, Toward a new medical ethics: Implications for ethics in nursing, in *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*, ed. P. Benner, Sage Publications, Thousand Oaks, pp.85–98.
- Thompson, J. 1990, Hermeneutic inquiry, in *Advancing Nursing Science Through Research*, ed. L. Moody, Sage Publications, Newbury Park, pp.223–280.
- Thorne, S. 1990, Mothers with chronic illness: A predicament of social construction, *Health Care for Women International*, 11, pp.209–221.
- Thorne, S. 1993, *Negotiating Health Care: The Social Context of Chronic Illness*, Sage Publications, Newbury Park.
- Thorne, S. & Robinson, C. 1988a, Health care relationships: The chronic illness perspective, *Research in Nursing and Health*, (11), pp.293–300.
- Thorne, S. & Robinson, C. 1988b, Reciprocal trust in health care relationships, *Journal of Advanced Nursing*, 13, pp.782–789.
- Thorne, S. & Robinson, C. 1989, Guarded alliance: Health care relationships in chronic illness, *Image: The Journal of Nursing Scholarship*, 21, pp.153–157.
- van Kaam, A. 1959, Phenomenological analysis: Exemplified by a study of the experience of being really understood, *Individual Psychology*, 15, pp.66–72.
- van Manen, M. 1990, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, State University of New York Press, Albany.
- Vaughan, B. & FitzGerald, M. 1992, Caring for the acutely ill, in *Knowledge for Nursing Practice*, ed. K. Robinson & B. Vaughan, Butterworth Heinemann, London, pp.142–156.
- Wahlquist, A. 1995, Farming our parched land, *Sydney Morning Herald*, 10 April, p.13.
- Walker, K. 1994a, Confronting 'reality': Nursing, science and the micro-politics of representation, *Nursing Inquiry*, 1(1), pp.46–56.
- Walker, K. 1994b, Research with/in nursing 'troubling' the field, *Contemporary Nurse*, 3(4), pp.162–168.
- Walters, A. 1992, The phenomenon of caring in an intensive care unit, PhD thesis, Deakin University, Geelong.
- Walters, A. 1994a, The comforting role in critical care nursing practice: A phenomenological interpretation, *International Journal of Nursing Studies*, 31(6), pp.607–616.
- Walters, A. 1994b, Phenomenology as a way of understanding in nursing, *Contemporary Nurse*, 3(3), pp.134–141.

- Walters, A. 1994c, *Caring as a Theoretical Construct*, University of New England Press, Armidale.
- Ward, R. 1966, *The Australian Legend*, 2nd edn, Oxford University Press, Melbourne.
- Watson, J. 1985, *Nursing: The Philosophy and Science of Caring*, Colorado Associated University Press, Colorado.
- Watson, J. 1988, *Nursing: Human Science and Human Care: A Theory of Nursing*, National League for Nursing, New York.
- Whitman, W. 1979, When I heard the learn'd astronomer, in *I Like This Poem*, ed. K. Webb, Puffin, London, p.141.
- Williams, G. 1993, Chronic illness and the pursuit of virtue in everyday life, in *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*, ed. A. Radley, Routledge, London, pp.92–109.
- Wilson Ross, J. 1993, Fighting the enemy and other final chapters: Paying the price of our stories, in *On Nursing: A Literary celebration*, eds M. Styles & P. Moccia, National League for Nursing, New York, pp.310–316.
- Wolin, R. (ed.) 1993, *The Heidegger Controversy*, MIT Press, Cambridge.
- Woolf, V. 1948, On being ill, in *The Moment and Other Essays*, ed. V. Woolf, Harcourt, Brace & World, New York, p.14.
- Wright, J. 1970, South of my days, in *Collected Poems 1942–1985*, ed. J. Wright, Angus & Robinson, Melbourne, pp.14–15.
- Zaner, R. 1970, *The Way of Phenomenology*, Pegasus, New York.

## New England Tablelands Health Service

Armidale & New England Hospital  
Rusden Street  
Armidale NSW 2350  
Phone: (067) 73 4777  
Fax: (067) 72 8774

Incorporating:

Guyra District War Memorial Hospital  
Abercrombie Street  
Guyra NSW 2365  
Phone: (067) 79 1166  
Fax: (067) 79 1579

## SOCIAL WORK DEPARTMENT

### ISOLATED PATIENTS TRAVEL AND ACCOMMODATION ASSISTANCE SCHEME (IPTAAS)

#### What Is It?

- \* A reimbursement scheme
- \* Run by N.S.W. Department of Health
- \* For all residents of N.S.W. who need to travel 200 kilometres or more 1 way for specialist medical or dental treatment or services

#### What Does It Cover?

- \* Travel  
Return economy bus/rail travel and motor vehicle reimbursements of costs.  
  
The following conditions apply to air travel:
  - Air travel must be requested by referring doctor with a genuine reason for this mode of travel, e.g. life or death situation.
  - Approval for air travel must be obtained before travelling, by phoning the Tamworth Regional Office on (067)663 946.
- \* Accommodation  
Up to \$30.00 per night for commercial or hospital based accommodation (private accommodation cannot be claimed).
- \* Taxi Fares  
There is a limit set on the amount that can be claimed.
- \* Escorts  
A patient under the age of 17 is automatically entitled to one escort.  
  
For a person 17 years of age or over, an escort needs to be approved by the referring practitioner who must state in Question 5 (Section A) why an escort is medically necessary.

What Is required?

- \* The I.P.T.A.A.S. application form
  - \* A referral by a Doctor in Armidale
    - who must complete Section A of the form;
    - which is then sent down with the patient;
    - who arranges for the Specialist to complete Section B
  - \* Receipts must be kept for all services (except when claiming petrol costs, which are calculated for the return distance).
  - \* Section C is to be completed by the patient (or escort) after completion of the treatment.
  - \* Receipts must be attached
    - and the application must be mailed to the Tamworth Regional Office within three months of return (see back of form for postal address).
  - \* A patient contribution of \$40.00 is deducted from travel costs for each claim.
- 

ADVANCE PAYMENT

What Does It Cover?

In special circumstances, I.P.T.A.A.S. will send a cheque to the travel agency to cover the full cost of travel, in advance of travel. Advance payments are means tested.

What Is Required?

- \* An I.P.T.A.A.S. application form.
- \* Section A of application form to be completed by referring doctor in Armidale.
- \* Details of specialist to be noted (Section B), i.e. name of specialist, address and telephone number of specialist, time and date of appointment, outpatient or inpatient.
- \* You need to present to Community Health during business hours with the following, which will be faxed to the Tamworth Regional Office to support your application for advance payment:
  1. Section A (as above)
  2. Section B (as above)
  3. Advance Payments Undertaking (available from the Social Worker)
  4. Copy of Pension Card

5. Travel details:
  - type of transport for patient travel (i.e. car, bus, train or plane; concession or full fare)
  - a tentative travel booking must be made prior to presenting to Community Health to apply for advance payment. This must be done through a travel agent whether you are travelling by bus or by rail.
  - having made your booking, please bring:
    - \* actual name booking is made in
    - \* name of travel agent and date payment must be made by
    - \* booking number of your seat
    - \* date and time of departure and return (if known)
    - \* cost of travel
  
6. Also required are:
  - current Health Care Card
  - current bank account or latest bank statement, which will be photocopied at Community Health and faxed to the Tamworth Regional Office along with your pension Card.

### **Study aims to assist sufferers**

Tamworth people suffering from chronic illnesses are being offered the chance to participate in a study which may provide help for them and fellow sufferers in years to come.

The study is being undertaken by Mary FitzGerald, a nurse with more than 20 years of practical experience who is currently a postgraduate student in the School of Health at the University of New England.

Mrs [sic] FitzGerald has designed her study to find out just what it means for people to live with a long term illness.

She hopes to build up an authentic picture from the perspective of a sufferer by talking to a number of them about their lives.

So far 10 people from the Armidale area have taken part and Mrs [sic] FitzGerald is hoping another 10 from Tamworth will come forward to help.

Contributions will involve about three meetings with the first designed for people to meet Mrs [sic] FitzGerald, hear about her work and decide if they want to take part in the study.

Usually, another two, one hour meetings are needed for participants to recount their experiences.

Participants will be kept up to date as the study progresses and the final result will be put to practical use as Mrs [sic] FitzGerald hopes to work with community nurses to set up a service for people who have problems associated with chronic illness.

Until the end of this month she will be based at the Nursing Research and Teaching Unit of Tamworth Base Hospital and can be contacted on 669973.

Participants will need to be over 18 years of age and English speaking.



## Plain Language Statement

---

### **The Meaning of Chronic Illness Outline for Potential Participants**

#### **Introduction**

The study has been designed to find out *what it means to live with long term illness* in order that an authentic picture can be built up from the perspective of the experiencing person. The study will involve interviews with people who are chronically ill.

#### **The researcher**

I am a nurse with over twenty years of practical experience. I am currently studying at the University of New England and this research will be the thesis I submit for my PhD in nursing.

When the study is finished the results of the work will be put to practical use. I hope to work with community nurses setting up a service for people who have problems associated with chronic illness.

#### **Participation in the study**

I am looking for approximately thirty men and women (English speakers over the age of 18 years), who have a chronic condition which affects their health, to help me with the work. I have deliberately chosen not to define chronic illness as I want people to be self selecting and I wish to steer away from the tendency to group people by medical diagnoses. I am equally intrigued by people who manage their condition with minimum disruption to their lives as those who find coping difficult.

Contribution to the study would involve one or two interviews lasting approximately one hour each. During the interviews you will be invited to recount what living with long term illness means to you. All interviews will be conducted at your convenience and you may choose the time and place. In order to work with the information gathered, it will be necessary to tape record and transcribe the interviews.

I would like to keep interested participants informed as the study progresses. This will be done by letter or by meetings at people's convenience. The completed thesis will be made available for participants to read if they would like to.

Participants' names will be changed in order to preserve their anonymity. All tapes and transcripts will be kept locked at the University. Any participants will be free to withdraw from the study, if they wish, at any time.

#### **Study timetable**

Interviews will take place from May 1993 to August 1993. I expect to interview on average ten people per month. Whilst I expect the interviews to last approximately one hour, I am sure some participants may not be finished in this time. In this case the participants may choose whether I come back for another interview or continue. The study will then be interpreted and written up in the next eighteen months, and be ready for submission by April 1995.

Anyone who has more questions is welcome to telephone me on 734395 in office hours. If you are prepared to help me with the study please contact me either by letter or telephone.

Mary FitzGerald  
School of Health  
University of New England  
ARMIDALE NSW 2351  
Telephone 73 4395

**The Meaning of Chronic Illness**

The aim of this study is to detail the experience of chronic illness from the perspective of ailing people. This information should shed light in an area not often investigated in such depth. This study is being carried out by a nursing researcher at the University of New England for a PhD thesis.

The collection of data for the study involves interviews of approximately one hour each. At the interview or interviews the participant will be invited to talk about their everyday experiences and how their life is affected by their health.

Names will be changed in order to preserve anonymity. All tapes and transcripts will be kept locked at the University. Any participants will be free to withdraw from the study if they wish at any time.

**Consent to participate in the research study  
(The meaning of chronic illness)**

I ..... have read the information regarding the study and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used.

..... Date  
Participant or Authorised Person

..... Date  
Investigator

THE UNIVERSITY OF NEW ENGLAND

Deputy Vice-Chancellor's Advisory Committee  
on Ethics in Experimentation on  
Human Participants

MEMORANDUM TO: Ms M FitzGerald  
Department of School of Health

This is to advise you that the Deputy Vice-Chancellor's Advisory Committee on Ethics in Experimentation on Human Participants has approved the following:

TITLE OF EXPERIMENT: The meaning of chronic illness

COMMENCEMENT DATE: 1st March 1993


APPROVAL VALID TO: 30th November 1993

COMMITTEE APPROVAL N<sup>o</sup>: HE 930004

COMMENTS: Nil

Approvals are granted by the Committee for a twelve month period. A Final Report should be submitted on completion of the project if this occurs within 12 months. If the research project is to continue beyond twelve months the person responsible is required to submit an application for renewal. A copy of the Progress/Final Report Form (Part II) is attached.

17th February 1993.  
TM:CS-J

  
T. Moore  
Secretary