Tollefson, Joanne (2009) ***I live my life according to the pain: the lived experience of chronic pain in adults living in rural Queensland.*** **PhD Thesis, James Cook University.**

https://doi.org/10.25903/e2zn%2Dww11

I live my life according to the pain

The Lived Experience of Chronic Pain in Adults Living in Rural Queensland

Thesis submitted by

Joanne Marilyn TOLLEFSON
RN, DipNur, BGS, MSc (Trop Med)

For the Doctor of Philosophy

School of Nursing, Midwifery and Nutrition

James Cook University

Statement of Access

I, the undersigned author of this work, understand that James Cook University will make this thesis available for use within the University Library and via the Australian Digital Theses network, and elsewhere as appropriate.

I understand that as an unpublished work, a thesis has significant protection under the Copyright Act and I wish this work to be embargoed until June 2009.

31st March 2009

……………………

Signature Date

Electronic copy

I, the undersigned, the author of this work, declare that the electronic copy of this thesis provided to the James Cook University Library is an accurate copy of the print thesis submitted within the limits of the technology available.

………………………………… 31st March 2009

Signature Date

Statement of Sources

Declaration

I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is provided.

31st March 2009

………………

Signature Date

Statement of the contribution of others

This thesis has been made possible through the support of many people, as follows:

Supervisors:

Primary supervisor:

Professor Kim Usher, School of Nursing, Midwifery and Nutrition, James Cook University

Secondary supervisors:

Associate Professor Kim Foster, School of Health Sciences, University of Sydney

Dr Lee Stewart, School of Nursing, Midwifery and Nutrition, James Cook University

Previous supervisors:

Professor Dawn Francis (retired), School of Education, James Cook University.

Dr Narelle Biedermann, (retired), School of Nursing Sciences, James Cook University.

Peer Reviewers:

Professor Kate Caelli, School of Health Sciences, University of Alberta, Canada
Dr David Lindsay, School of Nursing, Nutrition and Midwifery, James Cook University, Townsville, Queensland, Australia

Financial Contributions to this research study:

The Queensland Nursing Council awarded me a grant of $4,651 in June 2005 for this research project (Grant RAN0516). I thank them for selecting my project for funding.

James Cook University granted me a ‘Teaching Relief Award’ of $12,800 for one semester in 2006. I am grateful for the time this provided.

Ethical approval for this project was sought and approved by the James Cook University Human Ethics Review Committee (H 2046) and the Townsville and District Health Services Institutional Ethics Committee (36/06).

Acknowledgements

Some people see the doctoral candidature as a journey. I felt it was a battle. There were long periods of quiescence, followed by short periods of intense activity. Preparation for the activity was pivotal to undertaking the bursts of activity. I fought a great number of personal skirmishes – intellectual, emotional, psychological and physical - during the period of my candidature and won against some of the most difficult health and personal problems that can come along. I did win, though.

As with any battle, it is not about the individual, but about the support and input of a team. I am greatly indebted to Professor Kim Usher, who was my friend first, then my supervisor. Her guidance and wisdom supported me and showed me the way. I thank her.

I thank Associate Professor Kim Foster (K2), as well, for her positive and helpful input into the writing phase of the thesis. Her unfailing enthusiasm and positive spin on things really helped a lot.

The School of Nursing, Midwifery and Nutrition is a great place to work and my colleagues were supportive and positive. Two of my colleagues must be especially acknowledged. Although I had a head start on both of them, they completed their doctoral studies ahead of me. Their urgings when I was having difficulties with the data collection and their constant support were inspirational. Thank you Drs Lee Stewart and David Lindsay.

I also thank the participants in this study for their courage, present in their willingness to act and to speak, in sharing with me their private thoughts, feelings and actions about living with chronic pain in their rural communities. Their honesty in sharing their experiences with (initially) a stranger was phenomenally spirited. Putting those experiences into words was enormously difficult and I thank them for their input.

Most importantly, I wish to thank my husband, Ken, whose unfailing love, support and good humour often buoyed me up when the going was tough. He also supplied me with a great deal of technological assistance, and soothed frayed nerves when the computer ‘lost my work’. I am very grateful to him for the editing assistance provided as well.

I dedicate this thesis to four people – my husband Kenneth Norman Tollefson and my family of origin – Louise Martha James, George Winston James, and Darryl George James. My Mom and my brother, Darryl, both died during the work of this thesis so never had the chance to celebrate its conclusion. I owe them both a debt of gratitude – my mother because it was she who taught me the importance of persistence, tenaciousness and fortitude. She was a strong and feisty woman as well as a lady. I miss her. Darryl’s humour and ability to see (some things!) clearly helped me to undertake the discussion of the influence of the rural context on us as we grew up. My father predeceased them both by more than a quarter of a century, but I am greatly obliged to him and owe thanks – he taught me to believe in myself and in my ability to do anything I wanted to. This thesis is the result of the belief of these 4 people in me, and in my ability to complete what I started.

Conventions used within the thesis

In the presentation and discussion of the analysis of the participant's transcripts (Chapters 6 through 9), excerpts from the transcripts were presented. The following conventions were used to acknowledge these:

Pseudonyms were assigned to each participant to preserve their anonymity.

All quotes were presented in italics

Identifying information such as the name of the town, or of an individual was removed and replaced with a generic description within a bracket in normal font.

Pauses within a quote are denoted by a dash (-).

Comments about the demeanor of the participant at that time (or other relevant information such as hesitation, tears) were also placed in brackets and presented in normal font within the italicized quote.

Each quote was ascribed to the participant, and the page and line numbers are indicated in brackets following each quote.

Three dots (…) indicate that words were left out of a quote, usually for brevity's sake.

An example of these conventions:

Gary is proud of his past accomplishments: *When we first moved here we had a beaut veggie garden. - We sat down one night there and we had nine different veggies on our plate that we'd grown off the land and we used to breed our own dairy goats, have, their own dairy fed milk and breed our own pigs and we used to feed the dairy goat milk to the* *piglets and have them on grain ration ... And the man over at* (Name) *Pig Factory here in* (Town) *said they were the best piglets he'd ever seen.* (p19, L642-648).

List of Figures

Abstract

Chronic pain is ubiquitous in people all over the world. Australia is no exception, with up to a fifth of the population claiming that they have experienced chronic pain over the past year. Chronic pain has been explored in a multitude of studies over the past century, with the majority being quantitative studies aimed at understanding the patho-psycho-physiological aspects of pain, or the psychological/behavioural management issues. More recently, qualitative studies have been undertaken to begin to understand the individual person's perspective on chronic pain in an attempt to inform health care professionals so they can better assist those they care for to live with their pain. In this study, living in rural areas provided a contextual background to living with chronic pain. Geographical distance often imposes restrictions on the health care services that are available, and these restrictions increase the impact of living with chronic pain in a rural area. The aim of this study was to answer the question: What is it like to live with chronic pain in a rural area of Queensland? An interpretive study using van Manen's (1997) approach to hermeneutic phenomenology explored the experiences of seven adults living with chronic pain in rural areas of Queensland. Hermeneutic phenomenology was chosen as the underlying philosophy for this study. Conversational interviews were conducted with adults between the ages of 23 and 55 years in small towns in several parts of Queensland. The interviews were transcribed verbatim, and the resulting transcripts analysed using van Manen's (1997) analytic approach. Several sub-themes emerged and fell into the four existential concepts or essences described by van Manen: spatiality, temporality, corporeality and relationality.

Spatiality - 'The country style of life' included four sub-themes. 'Distance is the biggest problem' spoke of geographical distance to sophisticated health care that was found to be a problem, both in additional physical discomfort during travel, and in personal and financial costs. As well, a diminution or lack of health care services in country areas was apparent. 'Living in a small town' assists the person to deal with their chronic pain quietly and privately. The 'Safety and comfort of living in a small town' revolved around the trust and the relationships participants developed with community members over the

years. ‘Retreating to private spaces’ permitted disengagement from others, both mentally and physically, fostering relaxation and reducing pain.

Temporality - ‘This is my life now’, was constituted by four sub-themes. The temporal discontinuity between ‘what was’ and ‘what is now’ was explored in ‘I am different to what I was’. Grief was endured because of these changes and lives and identities were fragmented. As part of this experience, participants also attempted to retrieve a sense of self. ‘This is my life now’ told of the endurance and acceptance of the pain, and the recognition that the pain would be a constant companion. ‘Things will not improve’ extended this theme with reference to uncertainty, maintaining independence and the value of distraction. ‘Pace of life in the country’ demonstrated some of the positive factors that assisted with living with chronic pain in a rural area – quiet, fewer interactions and the slower rhythm of the country lifestyle.

Corporeality - ‘Some days are better than others’ included four sub-themes. ‘Pain is invisible – but it really does hurt’, related the psychological burden of not being able to actually demonstrate the hurt, and feeling like a fraud. ‘Difficult to name – all there is is the pain’ emphasised participants’ inability to articulate pain and the increased necessity for health care professionals to be astute in their assessment of the person living with chronic pain. ‘What’s wrong? What’s wrong? – the meaning of pain’ tells of making sense of the pain for peace of mind and giving it a name so as to legitimize it. ‘Balancing the pain’ brought forth the experience of persisting versus pacing of activities to reduce the effects of the pain, being aware of personal limitations, use of analgesia, and distraction to cope with the pain. ‘Mind over matter – the scary mental side of things’ tells of believing in their own body rather than worrying that they were losing their mind, the effects of mind over the somatic body and of depression, of memory loss and of cognitive dysfunction.

Relationality - ‘Relationships in Pain’ included four sub-themes. ‘Silence on pain’ relates stoicism, reticence about the pain, independence and perseverance. ‘Privacy – you don’t have to look and act happy’ protects as it keeps the pain from others. ‘Support and comfort’ from family, friends, community, animal companions and God helps cope with the pain. Good, solid family relationships empower, but as the circle widens, support and comfort became less apparent. ‘He just doesn’t understand’ paints a telling story of participants’ relationships with health care professionals. Inadequate care and difficult interactions were often experienced. As a consequence, traveling great distances to consult compassionate doctors occurred, although nurses were seldom mentioned.

Several key recommendations arose from the findings of this study. In respect to education, suggestions for future curricula development to help health care professionals to learn to provide more empathetic assistance to people living with chronic pain were made. In respect to clinical practice, the development more effective strategies to assist people living with chronic pain is suggested. Advanced practice nurses with an interest in, and further studies in assessing and managing chronic pain are needed in rural areas, both as practitioners and as mentors to other nurses. Adoption of standardised pain management strategies by professional organisations, and especially dissemination of these through their rural networks would assist health care professionals to practice in a consistent and contemporary way. The importance of aggressive and thorough pain assessment of people seeking health care advice in rural areas is an important finding in this study and should be utilized by all first-contact health care professionals.

In reference to research, specific recommendations were made. Since pain assessment and pain management are currently taught in the health care disciplines and have been for at least a couple of decades (personal experience), research projects are urgently needed to determine why this knowledge has not translated into practice in order to address the indifference, lack of knowledge and the stigma that people living with chronic pain face from the professionals who are supposed to assist them. Further qualitative studies are recommended to increase the scope of knowledge of the experiences of people living with chronic pain in rural areas.

Table of Contents

Chapter 1 - Introduction

Beginnings

The seed for this study into chronic pain was sown in 1958. At that time, I began to experience fierce twice-weekly migraines. Since then, chronic pain has been a companion, a curse and a prod in my life. It has dictated my profession, and subsequently my career, as I found I needed to learn more about it and to teach other nurses about the effects of persistent pain. I have seen how poorly health care professionals deal with chronic pain from both sides and I have admired people who live with chronic pain for their fortitude and forbearance. I have always tried to help them when I could. Raised in a small country town, I spent many years working as a staff nurse in rural hospitals. I found the people in the country lived with their pain differently to others: hence this study. To bring the rural background of this study into focus, this chapter begins with a discussion of that context. The rural context is presented in relation to health and health service accessibility, as this is a contextual factor that both shapes health and impinges on health care. Some of the traits of the 'rural character' are raised that impact on an individual's ability to deal with adversity such as chronic pain. The concept of rurality is also explored, in terms of nursing, health care and medical literature. The significance of chronic pain is described, including the human, economic and health care costs, and the chapter concludes with the significance and the aims of the study.

The 'wide brown land'- defining 'rurality'

Distance is a defining feature of this country and the expansive context has implications in the development of the Australian culture, and especially on the culture of rural folk. Phillips and McLeroy (2004, p. 1661) assert that special consideration is required by the contextual issue of rurality. Australia's rural and remote communities are extremely diverse and constitute a heterogeneity of demographic and economic bases. The population's age, gender, ethnic/cultural background, occupation, socio-economic status, and the communities' social/economic structures, health and education facilities and size vary greatly across this 'wide brown land'(MacKellar, 1908) - Australia. To discuss such a diverse population, a definition of the term 'rural' is required, however, this term is difficult to define. The definition often depends on the purpose for which it is needed. Particular organisations define it to suit their specific interest. ‘Rural’ has also been defined at its broadest as anywhere that is non-urban. Subsequently, several classification systems have been developed to address the difficulty in nomenclature. One well accepted definition is the Accessibility/Remoteness Index for Australia (ARIA) – a geographic measure of remoteness from a range of services in terms of accessibility. This classification system has several advantages over older systems in that it is

- comprehensive, dealing with all non-metropolitan areas of Australia without anomalous results or the need for artificial adjustments;
- sufficiently detailed to avoid anomalies arising from aggregating heterogeneous areas;
- as simple as possible, avoiding refinements that make little difference to the outcome;
- transparent and defensible – not a ‘black box’;
- intuitively plausible in its results, ie make sense ‘on the ground’; and
- stable over time (ie the remoteness score of an area should change if and only if it becomes more or less remote, not simply due to changes in administrative boundaries (Bamford & Dunne, 2001, p. 2)

The accessibility of a locality is determined by using the road network from 11,338 “populated localities” (townships or villages of any size) to service centres (201 urban centres across Australia with at least 5000 population), which are subdivided into 4 classifications based on population size (5000-17,999; 18000-47,999; 48,000-249,999 and over 250,000). Distance of a particular populated locality from each category of urban centre is measured, then each of those distances is divided by the mean distance of all population localities from an urban centre of that category. This ratio to the mean is assigned a number under 3 and then the 4 assigned numbers are summed to give a value between 0 and 12, where 0 is high accessibility and 12 is extreme remoteness (Bamford & Dunne, 2001, p. 5).

“As the index of remoteness based on distance increases, access to the variety, quality and range of goods, services, facilities and opportunities decreases” (Peach & Bath 1999, p. 25). This statement, although made in 1999, remains generally true. It is important to this study because the adequate treatment of chronic pain is usually that provided by a multidisciplinary team consisting of a pain expert physician, psychologist, nurse, physiotherapist and occupational therapist (Jensen, Romano, Turner, Good, & Wald, 1999). In rural areas, adequate and appropriate treatment of chronic pain decreases as the distance from main metropolitan areas increases.

The context of rurality and distance is fundamental to this study as travel to centralised medical facilities for treatment and diagnosis is problematic for those living in rural communities (Keleher & Ellis, 1996, pp. 144-150). Travel takes time and costs a great deal of money – both in actual terms and in loss of work time/wages. Although many states in Australia offer compensation to the rural person for travel and accommodation expenses during illness and hospital visits, many rural people do not access this support because they are unaware of its existence or because it is quite inaccessible (Keleher & Ellis 1996). The National Health and Hospital Reform Commission ("Beyond the Blame Game", 2008) endorse the finding that rural people find it difficult to access the health care they need.

In this study, therefore, ‘rural’ indicates a moderately inaccessible area that measures at least a 3 on the 12 point ARIA scale. Participants who lived in or near ARIA ‘3’ towns were about 2 hours by road from a service centre, and 4 hours or more from an urban centre.

On *Being* Rural

Occupational and contextual differences mark the rural dweller from their urban counterpart. In rural areas, primary industries (agriculture, grazing and mining) are the largest employers of labour along with support and service industries such as farm implement sales, mechanical repairs and feed and fertiliser retail outlets. However, Bushy (2008) cautions us to be mindful that agriculture is not the only industry in the country. Many of the occupations in primary industry are fraught with frequent exposure to high risk jobs around machinery and animals, there is frequent to continual prolonged environmental exposure in the out-of-door occupations, and driving long distances is inherent in most of the occupations. On top of this, occupational stress grows from the combination of self-employment, dependence on the weather/climate, the extension into marginal lands and the economic decline of the rural sector.

Economic decline in many rural areas of Australia has been brought about by a combination of globalisation and the historical lack of services and facilities in rural communities (Hays 2002). Globalisation with the resultant decline in commodity prices has forced the rural sector to increase the efficiency of their production, often through mechanisation and/or corporatisation. This in turn reduces the need for farm labour and the resultant drop in employment in rural areas causes a decline in the need for services. Rural communities, because of their relatively smaller size (tax base) and geographical isolation from large population centres, cannot offer the range of services (eg banks, professional services, entertainment opportunities) available in larger centres. They are often not appealing to younger and professional people as a permanent home. The result of this is a drift (especially of the young) away from the rural areas to seek work in the larger provincial towns and cities. A vicious cycle is established that sees the loss of more and more services with increased unemployment and out-migration.

Thus, the ecological factors of low population density, reduced community infrastructures and geographical isolation work together to mould the rural person's attitudes to life. The connectedness of the individual to the environment because of the dependence on elemental factors such as the climate, droughts, distances and the land itself has also shaped the 'country person'. Slow change in country life is being wrought by influences such as increased information sharing and ease of transport.

However, although county life can be challenging, rural settings also afford positive influences for the individual. Socio-cultural interactions are usually less formal, with face-to-face interactions preferred. Availability and easy access to extended family provides strong informal support systems. As well, rural community members have lived within the same social group, often since birth and there is a personal understanding of most of the members of that community (Lane, 2004) either directly or as a friend of a friend. This intimate understanding of community members fosters close ties to the community with respect for individuals, developing into concern for the community as a whole. Hays (2002) relates a story that clearly demonstrates this community support. He writes of an urgent local radio plea for assistance to drive blood for testing to a regional centre 2 hours away and an immediate response by several community members – one of whom was not even planning a trip to the city that day. The strong influence of traditional social values that have arisen because of the homogeneity of the value systems in small centres can therefore sway people into both positive and negative health behaviours. Examples of positive health behaviour might be conforming to immunisation schedules. Negative health behaviours are seen when “shame, fear and stigma keep rural residents from seeking help for problems that are deemed socially unacceptable, such as mental illness, human immunodeficiency virus infection, acquired immunodeficiency syndrome, and domestic violence” (Stamm et al., 2003, p. 7). These positive and negative influences have shaped the character of country people

Bushies – the stoic, hard-working pragmatist

‘Bushies’ is a colloquial term for country people that evokes the rough and ready, the warmth and the generosity and the stoic, hardworking pragmatist that is strongly admired (and sometimes scoffed at) in Australia today. Smith (2004, p. 12) discusses “country-mindedness” and traces the historical development of the traits we associate with rural people in Australia. Hegney, Pearson and McCarthy (1997) discuss the development of what they term the Australian ‘rural character’. These authors attribute the various traits that developed to the necessity of early settlers to rapidly adapt to the isolation they found themselves in.

The ‘rural character’, then, is someone who is pragmatic, hardy, resilient, self-reliant, independent, stoic, and living within a strongly supportive context. Ingenuity or the creative use of resources is a distinctive part of the pragmatism found in rural people, as is the ability to deal with challenges (Bushy 2000). Hardiness, the endurance of difficult situations is an expected country trait and is part of resilience. Resilience is the ability of people to weather adversity and to regain or maintain their integrity (Jacelon, 1997). The constellation of traits that are responsible for resilience is aligned with many of the other characteristics espoused to be present in people living in the rural context – self-reliance, independence, strong social support and a warm, supportive home environment (Jacelon, 1997).

Hard work (Smith 2004) is also a hallmark of country people. Hard work is needed in the harsh occupational and environmental climate of the rural dweller. Holmes (1981, cited in Pashen, Grant, Veitch, Sheehan, & Chalmers, 2002) attributes the hard working rural person to self selection as those who are not prepared to work hard and thrive in the harsh environment tend to leave it. Hays (2002, p. 51) extends the idea of hard work with the statement that “rural people expect to work hard and do not respect those who will not”. Not only is hard work expected, but it must be done stoically.

Stoicism the trait of enduring adversity without complaint, develops in response to the hardships faced (Hays, 2002). The stoic nature of rural people develops from work and distance related factors and the emphasis on function rather than personal comfort (Pashen et al 2002). Work must get done. The self-employed person has no fallback position with health cover or sick days to count on. Long distances, often over washboard roads and measured in time rather than kilometres, make travel to health care facilities impractical and uncomfortable. Unless the problem is life or function threatening, a doctor’s visit is simply not done. If the person is not incapacitated, they continue to work until they are forced to seek help by the altered function. Pragmatism (Hays 2002) is another ‘Bushie’ characteristic that is closely aligned with stoicism. Practical matters come first, and problems are solved in a realistic way, using the materials at hand and in accord with the present conditions.

However, not all of the traits found in the rural person can be considered to be positive. Racism in those living in rural areas has evolved from the lack of acceptance of newcomers – ‘new chums’ and the exclusion of Aboriginal and Torres Strait Islanders from mainstream Australia (Hegney, Pearson & McCarthy 1997, p. 37). This attitude to foreigners or indeed, any new comers to a rural community can be seen in the lack of engagement with people who are new to the district. Sometimes, people are newcomers for an entire generation. This, as well as work and distance factors, has an impact on the health status and health care of country folk.

Preston (2001) asserts that Australians living in rural and remote areas experience different health status than their urban compatriots with both morbidity and mortality higher. Other authors concur (Hays, 2002; Smith, 2004; Strasser, 2000). This difference in health status is attributed to geographical distance from services, relative lack of health care personnel and resources (Eyles & Smith, 1995). In fact, DeLeon, Wakefield and Hagglund (2002a, p. 28) assert that “access to [health care] clinicians is *essential* for economic survival” of rural towns.

The national and state governments within Australia have recognised these inequities of health care distribution for the 30% of their population that live in rural and remote Australia. Within the past decade, most of the states as well as the Commonwealth have introduced policies for health care to rural and remote peoples to reduce the inequities brought about by living and working in rural (and remote) Australia. At the same time, economic rationalism (or capitalist driven economic policy) has forced the closure of hospitals and health care facilities in many small centres. The adoption of a managerialistic approach to health care has altered the previous health care system into a managed one with ‘consumers’ rather than care recipients and health care itself becoming a commodity. As well, with the conceptual move from the need-base of health care to a fiscal base, privatisation of health care (eg nursing homes, pharmacy supply), loss of decision making at the local level and increasing gaps in health related areas have developed. As well, service delivery is still based on the medical model with professional or clinical strands which are too specialised for country areas and resulting in “poor distribution of services, lack of preventative strategies, fragmented, disjointed policies on early discharge and community care” (Harvey, Sandhu, & Strasser, 1995, p. 36).

Each person’s perception of health is multidimensional and these perceptions influence the individual’s health seeking behaviours. Health is defined by many rural dwellers, especially men, as the “ability to work” (Bushy, 2000, p. 36), whereas rural women look at health as having the ability to adapt and to cope. Rural elders feel healthy when pain and fatigue do not plague them. Of course these are broad generalisations and do not necessarily encompass the various cultural or ethnic health perceptions found in communities that are predominantly (for instance) Aboriginal. However, the individual’s perception of their health does influence their readiness to seek health care and these generalisations do give an idea of how rural people react to ill health. For instance, they often seek care when the symptoms become overwhelming, rather than earlier in the course of a disease because they could cope with the problem and complete their roles then. Or a severely debilitating condition (eg fractured arm) may be viewed with more alarm than an ongoing chronic condition (eg hypertension, diabetes) that, although potentially more harmful, does not currently stop the person from working (Bushy 2000, p. 39). Often, the traits that country people have developed assist them to deal with adversity such as living with a chronic pain condition.

Significance of chronic pain

Chronic pain is defined by the International Associate for the Study of Pain (1986, p. 229) as pain that lasts continuously or intermittently for a period of 6 months. The cause of chronic pain is often unknown. In a study conducted by telephone interview with 17,000 randomly chosen adults, the incidence of chronic pain was estimated at 17.1 % (males) and 20% (females) of the adult Australian population (Blyth et al., 2001). Eleven percent of the males and 19% of the females experienced interference with activities of daily living from their chronic pain. Estimates in other developed countries vary according to the definitions of chronic pain used and the methods used to obtain the statistics, although the incidence of chronic pain is fairly stable in developed nations at between 15 and 25% of the community (Brennan, Carr & Cousins 2007, p. 207). Under-reporting of chronic pain states is suspected because of some studies that indicate the magnitude of the problem is greater than reported. For instance, in one study, a community survey of 600 randomly chosen participants indicated that between 1/3 and 1/2 of people in a regional American city believed common pain treatment myths. Many of these people were more likely to endure pain than to report it (Mayer, Torma, Byock, & Norris, 2001).

In a National Health and Medical Research Committee report from 1990, chronic pain costs Australian society $10 billion annually (Aoun & Howe, 1998b). Of this, van Leeuwen, Blyth, March and Cousins (2006, p. 161) estimate that 5.1 billion is lost due to absences and substandard productivity as well as unemployment due to health reasons. This societal cost is monetary only and does not take into account the social, cultural and intellectual contribution that is lost due to the disengagement of the person living with chronic pain from the mainstream of work and social intercourse (Tollefson, Piggott & Fitzgerald 2008).

Not only are monetary and societal costs attributable to chronic pain, but the personal costs are also high. People lose self-esteem, body image changes; there is an alteration in personal relationships and a loss of trust in the health care system. Indeed, Mayer et al (2001) state that pain that is not well managed destroys the person’s trust in the health professional and can result in failing health and increased financial commitments. Palmero, Harrison and Koh (2006) concur and suggest that the pain experience impacts significantly on health and wellbeing in children with uncontrolled chronic pain. Oddson, Clancy and McGrath (2006) also found this negative impact of pain in children with spina bifida.

There have been great advances in knowledge about pain – from the causes to the management, but to date, only sporadic process has been made in the actual understanding of key aspects of therapy such as adaptation to disease, reconciliation following loss and perhaps what is the core task of rehabilitation: accepting that one must relinquish the search for a cure and engage in the work of learning how to live with pain (Risdon et al, 2003, p. 376). This study helps to set the stage for health care professionals to help people living with chronic pain in rural areas to learn to live with their pain in a more peaceful and fulfilled way through revealing dimensions of their experience.

Significance of this study

This study is a hermeneutic phenomenological exploration of interviews with seven people who are living with a chronic pain condition in a rural area. That is, these people’s pre-reflective thoughts and ideas about living with chronic pain in a rural area were gathered in interview format, and their words were analysed using an interpretive framework. The interpretation and discussion of the findings illuminate and highlight the meanings in these texts that can improve understanding of the phenomenon of living with chronic pain in a rural context. Not only does a phenomenological study explore the common experiences of a phenomenon within a context, it also picks out and brings to light different experiences, thereby broadening the possibilities inherent in the situation. Health care professionals can read, reflect upon and further interpret these common inferences as well as the possibilities in order to provide more compassionate and effective care to people living with chronic pain in any rural setting.

Study aims

This study aimed to answer the question: What is it like to live with chronic pain in a rural area of Queensland? To this end, the main aims of the study were to interview people who lived in a rural area of Queensland who lived with chronic pain. No distinction was made about the cause of the pain, only that it was chronic.

Structure of this thesis

This work is a striving to understand the significant experiences of those who live in a rural area and who also live with chronic pain.

The second chapter entitled Chronic Pain Literature Review is presented to inform and set the scene for the study. Chronic pain has been well researched in its' many facets, both using the quantitative paradigm, and increasingly, qualitative approaches. An historical outline, followed by a brief discussion of the theories of pain are presented. Pain and chronic pain are defined. The epidemiology, physiology and psychological effects of chronic pain are outlined. Aspects of pain management are sketched. The pain experience is described, using a representative portion of the qualitative studies undertaken to begin to understand the intricacies of chronic pain.

Chapter three discusses the hermeneutic phenomenological approach according to van Manen as the methodology for this study. An understanding of this philosophy is explicated in this chapter.

Chapter Four describes the methods used to complete the study. Ethical considerations, participant recruitment, data collection methods, data analysis and management, the strategies used to enhance rigour are presented. There is also a discussion of the researcher's various roles.

Chapter Five consists of descriptions of all of the participants in the study to give background information prior to presenting and discussing their lived experiences of chronic pain in the rural areas. This chapter also encompasses a narrative written to 'bracket' my own understanding of the experience of chronic pain in a rural area. This chapter is called 'Portraits'.

The next four chapters, Six, Seven, Eight and Nine, outline the findings of the study with interwoven discussion of individual findings pertinent to the lived experience of chronic pain in a rural area. The discussions are supported by interesting information from a range of literature. The findings are presented using the four existential themes (van Manen, 1997) of temporality, spatiality, corporeality and relationality.

Chapter Six presents the theme of spatiality in ‘The Country Style of Life’ and how chronic pain and rurality interact within this concept. Chapter Seven explores the essence of temporality - time - in relation to pain and the rural context. This chapter is entitled ‘This is My Life Now’. Chapter Eight ‘Some Days are Better Than Others’ explores how chronic pain and the rural setting impact on the participant’s bodily experiences. The final findings/discussion chapter, Chapter Nine, entitled ‘Relationships in Pain’, delves into the relationships and their effects on the participant’s experiences of chronic pain in rural areas.

The penultimate chapter, entitled ‘Closing the Circle’ uses understandings from the previous four chapters and draws the disparate findings together to reinforce aspects of each of the four existential themes that are particularly relevant to the rural context.

The final chapter is a description of the implications of the study, along with the limitations of the research and recommendations for practice, education and further research.

Conclusion

This introduction has provided the reader with some background to this study. Information about the rural context has been followed by a definition and brief discussion of the significance of chronic pain. The significance of this study was discussed and the aims of the study presented. A brief summary of the structure of the thesis was presented. The following chapter, the literature review explores in depth important concepts in chronic pain and offers explanations and recent understandings of these concepts.

Chapter 2 - The Literature Review

Chronic Pain

Introduction

Chronic pain is a complex phenomenon that health care professionals are required to deal with on a daily basis. The literature on chronic pain and the research into and about this symptom is voluminous. It is beyond the scope of any one review to discuss all of the aspects of chronic pain and all that has been written about it. This literature review will approach chronic pain by outlining some historical views of pain, then discussing briefly the quantitative research literature and finally the qualitative literature. This chapter reviews the health related literature on pain. There is an enormous body of empirical literature on pain and chronic pain, much of which is important in understanding the physical and psychological effects of pain which impact on individual experience. Since the 1950's, pain has been recognised to consist of several categories. This review will begin with a general discussion of pain, then move into a discussion of the effects of chronic pain, which is more relevant to this study. The personal experience of chronic pain has received relatively little attention. The final part of this review will address some qualitative understandings of the experience of living with chronic pain.

Literature was accessed from several sources. Manual searches of journals, textbooks and print material were undertaken periodically from 2002 until late 2008. The same timeframe was used to search databases such as Ingenta, Proquest 500, Medline, CINAHL, Google Scholar, and lately, X-Search. Medical and allied health literature as well as nursing literature was sought. Search words included 'chronic pain', 'rural', 'qualitative' 'phenomenology', as well as particular aspects of the phenomenon of living with chronic pain that became apparent through the general searches, such as 'pathophysiology', 'assessment', 'depression', 'suffering', 'resilience' and 'coping'. Material was also accessed from conference proceedings. No time limits were imposed on the supporting materials used, as long as the material sourced was relevant to the study.

A potted history of pain

Physical pain is as old as mankind and discourse about pain has been found in texts dating from antiquity. Prehistorically, extracting the intruder or drawing off the magic, evil or demons that had invaded the body treated pain. Evidence exists of these efforts in such remains as burr holes in mummified skulls, and in the instruments used to ward off the demons or appease the appropriate deity (Bonica & Loeser, 2001, p. 205). Texts from ancient cultures such as India, China, Babylon, Egypt, Mesoamerica and Greece ascribe causes and describe treatments for pain and many notable scholars and philosophers have written about pain. Huang Ti (2600BC), Pythagoras (566BC), Plato (477BC) and Aristotle (384 BC) wrote of the existence of pain and of its effects on people (Bonica & Loeser, 2001). As it is a phenomenon to which we ascribe meaning, throughout the ages, pain has meant different things to different peoples. Rey (1995, p. 17) describes the various meanings of pain and its causes and management in the history of the western world. She states that pain was viewed as part and parcel of everyday life during antiquity. Livingstone (1998, cited in Fields, 1999, p.S61) further illuminates the concepts of pain to the ancient Greeks as an emotion, opposite to pleasure, rather than the complex phenomenon it is currently viewed as. However it was viewed, pain was treated by specialised authorities who were seen to have supernatural powers that enabled exorcism of the pain. These shaman, medicine men, priests or wise-men also became adept at prescribing heat, cold, pressure, massage, diet, exercise and specific herbs to assuage their patient's pain. The Chinese have used acupuncture and moxibustion, although the origins of these treatments have been lost over the millennia.

The Middle Ages saw monasteries as the repository of knowledge remaining from the Greek and Roman and earlier times. The monks and nuns kept knowledge of herbal medicine and treatments alive in the western civilisations. However, there was a division between the literary tradition of the monasteries and the practices and beliefs of the populace outside their walls. Rey (1995, p. 49) describes the perception that pain is a sign of divine retribution or of having been ‘chosen’ during the medieval era. Bonica and Loeser (2001, p. 6) discuss the scientific thought on pain during these times. The concept that the heart was the organ responsible for pain was a widely held, although not exclusive view during the medieval times. The Arabian physician, Avicenna (980 - 1038) advanced the idea that the ventricles of the brain were the seats of sensation. This concept was resurrected and flourished during the Renaissance (sixteenth century) when DaVinci described nerves as tubular structures that along with the spinal cord, carried sensation to the brain. Rey (1995, p. 67) describes pain as a sanctified and private, individual experience during the Renaissance. Bonica and Loeser (2001, p. 6) claim there were virtually no advances in the treatment of pain during these centuries.

Advances in science and technology, more systematic observation and the ideals of rationality marked the Enlightenment and the emergence of scientific medicine spanning the late 17 to late 18th centuries. In this period there was a decline in dependence on superstition and religion. Until the 18th century, the causes of pain were attributed to either the physical environment or to moral misdeeds. Rey (1995, p. 85) describes the belief that pain was a phenomenon with the dual facets of soul and body during the Classical age. Pain was seen as a secular symptom of physiological origin in the Age of Enlightenment (Rey 1995, p. 91). During the seventeenth century, the heart continued to be seen as the seat of sensation in parallel with the brain. Descartes (1596-1650) described the nerves as tubes containing fine fibres that carried the pain sensation from the peripheries to the brain (Descartes 1664, cited in Bonica & Loeser 2001, p. 6). During that century, Harvey (1628) wrote that the heart was the site where pain was felt (Bonica & Loeser 2001, p. 6). These authors (2001, p. 7) further describe great advances in the knowledge of the anatomy and physiology of the central nervous system during the eighteenth century. They acknowledge the beginning of the age of anaesthesia with the discovery of nitrous oxide by Priestly and its subsequent use as analgesic as well as anaesthetic by Sir Humphrey Davy. During the Age of Discovery, the development of further technology such as the microscope occurred. Laboratory experimentation meant that medical diagnosis became the domain of trained specialists dealing with material that was invisible to the naked eye. Because of scientific knowledge and experimentation as well as discoveries in anatomy and physiology, improvements in pain treatment continued throughout the following century.

During the nineteenth century, the following advances were made in the treatment of pain. Morphine and other opioid drugs were isolated from opium. Acetyl salicylic acid (aspirin) was compounded from various isolates of natural plant extracts. Ether was demonstrated to be an effective general anaesthetic. The needle and syringe were developed and led to the injection of analgesics and later local anaesthetics (initially cocaine). These advances contributed to the development not only of surgery, but also diagnosis and treatment of non-surgical pain. Also, during the nineteenth century, hypnosis and psychotherapy were employed for both surgery and non-surgical pain management. With the advent of anaesthesia, asepsis and using the specificity theory, neurosurgical procedures were used to control previously intractable chronic pain (Bonica and Loeser 2001, p.7)

During the twentieth century, the clinical application of the espoused theories (see below) meant there were remarkable advances in the treatment of pain. Techniques were developed using regional anaesthesia and neurosurgical operations to control both acute and what we now know as chronic, pain conditions. Methods were developed to destroy specific nerves and relieve severe, intractable cancer or other pain. These methods and techniques have however, fallen into disuse with the more recent, sophisticated understandings of nerve physiology. Hypnosis and psychotherapy have enjoyed short periods of enthusiastic use. Synthetic analgesics have been developed (eg Pethidine, paracetamol) and many classes of drugs that reduced pain (eg anti-inflammatory drugs) have been developed and introduced. These drugs are readily available, inexpensive, easy to administer and reasonably effective in relieving various types of pain. Not only the advances in understanding physiology of pain and techniques for its control developed over the years, but consolidating theories were also proposed.

Theorising on Pain - Rival Theories

Rey (1995, p. 135) discussed pain as a phenomenon for examination (and introduced the specificity theory) during the Age of Discovery. Bonica and Loeser (2001, p. 7) concur that the physiological research centred on sensation culminated in the development of the specificity theory by Muller in 1840 and its definitive formulation by Schiff in 1856. Bonica and Loeser (2001, p.7) outline the specificity theory as pain being a sensation that is felt when information is transmitted through a system of pain-energy carrying nerves from the pain sensory organ to the pain centre in the brain. During those years, a rival pain theory was developed from the original thinking of Aristotle that pain arose from increased sensitivity to every sensation. Erasmus Darwin, during the eighteenth century, had refined this thinking and attributed pain to excessive stimulation of the sense of touch. Finally, Erb in 1874 explicated the theory that “every sensory stimulus was capable of producing pain if it reached sufficient intensity” (Bonica & Loeser 2001, p.8). Goldschieder in 1894 completed the theory by adding central summation to the stimulus intensity as critical determinants of pain (Bonica & Loeser 2001, p. 8). These authors discuss the third pain theory that arose, again from Aristotelian thinking by a number of researchers. This was that pain was an affective quality. The proponents of the pleasure-pain theory were bitterly opposed to the physiologists who held with either the specificity theory or the intensive theory. Fierce controversies raged. The then president of the American Psychological Association, Strong in 1895, controversially proposed that there was also a psychic reaction to the sensation.

More recently, pain has been a subjective symptom to be understood and controlled during the Modern age (Rey, 1995, p. 336; Vlaeyen & Morley, 2005). Bonica and Loeser (2001) trace the development and thinking about pain theories during the first 6 decades of the twentieth century. Several theories were proposed to take into account the observations and discoveries made by both physiologists and clinicians. The pattern theory proposed by Nafe (1934) and subsequently Sinclair and Weddell, suggested that all nerve fibres are alike and pain arises by intense stimulation of non-specific receptors (Gatchell, Peng, Peters, Fuchs, & Turk, 2007). Bonica and Loeser (2001) outlined the central summation theory proposed by Livingston (1943) describing a complex interaction of spinal cord activity in response to stimulation from damaged nerve endings that was termed reverberation. The reverberation activates the somatic and sympathetic nervous systems as well as the brain mechanisms that underpin pain sensation. The 'fourth theory of pain' resurrected Strong's duality idea from the turn of the century. This theory proposed that pain is both a neurophysiological process similar to touch (ie a combination of the specificity and intensive theories) and is also a complex physio-psychological process involving cognitive functions and influenced by cultural factors, past experience and other psychological factors to produce great variation in response to pain. The first fifty years of the twentieth century saw both the intensive and the specificity theories explored, developed, used and taught, but by mid century, the specificity theory had become accepted. Noordenbos (cited in Bonica & Loesser, 2001, p. 9) proposed the sensory interaction theory in 1959. This theory suggested the existence of two systems involved in the transmission of pain - a slow system of unmyelinated fibres and a fast, myelinated nerve track. The slow system terminates in the dorsal horns of the spinal cord and summation of inputs from the slow fibres produces neural patterns that are transmitted up the spinal cord to the brain where they are perceived as pain. The fast fibres inhibit transmission of impulses from the slow fibres and prevent summation from occurring.

The recent and current research has been mainly quantitative research, which circumscribes the phenomenon of pain. Areas such as physiological (neural pathways, modulating factors) mechanisms have occupied biological researchers for most of the last half of the twentieth century. Melzack and Wall (1965) introduced a theory of pain that removed pain from a peripheral phenomenon to a central one, with the central nervous system playing a major role. They also postulated that pain is not a pure sensation but is modified by the person's internal and eternal world. The gate control theory states

- There is a ‘gate’ mechanism at the spinal level that modulates incoming sensory nerve impulses
- The gate mechanism is activated by the amount of activity in large diameter nerve fibres (closing the gate/inhibiting transmission) and the activity in small nerve fibres (which opens the gate/facilitates transmission)
- There are influences on the spinal gating mechanism from nerve impulses that descend from the brain.
- The central control trigger (a specialised system of large fibres that conduct rapidly) activates particular cognitive processes that direct (using descending fibres) the modulating properties of the spinal gate mechanism. Precise information about the location and nature of the stimulus is carried rapidly upward and cognitive influenced responses downward, influencing the sensory input of the gate control system and at other levels of the neuraxis. These rapid transmissions allow the brain to identify, evaluate, localize, and selectively modulate the sensation before action systems are activated.
- When the sensory input surpasses a threshold at the gate, an action system activates, resulting in the complex experiences and behaviour that signal pain. (Bonica & Loeser, 2001, p. 10)

Subsequently the gate control theory was modified to take into account new knowledge and information on physiological mechanisms, behavioural research results, and psychiatric findings. The motivational, affective and cognitive aspects of the pain experience have been explained by neural systems beyond the gate and involve interaction of various regions of the brain (Bonica & Loeser 2001, p. 10) and Melzack and Casey (1968) hypothesised that pain can be divided into sensory/discriminative and affective/motivational components. The gate control theory had been widely disputed but after a decade, numerous research studies had demonstrated its strengths. The theory has been widely accepted as established fact (Fields 1999) and has had enormous implications for pain research. Melzack (1999) emphasised that "the theory forced the medical and biological sciences to accept the brain as an active system that filters, selects and modulates inputs" (p.S121). The gate control theory of pain modulation has dominated the research into pain by physiologists, neurologists and psychologists for a quarter of a century. However, Fields (1999) suggested that this theory was no longer useful, and actually could be impeding neurobiological research. He proposed that to understand the nature of pain as a combination of unpleasant somatic sensation plus a unique 'pain-sensation', which he terms 'algosity', necessitates the re-examination of the dichotomy proposed by Melzack and Casey (1968). Melzack himself has also concluded that there is more to the phenomenon than can be explained by the Gate Control Theory. He proposed the neuromatrix theory of brain function (1999).

The neuromatrix theory is a new conceptual model of the nervous system and is based on four conclusions made while studying phantom limb pain. These conclusions are:

- Normal body sensation is subserved by the same neural processes in the brain, which are activated and modulated by inputs from the body, but can act in the absence of inputs.
- The origin of the patterns that underlie the qualities of experience lie in neural networks in the brain: stimuli may trigger the patterns but not produce them.
- The body is perceived as a unity and is identified as the 'self', distinct from other people and the surrounding world. This unity is produced by central neural processes and cannot derive from the peripheral nervous system or the spinal cord.
- The brain processes that underlie the body-self are 'built-in' by genetic specification that is modified by experience (Melzack, 1999, p. S123).

The efficacy of this pain theory will require further research to demonstrate its worth.

All of the above theories have dealt with mechanisms of pain that was caused by damage to tissue/peripheral nerves/ central nervous system. During the last half a century, interest has turned to chronic pain for which no organic cause can be found. In 1976, Fordyce developed a concept of operant (behavioural) conditioning and in 1980, Pilowsky proposed the concept of chronic abnormal illness behaviour (Siddall & Cousins, 2004). Both these hypotheses have been developed to explain chronic pain behaviour in patients who have minimal or no demonstrable pathology. Sidall and Cousins (2004) argue for the recognition of persistent pain as a separate disease entity, certainly with its own pathological explanation and perhaps with a genetic component that occurs within a specific modifying environment. Gatchel, et al. (2007) underline that within the neuromatrix theory, pain is a result of the interaction of the widely distributed brain neural network rather than a sensory response to a pathology or tissue insult, and in fact, a pain experience can be felt with no actual sensory input.

But Pain Persists

Pain is still the greatest clinical problem (Gatchel et al., 2007) and there is evidence to suggest that many types of acute and most chronic non-malignant pain remains unrelieved. Bonica and Loeser (2001) suggest three reasons for this deficiency. The first is a void in knowledge. Although there have been great advances over the twentieth century in understanding pain, the research has not been commensurate with the clinical importance of pain until the last two decades. They attribute the lack of research to the fact that acute and chronic pain were not differentiated until recently, that fragmented independent research has been carried out in isolation, the emphasis of the specificity theory in the first half of the century, the lack of appropriate funding and research education focussed on pain. The second reason is inadequate application of available knowledge and therapies. Lack of in-depth education about both acute and chronic pain has led to use of pain as a diagnostic indicator. Treatment is aimed at acute pain, leaving patients with chronic pain syndromes to be ineffectively treated. Under-prescribing and under-administering analgesics by health care professionals is due to the lack of understanding of the pharmacology of the drugs and overestimating their deleterious effects. The final reason is lack of effective communication. Up until the 1970s dissemination of research findings occurred in highly specialised journals and conferences. This prevented scientists from different disciplines using each other's work, and clinicians from benefiting from important findings. There has also been a lack of national and international data banks and a standard taxonomy of pain and pain syndromes. These factors have all inhibited vigorous and fruitful basic and applied research in the area relating to chronic pain. Most recently, persistent pain is being redefined from the previous understanding of this phenomenon as symptomatic of some disease process to being a disease entity in its own right (Siddall & Cousins, 2004). From this outline of the historical and theoretical perspectives of pain, the duality of mind/body, and from these links a definition is drawn.

Towards a definition of pain

Pain definitions are evolving as more is learned about pain. Wall, an eminent researcher into pain theory and pain physiology states that “Pain is” (Melzack & Wall, 1975, p. xx) and McCaffery (cited in Black, Hawks, & Keene, 2001, p. 463) describes pain as “whatever the experiencing person says it is and exist whenever he says it does”. These definitions, although highlighting the subjective nature of pain and certainly guiding pain management, are not particularly useful in understanding the nature of pain. The International Association for the Study of Pain (IASP, 2008) describes pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage”. This definition is more easily used in an attempt to understand the nexus between the physiological sensations and the psychological context of pain. There are other definitions of pain, but this one is useful since it does not delimit pain to a physiological process

Indeed, Chapman and Gavrin (1993 p. 6) state that the IASP definition suggests that pain involves at least 2 kinds of processing within the central nervous system: the sensory processing giving spatial, temporal, and qualitative information to the brain and the affective processing providing the individual with the (usually) negative emotional reaction to tissue insult. Price, Curless and Rodgers (1999) suggest a more evolved definition of pain as having three interdependent aspects. These are the sensations like those that occur during tissue damage, a feeling of threat from these, and a negative emotional reaction to the perceived threat. This explanation parallels Sternbach’s 1968 definition (cited in Black et al., 2001) of pain as an abstract concept of a personal, private sensation of hurt referring to a harmful stimulus that signals current or impending tissue damage; and the resultant pattern of responses to protect the individual from harm. As can be seen from this brief outline of the definitions of pain, this field of study is not static. As new understanding is gained from research, the definition of pain will continue to develop and mature.

Acute pain is the type of pain most people will experience in the course of their lives. It is defined as pain of short duration and is due to an identifiable, immediate onset, with a limited, predictable duration. It is considered a useful and limiting pain because it induces people to seek relief – either by physically limiting movement or by seeking professional assistance (Black et al., 2001). Acute pain is not the focus of this literature review but is included here for the sake of distinguishing acute pain from chronic pain. Defining chronic pain is complex because of the interrelationship of pain with an extended temporal component that causes the development of alterations in behavioural response, lifestyle changes, alterations in interpersonal relationships as well as the alterations wrought in the affected person's concepts of themselves. The International Association for the Study of Pain (IASP, 2008) further defines chronic pain as pain that lasts continuously or intermittently for a period of 6 months. The cause of chronic pain is often unknown.

Chronic malignant pain is chronic pain that is progressive (IASP, 2008). It is expected to increase in intensity or duration, or both. It is usually due to the effects of cancers, but can arise from non-neoplastic diseases such as some types of rheumatoid arthritis or ankylosing spondylitis. Chronic non-malignant pain (IASP, 2008) is chronic pain that is not expected to progress or to progress very slowly over a long time frame. Low back pain, osteoarthritis, neuropathological pains such as those encountered in spinal damage or in diabetes are examples of chronic non-malignant pain.

Physiology of pain

The complexity of pain neurophysiology is currently under intense scrutiny. Dozens of articles appear monthly that advance knowledge about the mechanisms that promote and regulate pain, and about the functions of the brain that are concerned with pain. The present understanding of the neurophysiology of pain (initially of acute pain, then an explanation of chronic pain) was synthesised from a number of sources. The structures involved in the stimulus recognition and subsequent transmission and perception of pain are termed the nociceptive system. This system can be affected by many different factors that may be internal or external to the individual. Nociception begins with the identification of intense, potentially damaging stimulation of nociceptors (pain receptors) located near the skin, in joints, fascia, muscle, tendon, periosteum and corneal tissue. The perception of visceral pain uses a system of multipurpose nerve fibres rather than the specific nociceptors, which are located only in the capsules of some of the organs. The stimulation can be mechanical, thermal or chemical in nature. The nociceptor has a complex multidirectional pathway. Nearest to the nociceptor, branches stimulate blood vessels to dilate and mast cells to release histamine. Sweat glands and hair follicles are stimulated. If there has been actual tissue damage, chemical mediators are released that cause vasodilation and increased vascular permeability as well as increase the transmission and perception of pain. These mediators are histamine, bradykinin, prostaglandin, serotonin, hydrogen, potassium, leukotrienes, nerve growth factor (if a nerve cell was damaged) acetylcholine and substance P. More centrally, the nociceptor pathway branches off and stimulates the paravertebral sympathetic nerve chain and thus the viscera, producing the vasomotor, autonomic and visceral effects of pain. Yet other branches of the nociceptor reach and terminate in the dorsal horn of the spinal cord. These are termed A-delta fibres and C fibres. A-delta fibres relay sharp, cutting or stabbing sensations. C fibres relay dull, burning sensations. These branches stimulate the ascending sensory pathway so the impulses are relayed to the lower and mid portions of the brain. Here the impulses are transmitted to the cortex of the brain where interpretation occurs. There are, however some important intermediate structures that can alter the transmission and perception of the pain stimulus (Byers & Bonica, 2001; Chudler & Bonica, 2001; McCance & Huether, 2006; Porth, 2005; Terman & Bonica, 2001; Tortora & Grabowski, 2003).

The interpretation and response to pain occur within the central nervous system. The thalamus acts as a relay transmission centre, and is essential for pain perception as all of the tracts that are important in pain production synapse directly or indirectly in the thalamus. The limbic system is a poorly understood group of structures including the hypothalamus, hippocampus, and amygdala, part of the frontal lobe and areas of the cerebral hemispheres. In pain, it is responsible for emotional and instinctive reactions, body rhythms such as the sleep cycle, translating short-term memory into long-term memory and some of the activities of the autonomic nervous system. The spinoreticular pathways between the medulla and the thalamus within the brainstem stimulate the reticular formation, which influences an individual's level of attention to the noxious stimulus. The reticular formation interconnects within its own structure as well as with the cortex, pons, limbic system, medulla, thalamus and hypothalamus forming the reticular activating system. This system sorts and sends sensory organ information (including pain sensation) to the appropriate part of the cortex. Additionally, the reticular activating system has a descending feedback loop from the cortex to the thalamus and back to the reticular activating system which, when stimulated, increases the electrical activity within the loop and heightens the stimulation/ sensation. The central cognitive processing mechanisms occur in the cortex. Memory, learning, judgment and abstract thought are brought to bear on the pain sensation and modify its effects (McCance & Huether, 2006; Porth, 2005; Tortora & Grabowski, 2003).

Chronic pain has an added layer of complexity. Recently, the physiological mechanisms of chronic pain such as imbalances in serotonin and other neuromodulating agents, have served to differentiate it from acute pain (Porth, 2006). Chronic pain can be termed pathological. Pathological pain reflects disruption of normal sensory mechanisms. It occurs in response to “normally innocuous stimuli or ill-defined stimuli and the pain response to noxious stimulation may be exaggerated and prolonged. During pathological pain, nociceptor thresholds become lower (sensitisation), signals become amplified and aversive sensations greatly outlast the duration of the stimulus that provokes them” (Chapman & Gavrin, 1993, p. 8). As well, Burrell, Gerlach and Pless (1997, p. 198) describe both benign chronic pain and pathological pain. They discuss the structural changes that occur such as muscle spasm, low-grade inflammatory responses that contribute to ongoing pain and the injury to peripheral or central nerves with the cascade of neurochemical events that alter the neurons resulting in aberrant impulse firing.

Chronic pain promotes an extended and destructive stress response characterised by interruption in the neuroendocrine system, fatigue, dysphoria, muscle pain and impaired mental and physical performance. Chapman and Gavrin (1993) suggest that the effects of a chronic stress response become maladaptive over time, making the individual less resistant to all types of stress. Brennan, Carr and Cousins (2007, p.

205) concur and add that physiological responses to chronic pain also include reduced mobility, and resultant loss of physical strength, disturbed sleep, and decreased immunity resulting in increased susceptibility to disease. This constellation of discomforts and functional limitation can foster negative thinking and create a vicious cycle of stress and disability. The idea that one's pain is uncontrollable in it leads to stress. Patients suffer when this cycle renders them incapable of sustaining productive work, a normal family life and supportive social interactions (Chapman & Gavrin, 1999, p. 2235). Liebeskind (1991, p. 3) states that evidence from laboratory experiments shows that pain can accelerate the growth of tumours by impairing the immune system and thus increase mortality - “pain can kill”.

The link between chronic pain and depression is also firmly established (Gatchell et al., 2007). One or both of the neurotransmitters serotonin and norepinephrine have become depleted in both chronic pain and in depression (Gallagher, 2002). Gallagher (2002) cites many studies conducted over the past two decades in both animals and humans, that combined, demonstrate that the following hypotheses are at least partially correct. These hypotheses are: chronic pain is a symptom of masked depression; the stress of chronic pain causes depression; and the stress of depression causes chronic pain. These hypotheses require one more factors to be considered. Genetic predisposition seems to dictate individual reaction to chronic pain/depression, explaining why some people do have both symptoms simultaneously, while others do not. Neuro-physiologists continue to unravel the complexities of pain.

Epidemiology of chronic pain

Blyth, et al (2001) undertook a computer assisted telephone survey (i.e. they did not use telephone directories as the sampling frame so that people with unlisted numbers were included) of a randomly selected sample of the adult Australian population. The response rate was 70.8%, yielding 17,543 interviews. Overall, 17.1% of males and 20.0% of females reported pain that was experienced daily for 3 months of the 6 months prior to interview. In the 65-69 year age group, males had the greatest representation at 27% and females’ chronic pain prevalence peaked in the oldest age group (80 - 84) at 31%. Interference with activities of daily living was reported in 11% of males and 13% of females. People living with chronic pain were six times as likely to be unemployed due to health reasons as those without chronic pain. Blyth, March et al (2001, p.127) concluded that chronic pain impacts on a significant proportion of Australian adults of working age and is associated with socioeconomic disadvantage. This study included only residents of NSW, which is 77% urban dwelling, although it did make provision for non-English speaking participants by using interpreters in 6 languages other than English.

James, Large, Bushnell and Wells (1991) discuss an epidemiological survey of an urban centre in New Zealand. Although their survey did not specifically address chronic pain, it produced results that indicate that the majority of the 1498 adults surveyed experienced one or more life-disrupting episodes of pain. Von Korff, Dworkin, Le Resche and Kruger (1988) surveyed a large number of adults enrolled in a health maintenance group in an urban area of the United States. They found between 12% and 40% of their sample reported persistent pain that interfered with some of their life activities, depending on the location of the pain. Twelve percent of patients reported facial pain, 35% headache and 40% back pain. Pain is often not reported, though, because there is no appropriate treatment or because people endure and manage their pain in their own way rather than seeking assistance and therefore avoid being registered as a chronic pain' statistic (Mayer et al., 2001). Besides the underlying physiology and structure of pain, and its prevalence in the population, research has explored various other aspects of the pain experience.

Effects of chronic pain

Depression and chronic pain

Depression is a frequent accompaniment to chronic pain. The dysphoria of depression is thought to result from a similar cascade of chemical disturbances in the brain that result in chronic pain (McCance & Huether, 2006). Gray (2001) reviewed recent literature on chronic pain and depression and found that there is a relationship between chronic pain and depression, but was unable, from the literature she reviewed, to pinpoint the nature of the relationship other than that social, biological and psychological factors influence the relationship. Gatchel et al (2007) extend this understanding of the reciprocity of chronic pain and depression and implicate the interdependence of cognition and affect – that is, the effect that the pain has on the person's life and their level of control over the pain and their lives.

Depression has been postulated as a mediating factor in elderly people’s perception of and reaction to chronic pain (Gagliese & Melzack, 1997). These authors also suggest that there is considerable evidence of the co-morbidity of pain and depression and that clinical differentiation is not necessary as long as a comprehensive pain assessment and psychological evaluation is carried out prior to treatment. Others pursued the cause. In a well-constructed 4 cell design family study of patients with chronic pain myofascial pain (a musculoskeletal pain syndrome) was determined to be a risk factor for depression and the authors supported a pain-as-causal-stressor hypothesis (Dohrenwend, Raphael, Marbach, & Gallagher, 1999). Williams, Jacka, Pasco, Dodd and Burke (2006) conducted a literature review of depression and chronic pain and concluded that there are neurobiological mechanisms linking chronic pain and depression which are mutually interacting. These findings have considerable implications on the treatment of chronic pain and depression and also on the patient’s experience of these phenomena. In a cross sectional retrospective path analysis methodology study of 126 people living with chronic pain, pain intensity, chronic pain self-efficacy, pain disability and depression were measured (Arnstein, Caudill, Mandle, Norris, & Beasley, 1999). These authors demonstrated that higher pain intensity and reduced self-efficacy contribute to disability and depression. They also found that it may be the person’s self-efficacy (belief in their own ability to accomplish a task) rather than disability that caused depression (Arnstein et al., 1999, p. 488).

Chronic pain and depression have been associated with suicidal ideation. Three groups of people with chronic pain conditions - those who were depressed with suicidal ideation, those who were depressed without suicidal ideation and those who were not depressed were studied to determine the causation of suicide ideation (Fisher, Haythornthwaite, Heinberg, Clark, & Reed, 2001). The groups were small, but matched for age, sex, race and socioeconomic background. The authors found that the severity of depression, not chronic pain or disability is an underlying cause of suicide attempts. The patients experiencing chronic pain without depression espoused no suicide ideation. Other risk factors were associated with suicide attempts- active suicide thoughts, previous attempts and close family relatives who are substance abusers seem to be more predictive of suicide attempts than is severe chronic pain and disability. Depression also contributes to an individual’s perception of suffering.

Suffering and chronic pain

Chapman and Gavrin (1999, p. 2235) define suffering as the “perception of serious threat or damage to the self”, and it emerges when a discrepancy develops between what one expected of one’s self and what one does or is. They outline the complexities of the psychological self (neurological, agent, cognitive and dynamic) and how each is affected by suffering. They propose a model of the mechanisms and effects of stress in patients with chronic pain and demonstrate how chronic pain causes suffering through a destructive cascade of neural and endocrine responses that erode both physical and psychological well being. More simply, suffering is a negative affective response (distress) to the perception of a noxious stimulus by the central nervous system. The noxious stimulus can be pain, but can equally be emotional states such as fear, anxiety or depression (Atli & Loeser, 2004).

Morse and Penrod suggest a model of suffering that relates this concept to the “emotionless state of enduring” (Morse & Penrod, 1999, p. 145). Using previously gathered data from 3 separate qualitative studies involving all of the concepts of suffering, enduring and hope, Morse and Penrod integrated the 3 concepts plus 'uncertainty' to assist in understanding the work that people must do when faced with a catastrophic event in their lives. This could help nurses gain insight into patient behaviour and to identify appropriate strategies to deal with patient discomfort in clinical situations.

Rodgers and Cowles (2008, p. 1066) discuss suffering as an individual experience, complexly and subjectively synthesised using very negative constructs of an event or threat. Within the complexity of suffering lie cultural, personality, gender and contextual roles, and the trajectory of suffering also alters the expression of this concept. Morse et al, (2003) suggest that there are two behaviour states within suffering, enduring or suppression of emotion and emotional suffering or the release (teariness, crying, cracked voice, sighs) of the emotions associated with suffering – chronic sorrow, distress, loss, grief and bereavement. Their research, an observational study of facial expression paired with verbal interview tapes, suggests that there is a pattern of facial cues in the transition phase between enduring and emotional release which can be observed and described.

As the discussion above indicates, there is no consensus on the definition of suffering, and each of the definitions and discussions is restricted in some way. Suffering is viewed as being caused by negative emotion or threat to self and can be influenced by a multitude of factors – indicating that suffering is a distinct phenomenon from chronic pain, although both these phenomena may, and often do occur together, with the chronic pain being one of the initiating factors of suffering. Suffering, then, may constitute one dimension of the chronic pain experience that impacts on the patient's perception of their quality of life. Suffering is not the only possible consequence of chronic pain; some people become severely disabled by their persistent pain.

Disability and chronic pain

Disability includes a wide spectrum of problems in meeting our own or the societal norms. Disability may be psychological, physical, intellectual or sensory. On disability, Ross and Crook (1998) assert that despite increasing evidence that pain is a problem with which many in their later years must contend, little is known about the experience of community-dwelling seniors who require the assistance of home nursing services to remain independent and functional in their homes. This study investigated the prevalence and experience of pain among seniors who were recipients of home nursing services. The World Health Organisation Classification of Impairment, Disability and Handicap guided the study. Face to face interviews were conducted with 66 individuals who reported whether they were often troubled by pain and/or had experienced pain of a noteworthy nature within the 2 weeks prior to the interview. In addition, they responded to standardised questions about their pain experience and their levels of disability and functional competence. Findings revealed that although three-quarters of respondents reported pain, there was no association between pain and measures of disability. Findings, however, revealed an association between pain and measures of functional competence, more specifically, global function, level of depressive symptomatology, sleep impairment and satisfaction with life. Ross and Crook (1998) outlined the implications for nursing: the need for a heightened awareness of the prevalence of pain in community-dwelling older adults and the development of assessment and intervention strategies that support their quality of life.

Chapman and Gavrin (1999) contribute to the discussion on disability. They contend that the disability that chronic pain causes has a greater negative effect on the patient’s quality of life and sense of self than does the sensory awareness of pain. This is because disability arises not just from the pain but also from the constellation of attending symptoms that develop as a maladaption to an ongoing negative stressor – chronic pain. The symptoms they list are fatigue; dysphoria with muscular aches and pains; disrupted or non-restorative sleep; somatic hypervigilance; reduced appetite and libido; impaired physical functioning and impaired concentration (p.2235). People living with disability caused by chronic pain feel sick, exhausted and impaired and their ability to maintain a normal, productive life is altered as a result. Other researchers have explored other aspects of chronic pain-related disability.

Crombez, Vlaeyen, Heuts and Lysens (1999) undertook a series of studies using a small sample (38) of patients with chronic low back pain. They examined the relationships between pain-related fear, chronic pain and disability. Their findings supported earlier studies that pain-related fear is more disabling than the chronic pain itself and that pain-related fear measures proved superior at predicting disability and poor behavioural performance than did biomedical and symptom scales, including pain intensity. On the other hand, some measures tend to reduce disability related to chronic pain. Jensen, Romano, Turner, Good and Wald (1999) hypothesised that the positive associations between the beliefs that pain signals harm, that one is disabled, that solicitous responses from others are appropriate and patient-reported physical and psychological dysfunction and pain level would decrease following participation in a multidisciplinary pain management program. They also explored the partner's report of the patient's pain and had independent observations of pain behaviours. There were strong associations between the partner-reported pain levels, the observed levels and the self-reported levels of pain, with the self-reports being most strongly associated with the pain beliefs. Their findings supported the cognitive-behavioural model of adjustment to chronic pain and offered strategies for altering pain beliefs and thereby reducing pain behaviour. This paper was so ‘experimentally’ reported that the patients did not seem to be human, but were reduced to ciphers and spoken of in laboratory terms. As much as a chronic pain condition affects the person and their partner, there are also effects on the entire family.

Effects of chronic pain on the family

Family forms the immediate context for the person living with chronic pain, and their familial interactions assist or hinder the person from adjusting to the pain condition. Smith and Friedemann (1999) undertook a qualitative study of family dynamics in relation to chronic pain. They used a semi-structured interview related to family function to elicit narrative descriptions from 30 participants who were living with chronic pain. The themes that emerged included emotional distress, distancing from family members, inability to share difficult feelings, intense mutual involvement with family and identification with other's problems, family isolation from community and attempt at healing. Family dynamics were altered by the chronic pain experience. The partner’s effect on the person living with chronic pain was explored by Romano et al. (1995) who used a strong observational design study of patient-spouse interactions to demonstrate that spouse solicitous responses to non-verbal pain behaviours predicted physical disability in the more depressed patients. They also showed that the solicitous behaviour toward non-verbal pain behaviours increased rate of the incidence of those pain behaviours in patients who had the greatest pain severity. Partners have a precarious line to maintain between being solicitous and thus increasing the negative effects of chronic pain and being supportive of their spouse. One of the factors within a partnership is that men and women respond differently to chronic pain.

Gender and chronic pain

Keefe, et al. (2000) utilised previous research to identify gender differences in the pain experience. These were: differences in socialisation of men and women regarding the expression of pain, (Bem, 1974; Otto and Dougher 1985; Unruh 1996; Fearon et al 1996, cited in Keefe, et al., 2000); that men and women may differ in their emotional response to pain and that expectations regarding social roles may alter the response to pain (Unruh 1996, cited in Keefe et al., 2000). Keefe, et al. sampled 168 people living with osteoarthritis and found significant differences in pain, pain behaviour and physical disability in men and women. Women reported significantly higher levels of pain and physical disability, and exhibited more pain behaviour during an observation session than did men. Further analyses revealed that catastrophising (the impact of negative thinking related to pain as well as catastrophic ideation) eliminated the effects of gender in relation to pain outcomes, even after controlling for depression. These findings highlight the importance of both gender and catastrophising in understanding the osteoarthritis pain experience and may have important implications for chronic pain assessment. Not only the experience of pain itself is influenced by gender, but there is an additional layer of intricacy in the health care provider- person with chronic pain interaction when the person with chronic pain is female (Frantsve & Kerns, 2007, p. 30). Negative gender stereotypes interfere with women's ability to authentically convey their pain experience.

Locus of control

Locus of control is a construct first introduced by Rotter in 1954 (cited in Buckelew et al., 1990). There are two styles described that impact on health. These are internal (belief that one's behaviour influences health) and external (belief that consequences of behaviour are contingent on outside forces such as God, fate, or powerful others). Bucklew et al (1990) determined that high internal locus of control in people experiencing chronic non-malignant pain indicated that these people would use cognitive self-management strategies more than either mixed (i.e. both internal and external locus of control features) or external locus of control patients. Research by DeGood and Keirnan (1996) supported these findings and suggests that those who have an internal locus of control adjust to the chronic pain and live fuller and richer lives. DeGood and Kiernan (1996) used a convenience sample of 188 patients who were attending a pain clinic for the first time. They examined the patient's perception of fault in relation to several parameters of the pain experience. They found that if the patient attributed the blame for their injury or pain to someone (employer, other driver, doctor), rather than no one, they reported greater mood distress and behavioural disturbance, as well as poorer response to past treatment and lesser expectation of future benefit. The findings about locus of control have implications for the facility with which an individual regains their lives – their resiliency.

Resiliency

Resiliency is the ability of an individual to adjust to the situational and cognitive challenges of stressful life circumstances such as chronic pain (LeFort, 2000). Aroian and Norris (2000) further elucidate the idea of 'resilience'. They consider resilient individuals to demonstrate a range of personal and interpersonal skills that assist them to adapt to stressful situations, either by altering the situation to a less stressful one or by supporting the person to come to terms with aspects of life that are uncontrollable. Although not qualitative, the questionnaire based study by Zautra, Johnson and Davis (2005) demonstrated that positive affect was influential in increasing resilience in the 124 women with chronic pain who participated. In 2006, another non-qualitative study demonstrated that positive affect bolsters resilience and assists patients to experience chronic pain fluctuations as less distressful than at lower levels of positive affect (Strand et al., 2006). Although this is an important aspect of living with chronic pain, this area of personal attribute is relatively unexplored in chronic pain literature and there is a need for further research in this topic. Resilience is closely aligned to coping with the chronic pain.

Coping with chronic pain

Research into the behavioural aspects of pain has added to the growing understanding of the pain experience. Studies on coping and coping mechanisms are frequent for different populations and for different disease processes that cause pain. Discussion of a sample of these studies follows.

The effect of age on coping with mild and severe chronic pain was examined using a quantitative approach. An age-stratified sample of 121 people with rheumatoid arthritis completed a modified Coping Strategies Questionnaire re: mild and severe pain. The questionnaire was determined to be both valid and reliable. The findings were that older adults are more likely to report use of maladaptive coping strategies in mild but not severe pain; older adults’ coping patterns reflected less-than-expected expertise in dealing with rheumatoid arthritis pain; individuals, regardless of age, used more active coping methods when in mild pain and more passive methods of coping when in severe pain (Watkins, Shifren, Park, & Morrell, 1999).

The effect of anxiety on coping with chronic pain was studied. In an empirical study, using the Multidimensional Pain Inventory, patients with chronic pain were classified as dysfunctional, interpersonally distressed or adaptive copers. This study compared 190 patients with chronic pain on measures of pain-related anxiety and pain acceptance. The dysfunctional group reported greater pain-related anxiety and less acceptance of pain that the other groups. Additional analysis controlling for depression and pain severity again demonstrated that anxiety and acceptance contributed to classification. Pain -related anxiety and acceptance of pain appear to be unique behavioural dimensions of adjustment to pain (McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999). Ashgari and Nicholas (2006) demonstrated the relationship of one personality dimension (neuroticism) of five dimensions on the pain related beliefs and the ability of people with chronic pain to use positive coping strategies for their pain. They suggested that people with a basic dimension of personality termed neuroticism might be more vulnerable to developing lower self-efficacy beliefs and perceiving themselves as having less control over their pain than those who are lower in the neuroticism dimension. Previous studies had demonstrated a strong link between neuroticism and suffering (Wade & Hart, 2002). Coping with chronic pain is one aspect of the wider aspect of adaptation, which in turn is heavily influenced by the adequacy or otherwise of their pain management.

Use of a bio-psycho-social model of pain management on the ability of the person living with chronic pain to cope was explored. Richardson, Adams and Poole (2001) combine a discussion of coping and pain management to illuminate the difficulties of measuring coping in people who are experiencing chronic pain. Secondary difficulties such as altered socioeconomic status compound the chronic pain problems. They propose a nursing model for the assessment of a patient’s ability to cope with chronic pain and to manage their pain without disability. To assess and manage the care of a person living with chronic pain, the health care professional must initially establish a therapeutic relationship with the individual. Such an endeavour can be hampered by the health care professional’s attitude toward people who live with chronic pain.

Health Care Professionals attitudes to people living with chronic pain

Physician and nurse's attitudes to chronic and persistent pain have been explored and as a result, educational research has been done to alter the negative attitudes and beliefs of health care workers people reporting chronic pain (McCaffery & Ferrell, 1996). Dohrenwend et al. (1999) discuss the stigmatisation of patients with pain that occurs in the absence of nociceptive stimuli or neuropathic mechanisms. They state people with chronic musculoskeletal (myofascial) pain often report health care professionals and others view their pain as psychological and evince negative attitudes toward them (Dohrenwend et al., 1999, p. 190). Smith supports this contention and suggests people with chronic pain are frequently mislabelled as hypochondriacs or malingerers because the cause of their pain is obscure, and the nature of pain is both complex and subjective (Smith, 1999, p.543). There remains a great deal of misinformation about people who live with chronic pain.

Brennan, Carr & Cousins (2007, p. 208) outline a number of entrenched myths that continue to prevent or delay adequate pain management and state that these myths are shared by health care professionals and people living with pain alike. They include the beliefs that: pain is an inevitable part of the human condition, and especially of aging and is required for diagnosis; is natural and beneficial; good patients do not complain; little economic consequence occurs because of untreated pain; people with chronic non-cancer pain are either malingerers or have psychological problems; and with opioid use, the fears are of uncontrollable side effects, drug abuse, diversion and addiction. They state that these powerful myths “continue to spread with the ease of an epidemic, independent of any need for logic or rationale” (p. 208). These authors argue that adequate pain management is a human right and that professional health personnel who disregard their responsibility to supply relief are morally, ethically and legally negligent. The myths need to be dispelled and health care personnel have an obligation to provide support to people living with chronic pain. One aspect of support is effective communication. Frantsve and Kerns (2007, p. 25) undertook a literature review on patient-provider interactions. They discuss the complexity of caring for people with chronic pain and recommend that health care providers work to enhance their communication skills and to improved assessment (especially considering the variety of factors that impact on chronic pain) and management skills.

Pain Management

Since chronic pain is prevalent in Australian society and the most frequent reason that people access health care (Blyth et al., 2001; Blyth, March, & Cousins, 2003), pain management is essential to relieve the pain and assist people to live their lives fully and/or reasonably comfortably. Excellent pain management starts with effective assessment, and follows up with various evidence-based approaches that are tailored to the individual’s situation. The following section will briefly introduce some of these characteristics of pain management.

Pain Assessment

Pain assessment is a vital first step to managing pain. Jensen, Turner, Romano and Fisher (1999) conducted a study to test the reliability and validity of the 0-10 scales of current, worst, least and average pain intensity measures. Their findings demonstrated sufficient psychometric strength to be reliably used for research in chronic pain and provide justification for the clinical use of these assessment measures. Wade and Hart (2002) explain how the visual analogue scale has been dependably demonstrated to separately measure pain intensity and affective dimensions. Jensen (2006) suggests that using a pain quality assessment tool as well as the usual intensity tools, can potentially assist the pain manager to more accurately assist the patient with chronic pain.

There are a myriad of pain assessment tools designed and demonstrated to be valid and reliable for various age groups and for people with normal and impaired cognition, or who do not have language availability (Hadjistavropoulos et al., 2007). These are nearly entirely self-report and/ or observational. Many of the tools are purpose specific to assess intensity, quality, functional aspects, interference with activities of daily living, impact of the pain and adaptation to it. Assessment using tested tools can also be done to determine the psychosocial response to pain. However, assessing the person in chronic pain should not be limited to use of various tools. Mayer et al.(2001) described a 3-year project to improve the consistency of assessment of pain in a regional American city. The project included the community as well as health care professionals in its education about the importance of pain assessment to adequate treatment. They state that the project increased both public and health care providers’ awareness of pain assessment and has improved treatment as a result. Often listening to the person will assist with developing an effective pain management plan.

Pain management

The management of pain is another behavioural focus of chronic pain research. Multidisciplinary pain management approaches enhance the outcomes for individuals with chronic pain (Aoun & Howe, 1998b, p. S142). Woolf and Decosterd (1999) propose a new approach for classifying pain, because pain is not a single sensation but is a myriad of sensations in both the well, normal person in the person in various disease states. They have based their classification on an analysis of the mechanisms that cause pain and discuss how this approach could be adapted to assess pain clinically and to provide an evaluation tool for the efficacy of new treatments. This proposed approach to pain management would move the medical treatment of pain away from the traditional empirical paradigm, where treatment is based mainly on “folk observations and serendipity” (Aoun & Howe, 1998a, p. S141) to treatments based on the application of the findings of basic science about the generation of pain. Theirs is an interesting concept that moves away from the classification of pain based on disease states to one based on the mechanisms causing the pain.

Analgesic is currently the most utilised pain management tool (Blyth et al., 2003). There have been quantitative studies that determine the efficacy of various treatment options for every conceivable type of chronic and persistent pain (MacPherson, 2000). MacPherson’s review paper thoroughly discusses the contemporary pharmacological treatment of pain in Australia, as well as future trends, basing the discussion on recent physiological and pharmacological research. MacPherson discusses the use of opioid drugs in chronic pain states as well as the more traditionally used non-opioid drugs. It is heartening to see the change toward opiate prescriptions for people living with non-malignant chronic pain, as there is hope that for some people, the pain can be managed more effectively with the addition of this class of drugs. As well, there is interest in non-pharmacological treatments for chronic pain.

Non-pharmacological interventions for chronic pain are also currently being examined for efficacy. Transcutaneous Electrical Nerve Stimulation is one method of pain relief that has been researched, although Nnoaham and Kumbang (2008, p. 10) conclude that the vigour of the methodology of the studies they examined do not permit firm conclusions to be drawn about the usefulness of this intervention. Not only medical management is important, nursing management can also contribute to pain prevention and relief.

Larsen (2000) discusses the nursing management of frail elderly in a post-operative setting. Although the focus of this paper is on acute post-surgical pain, some salient points are made for the elderly person living with chronic pain. Under-medication for pain is rife in the elderly population because of the nurse’s fear of the detrimental effects of analgesia administration. These are seen as due to polypharmacy, co-morbidities, physiological changes that occur during aging and nutritional deficiencies that affect the pharmokinetics and pharmodynamics of drugs given to the elderly. Brennan, Carr and Cousins (2007) contend that these fears are based in lack of education for all levels of health care professional about pain and about the drugs used to treat it.

Some of the patho-physiological, epidemiological and behavioural aspects of the pain experience have been presented from the plethora of available literature. This gives a scaffold for beginning to appreciate the impact that chronic pain has on an individual's life. There have been great advances in knowledge about pain – from the causes to the management, but to date, only sporadic progress has been made in the actual understanding of

> key aspects of therapy such as adaptation to disease, reconciliation following loss and perhaps what is the core task of rehabilitation: accepting that one must relinquish the search for a cure and engage in the work of learning how to live with pain (Risdon, Eccleston, Crombez, & McCracken, 2003, p. 376).

This insight develops from an intimate exploration of the chronic pain experience with the individuals who are suffering, coping, adapting, reconciling and learning how to live with the chronic pain. This appreciation comes about through qualitative research. Pain is linked to life and since the beginning of time, humans have sought to understand pain, to explain why it occurs and to control and eliminate it from their lives, or to learn to live with its devastating effects.

The experience of chronic pain

Qualitative studies completed over the past decade have begun to illuminate some of the personal, individual aspects of living with chronic pain that can be used by health care professionals to improve the care they are able to provide people living with chronic pain.

A systematic review of qualitative studies exploring patient's and practitioner's beliefs and expectations about chronic musculoskeletal pain demonstrated four coherent themes. These were: beliefs about the causation of pain and the influences on these beliefs; expectations of the consultation and the influences on these expectations; gaining trust through diagnosis and referral; and patient education (Parsons et al., 2007). These British authors found that the relationship between the GP and the chronic pain patient was conflicted in most aspects other than the desire for clear communication and the desire for respect. They found that some of the conflicts that were identified indicate that change is required not only at the individual level, but also at an educational and organisational level so that seemingly insurmountable conflict does not prevent positive outcomes for chronic pain patients.

Carson and Mitchell (1998) undertook a descriptive exploratory study of 17 individuals living with persistent pain. They interpreted their findings using Parse's 'Human Becoming Model'. The first theme they uncovered was "forbearance surfaces with the drain of persistent anguish" (p.1246) and they utilised Parse's first principle to develop and demonstrate "through words and movement the meaning of human belief and values" (Leddy & Pepper, 1998, p. 223). The second theme presented by Carson and Mitchell (1998) was "isolating retreats coexist with comforting engagement" (p. 1246) which they linked to Parse's retreating-engaging pattern. The final theme was "hope for relief clarifies priorities of daily living" (p.1246) which the authors connected to Parse's principle of 'transcendence'. This work helps nursing professionals to understand the unique ways people live with persistent pain.

Thomas (2000) used a Husserlian approach to her phenomenological study of chronic pain. She interviewed 13 men and women who had lived with chronic pain for from 7 months to 41 years. The major strength of her study was the rigour as a research group undertook the analysis of participant's experiences. The transcriptions were read and the meaning of each statement was explored. Each thematic statement was then supported by the actual transcriptions. The study could have gained strength if there had been a return to the participants to verify the description of their experiences. Thomas (2000) described chronic pain as an individual dyadic process between the person and the pain. The themes she extracted included the "altered, recalcitrant body" (p.689), the "separation from other people" (p.691), and the "expansion of the moment into a lengthy unit of time" (p. 693). Her descriptions eloquently speak to nurses about living with chronic pain.

Culture is an important consideration when discussing people's experiences of chronic pain (Davidhizar & Giger, 2004). Awareness of the intrinsic values of each nurse's own culture will increase their effectiveness in understanding and helping those of another culture. Australia is a multicultural society, and yet, often the health care system does not cater to health beliefs other than those of the scientific western way of thinking (Boogaerts & Merrit, 2008).

People have immigrated to this country from all the lands on earth, leaving the ‘mainstream’ Australian health care workers often with little understanding of the belief systems that sustain the new Australians (McLachlan & Waldenstrom, 2005). These authors suggest that pain expression and pain management are different for the ethnic groups (Turkish and Vietnamese women) they interviewed compared to a matched group of Australian women with an English-speaking background. Lovering (2006) used a collaborative inquiry methodology to demonstrate that people from various culturally diverse backgrounds experienced and expressed physical and emotional pain differently from each other in a study undertaken in the multicultural health care system of Saudi Arabia. Her findings can be reasonably applied to the similar multicultural society of Australia.

There have been some studies done of Aboriginal peoples who are living with chronic pain. Fenwick & Stevens (2004) used a grounded theory approach to understand the pain behaviours of Australian Aboriginal women. They found that there is cultural conflict between the (white) nursing staff and their aboriginal clients with a great deal of misunderstanding about the pain experience arising from expectations on both sides. Although the study was small and addressed women from a single cultural group who were experiencing acute pain, it did point out that different cultures experience, exhibit and communicate pain in different ways. McGrath (2006) interviewed both Aboriginal people living with pain and their health care providers during palliative care and found that Aboriginal people may be less likely to complain of chronic pain. They had very different concerns about the pain than do their Caucasian counterparts, fearing that Western medicine and medications will hasten death and reduce their ability to pass on essential end of life business to others.

Previous research on chronic pain experience has focussed on the coping strategies and the management of the pain or disease causing the pain. There is little written about the patient's perception of the experience of chronic pain. More research is needed that examines personal experience and insights into the phenomenon of chronic pain so that nurses can understand the experience and incorporate this understanding into their care. Understanding these factors as salient considerations in the assessment of pain, effective management and in the support of people who are enduring persistent non-malignant pain will facilitate nursing care and support of self care efforts of people who are living with chronic non-malignant pain.

Conclusion

This chapter has addressed many facets of chronic pain, each of which provides important background information to understanding the chronic pain experience. Because this phenomenon is so ubiquitous as well as extremely complex, the literature supporting it is broad and eclectic. Researchers cannot examine the whole of the concept of chronic pain, exploring, reporting and publishing on only a minute component of it. This plethora of papers made the choices of what to read, and what to leave daunting. The papers presented here seemed to be those which contributed most to an understanding of the phenomenon.

Until very recently, the medical model of pain and the emphasis on pathophysiology along with the quantitative paradigm of empirical research into the mechanisms of pain has been ascendant. This chapter has presented some small portion of the literature available on history of pain, pain theories, pain definitions, physiology of acute, then chronic pain, epidemiology and psychological and behaviour effects of chronic pain. The attitude of health care professionals has been raised. Pain management has been briefly addressed. Although qualitative research into chronic pain is relatively sparse, more is being published all the time. This chapter presented a sample of the qualitative research into individual experiences of living with chronic pain. Published research into chronic non-malignant pain is limited. No research into the experience of living with chronic pain in the rural context was located.

After decades of research and study into chronic pain and all of its ramifications, there are still people in rural and isolated areas who are living with pain in ways that are not yet described. A deeper understanding of the chronic pain experience, along with further research can provide a platform for change in the attitudes and behaviour of health carers when dealing with people who live in geographic isolation and who live with the burden of chronic pain. The next chapter, Chapter 3 - Phenomenology, will explain the philosophical underpinnings of this research study.

Chapter 3 - Phenomenology

Introduction

Phenomenology is a philosophical attempt to strip away the understandings, misconstructions, social, scientific or cultural traditions of an experience and come to know the phenomenon from within (Moran, 2000, p. 30-31) in order to describe the truth of the matter. This chapter presents briefly the major ideas about phenomenology needed to understand the philosophy.

The aim of this research is to develop an understanding of the experiences of adults who live with chronic pain in a rural environment. To do this, measuring objective data is not effective because the phenomenon of chronic pain in a rural environment does not lend itself to quantification or control. Most of the existing research on chronic pain has been undertaken from an empirical tradition and characterizes the person experiencing chronic pain as an entity – who is assessed, managed, given drugs or other treatments, learns to cope, and so on. These dimensions remove the 'person' from the immediacy of the chronic pain experience and permit the objectification of the experience. This in turn permits the use of descriptive and inferential statistics to describe a dimension that is decontextualised and generalisable rather than individually centred. The use of persons as units to find relationships between variables is a useful endeavour in many ways and for many professional disciplines, however, nursing is a holistic health care profession and requires a different vantage point from which to view and understand the person who is living with chronic pain. Thus a qualitative method of inquiry is needed.

Qualitative research is an increasingly viable alternative to quantitative research. Qualitative research allows the researcher to enquire into uniquely human experience that defies understanding using objective measurement. Qualitative understanding permits a humanistic perspective whereby each individual's reality is acknowledged as providing important contributions to a dynamic reality of the matter under the gaze of the researcher. To accomplish this, I have chosen a philosophically based, phenomenological approach.

Phenomenology

The use of a phenomenological research approach permits the researcher to explore the experiences of a few individuals in order to come to some understanding of this common experience, to better care for others who have also had the experience. In this study, the phenomenon is living with chronic pain. ‘Hermeneutic phenomenology…provides nursing with a theoretical basis for conducting research projects that does not reduce issues of human beings’ concerns to mere characteristics, absolute properties or brute data’ (Taylor, 1987 cited in Plager, 1994, p. 66).

In nursing, we are expected to be empathetic. Empathy is the quality of placing ‘oneself imaginatively and sensitively in the world of the other’ (Dunlop, 1994). Empathy is one of the potential applications of a phenomenological study. Because phenomenological research arose from and is embedded in a philosophical viewpoint, the character and central tenets of phenomenology require explication before the method of the current research is outlined. This is a very basic discussion of a complex and detailed philosophy and should be taken as a summary of important points only.

Phenomenology as a philosophy

Phenomenology is a philosophy born in and developed throughout the twentieth century in an attempt to counteract the objectification of the world (positivistic scientific thought) that arose from empirical methodology and to return the scientific world. Phenomenology is the revealing of the objective phenomenon through and in subjective perceptions, thoughts and feelings (Crotty, 1996). The objectivity of phenomenology is one of its outstanding characteristics. The researcher must go beyond a description of the subjective – the descriptions of the phenomenon obtained from the participants in the study – and draw out the essence of what it is that is being studied.

Moran (2000, p. 13) claims that “phenomenology’s success came in calling attention to aspects of experience neglected by empiricism, in particular, the horizons and background assumptions involved in all acts of understanding and interpreting”. Moran states phenomenology is

> best understood as a radical, anti-traditional style of philosophising, which emphasizes the attempt to get to the truth of matters, to describe phenomena, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experiencer (Moran, 2000, p. 4).

In order to get to this truth, the philosopher must avoid the misconstructions and impositions placed on the understanding of an experience by previous traditional, scientific, cultural, religious or even common sense knowledge of that experience (Moran, 2000). The early phenomenologists (Husserl and Heidegger) rejected the representational philosophies (that stated that knowledge of an object outside the mind came from its representation in the mind) and tried to delineate the way in which "the world comes to appearance *in and through* humans" (Moran, 2000, p.15).

The following discussions illuminate the major tenets of phenomenology as they were developed by, among others, Husserl, Heiddeger, and Merleau-Ponty. A chronological order is used because the ideas of each philosopher evolve from and builds onto the previous generation's work. Husserl was the originator of the phenomenological movement, although he, too, used and modified previous thinking. Husserl believed that a person's subjective perception of reality should be important to scientists because this was what motivated people to act (Lopez & Willis, 2004). Heidegger was Husserl's pupil and moved phenomenology from a descriptive to an interpretive philosophy.

The basic tenets of phenomenology

Phenomena, Consciousness, Perception and Intuition

Husserl (1917 cited in Husserl, 1981, p. 11) re-defined the term phenomena from the initial descriptive definitions of earlier philosophers (e.g. Kant) and used it in a philosophical manner. An understanding of phenomena is based on the other three ideas – consciousness, perception and intuition. Brentano (1889, according to Moustakas, 1994, p. 49) outlined the basic idea of consciousness that later guided Husserl's deliberations on the philosophy of phenomenology. Consciousness is based on perceptions -'the sensuously given realities' (Husserl, 1917, p. 12). Husserl divided perceptions into internal (mental) and external (physical). The internal perceptions can be proven to be true, the external ones cannot. (Moustakas, 1994, p.

50). Consciousness, based on perception, is directed toward objects, initially in an intuitive manner.

The intuition of Husserl and later of Merleau-Ponty designates the naïve comprehension of an event or object prior to any examination of the object to discern meanings or relationships that the event/object has for the person. It is the pure understanding, an insight, of the ‘given’ of the object/event as it presents itself to the person whether as an actual object perceived, a fantasy or a recollection. The often-repeated phrase ‘back to the things themselves’ (Husserl 1901, cited in Moran, 2000, p. 9) exemplified the first of Husserl’s principles, which was the self-evident givenness of insights in intuition (Moran 2000, p. 9). Intuition was the epitome of understanding, the legitimizing act of knowledge. Moustakas asserts “Husserl identified *a priori* knowledge with the intuition of pure essences” (Moustakas, 1994, p.33). Intuition is at the core of Husserl’s philosophy.

Intentionality

Intentionality is another central tenet of phenomenology. Husserl refined the earlier thinking on this aspect of consciousness when he discussed his ideas about intentionality. Streubert and Carpenter (1999, p. 45) attribute the clarification of Intentionality (from points understood from Aristotelian philosophy) to two early German philosophers, Brentano (1838-1917) and Strumpf (1848-1936) during the preparatory phase of the development of phenomenology. Streubert and Carpenter say “intentionality means that consciousness is always consciousness of something” (Streubert & Carpenter, 1999, p. 45). The object of our perception is out in the world, in time and in space – and our perception of the object is in our consciousness. Within phenomenological thinking, the intentional structure of consciousness seems to mean a reaching out of one’s consciousness to interact with objects and concepts as a means of relating to the world. Crotty explains intentionality as follows. “In-tending in our present context is not about proposing or planning but about *reaching into* (just as ‘ex-tending’ is about *reaching out from*) (Crotty, 1996, p. 38).” The subject not only interacts with the objects, but also questions it, ponders on it, embraces it and is altered by it. There is an indissoluble interdependence between subject and object making them distinguishable but united. Experience “cannot be understood to constitute a separate sphere of reality which is subjective and stands in contrast to the objective realm of the external world” (Crotty 1996, p. 41). Moustakas writes that "*directedness* is an intrinsic feature of intentionality, that the mind is directed toward some entity, whether the entity exists or not" (Moustakas, 1994, p. 28). Intentionality then, in phenomenology, is not purposive thinking or action, but an attempt to combine subjectivistic and objectivistic thinking without either being dominant. It means referentiality, relatedness, and directedness (Crotty 1996, p. 38).

Moustakas (1994) discusses intentionality by elucidating the terms *noesis* and *noema*. *Noema* is the "structural dimension", the "perfect self-evidence" (Moustakas 1994, p.31, 30) of a phenomenon, the "initial underlying meaning", the "perceived as such" (Husserl, 1931, p. 260) that a person has. *Noesis* is the layered perceptions of the original in which our experiences, judgments, angle of view, time and orientation synthesize a unique perception of the phenomenon (Moustakas 1994, p. 29). Husserl states that *noesis* altered by the way we attend to it "as a formative synthesis in its animating function shapes material elements into intentional experiences" (Husserl, 1931, p. 449). The *noema* and *noesis* are inextricably linked. Moustakas (1994, p. 29) uses the example of viewing a landscape to illustrate the *noema* and *noesis* of an experience. The *noema* of the landscape is my perception of the matter that permits the view to appear in my consciousness while the *noesis* is the joyful feeling that the landscape evokes in me. Thus, van Manen (1997, pp. 181-182) discusses intentionality as activity that is oriented and directed by whatever it is that evokes that orientation and which permits us to determine another's world. He says that intentionality is only available to awareness retrospectively.

Intersubjectivity

Intersubjectivity – the existence, presence and effect on the self of others - is an important aspect of intentionality because the 'other' is separate from the self and is co-present in any experiences that share a reality and permit the knowledge that the world is accessible to everyone – and is not a synthetic formulation of the self. Moustakas (1994, p. 37) outlines the process as

> I must first explicate my own intentional consciousness through transcendental processes before I can understand someone or something that is not my own, someone or something that is apprehended analogically. My own perception is primary; it includes the perception of the other by analogy.

We all base our knowledge of others' reality on our own experiences. We also seek affirmation of our perception of reality through social intercourse. By discussion and argument, we exchange ideas, perceptions, and judgments and so refine our own perceptions and validate them with others. Moustakas (1994, p. 59) warns that however much we crave certainty and validation of our perceptions, in the end, only self-evident understanding enables us to communicate intentionally with others.

Identity

When an object is experienced, its identity is constructed over time. Some object, a *noema*, becomes identifiable as a perception and each additional encounter with that perception – from a different angle, at a different time, or a recollection is synthesized into a separate identity as that particular object. It is much like viewing a structure at different times and from different angles. Eventually we will perceive the whole when shown a piece of the structure. During each encounter with the object, we also build a *noesis* for it – we layer judgments, feelings and thoughts around the object and they become fused with our *noematic* perception to create an identity. The multiplicity of encounters requires a temporal dimension – which may be instantaneous or much longer. Time is constituted by an imperceptible movement of consciousness from the present into the next temporal segment, leaving the now-present as the immediate past.

Horizon

Horizons are the different perceptions that emerge each time we experience the phenomenon. Every phenomenon has infinite horizons. Horizons are limitless because not only does the 'view' change each time we look or reflect, so do we as we age, become expert, gather experience, listen to friends or learn from others. To really understand an experience or phenomenon, we need to strip away the constructs of identity and their horizons - the maturation of those constructs. This is accomplished using phenomenological reduction.

Phenomenological reduction

The concept of intuition led Husserl to consider the attitude of 'epoche' or epistemological phenomenological reduction. Crotty (1996, p. 59) states that "reduction is a process of purification" and that Husserl attempted to purify consciousness (i.e., remove the overlying understandings, the natural attitude) by suspending “belief in the actual existence of the objects of experience’. Streubert and Carpenter, (1999, p. 47) state phenomenological reduction begins “when we suspend our beliefs, assumptions and biases about the phenomenon with the goal of the reductive procedure being to isolate of the unadulterated phenomenon, versus using what is already known about a specific phenomenon. That is, the goal is to isolate the central core meanings or features of the phenomenon; and to accomplish this task, the thinker must strip away all prior understandings of the phenomenon and approach it with a fresh and new attitude. This neutral stance (without either believing or disbelieving in the existence of the phenomenon, or anything about it) is called bracketing and Husserl contends it must be maintained throughout an investigation.

Lindseth and Norberg (2004, p. 148) conceptualise this idea somewhat more realistically. They believe that when we ‘bracket’, we suspend our judgment about the factual to become open to our own experience and to the understandable meaning implicit in this experience. Moustakas (1994, p. 33) puts this nicely – “the everyday understandings, judgments, and knowings are set aside, and phenomena are revisited, freshly, naively in a wide-open sense, from the vantage point of a pure or transcendental ego”. van Manen (1997) agrees and states that researchers must recognize and overcome their subjective, private feelings, preferences, and expectations. However, van Manen (1997, p. 185) expands the discussion of reduction to include a “wonder and amazement at the mysteriousness of the belief in the world”; to require a stripping away of theoretical or empirical conceptualisations and themes overlaying the phenomenon and to see past the individual lived experience (the particular) and grasp the essence or *eidos* (the universal) that is available as a conceptual construct. Phenomenological reduction results in essences.

Essences

In phenomenology, essences are the concepts that give common understanding to the phenomenon under investigation (Streubert & Carpenter 1999, p. 46). Husserl (cited in Moustakas 1994, p.37) states “each such statement of essence is an *a priori* statement in the highest sense of the word”. The essence is the identifying quality of a phenomenon – without which the phenomenon would not be recognizable. The researcher must ask van Manen’s (1997, p.63) essential phenomenological question – “what is the nature of this phenomenon?” What is common or universal in the nature, function, experience, meaning, and impact of this phenomenon that defines it as an essentially human experience (van Manen, 1997, p.177) defines essence as the “inner essential nature of a thing … what makes it what it is and without which it would not be what it is”. When the essential nature of the phenomenon is written in a truly phenomenological way, readers who have experience of that phenomenon will give it the ‘phenomenological nod’ as an indication that the writer has expressed it so there is resonance with their knowledge (M. van Manen, personal communication, 12.12.2000)

Husserl (1917, cited in Moustakas, 1994) concluded that there was no possibility of divorcing the self from the outside world and that every person in the world constructs the world they experience in a somewhat different manner from each other person’s world. Lindseth and Norberg (2004, p.146) express this essential tenet of Husserl as “an experience from within, not without, an experience of a logical coherence constituting meaning”. Although, according to Lopez & Willis (2004, p. 728), Husserl believed in an objective reality independent of history and culture.

Being-in-the-world.

Heidegger (1889-1976), Husserl’s pupil, refined the phenomenological philosophical stance by concentrating on the ontological question of what it is to be a person. Moran (2000)stated

> Heidegger’s central insight is that traditional metaphysical understanding is actually a sedimentation of a kind of everyday set of assumptions about reality, and this set of assumptions needs to be shown to be just that, through a deeper exploration of all the ways in which humans relate to the world (Moran 2000, p. 197).

Heidegger set about revealing the assumptions and stripping away centuries of thinking about being. He wrote of humans as questioning beings which differentiates them from other animals. This need to question is more important than other forms of interacting and reveals the “purely human mode of ‘being-in-the-world’ as a kind of projective caring and involvement in the world” (Moran 2000, p. 198). van Manen (1997) defines being-in-the-world as the “way human beings exist, act or are involved in the world” and exemplifies this with “…as parent, as teacher, as man, as woman, or as child” (van Manen, 1997, p. 175). These examples would indicate that each of us has different ways of Being-in-the-world.

The first premise that Heidegger discussed was the person as a being for whom things (including people) have significance and value. *Da-sein* is an active German word combination (verb and noun) that Heidegger uses to connote the entity that enquires about what it is to be, and is the object of the question as well and engages in the process of the enquiry at the same time. Heidegger states

> [*Dasein*] *finds itself* primarily and constantly *in things* because, tending them, distressed by them, it always in some way or other rests in things. Each one of us is what he pursues and cares for. In everyday terms we understand ourselves and our existence by way of the activities we pursue and the things we take care of (Heidegger, 1972, p. 158).

Da-sein has the basic state of Being-in-the-world (Silverman, 1987, p. 35). *Da-sein* is the total of our inherited interpretations of the world or our "past which is active in the present" (Polt, 1999, p. 37). Polt further explains *Da-sein* as follows:

> What is distinctive about *Da-sein* is the way it exists, the way it is enmeshed in its world, its 'there' somehow implies an understanding of Being- and allows us to raise questions about Being (Polt, 999, p. 31).

Leonard (1994) outlines the second essential premise of Heidegger as the world, and an individual's presence in that world. World is the shared skills and practices on which we depend for meaning and intelligibility. It is constituted by and constitutive of the self by

> a process that is not the causal interaction of self and world as objects but rather the non-reflective taking up of the meanings, linguistic skills, cultural practices and family traditions by which we become persons and can have things show up for us at all (Leonard, 1994, p. 47).

We are born into a world that is fully functional, and absorb its language, meanings and subtleties before we are even aware of ourselves as individuals. Heidegger (1962, cited in Leonard, 1994) argues that we are not the Cartesian self that possesses a body with specific characteristics and is free to choose any course but a self who is already situated within the world and not free to decide about the meanings of that world. The world thus creates the possible and dictates the choices we make. We make personal meaning within the situatedness of our world (common culture and language), each of us can also have common understandings with those who share the culture and language. As these common understandings move further apart, so do the worlds we inhabit and our ability to understand each other. An example would be the experiences of the Bushman with the coke bottle in the film ‘The Gods Must Be Crazy’. The Bushman had no point of reference when he ‘received’ the bottle and when it caused trouble (envy) he journeyed into a world he had no conception of and although he learned about this world, there was a fundamental void in his thinking that he could not cross.

In phenomenology, ‘world’ is entirely taken for granted. We do not think about most of the everyday events, objects and things we do. They are automatic and grounded in the meanings we have absorbed as we learned or used them. The taken-for-granted, all pervasiveness of world is only brought to conscious thought when there is a problem with it. Heidegger uses the example of a hammer, which is used in a non-reflexive manner (i.e. taken for granted) that is learned as its use rather than its qualities until it fails for some reason. In its failure, we find a sense of what ‘hammer’ means because it is not doing the assumed. Then we think of its qualities – size, weight, properties (handle, flat surface) usually as we cast about to find a substitute ‘hammer’ object. This is the everydayness – the non-articulated understanding of the world that we take for granted and the meaning that can be made visible through the linguistic and cultural practices of world.

Embodiment

The French philosophers Marcel, Sartre and Merleau-Ponty further developed the philosophy. One of the concepts developed during this time (mid-twentieth century) was embodiment. Embodiment is the bodily knowledge of the world – that all of our understanding of the world is based on our perceptions and thus our initial awareness of the object. Our senses offer a consciousness of the world that each individual experiences according to “history, knowledge of the world and openness to the world” (Merleau-Ponty, 1962a, p. 24). Bodily experiences are individually experienced. In fact, Merleau-Ponty (1962, p. 206) states that “we are our body” and that “we are in the world through our body” and perceive all with it. This idea of perception, the sensual and spatial relationship we have with the world through and within our bodies provides the “meaningful core” (p. 147) whose existence allows us to function.

From these beginnings over the century from mid-1800, the philosophy has been adopted and modified by several thinkers and researchers in Europe initially and over the past 50 years, across the world.

The concept of the situatedness of a person in their lifeworld is the major development of Heidegger’s phenomenology away from the objective eidetic phenomenology of Husserl. People are able to make choices only within the cultural, historical and contextual parameters of their lifeworld and others can only interpret what the subjective experience is from the descriptions of everyday lives – thus interpretive or hermeneutic phenomenology. Along with this interpretive slant, Heidegger also advanced the thinking about phenomenological reduction by recognising that, far from interfering with the consideration of a phenomenon, the conceptual framework and theoretical orientation used in a project can focus an inquiry (Lopez & Willis, 2004, p. 730). These authors also caution that the researcher has an obligation to disclose and explicate prior understandings.

van Manen adapted the philosophy of Heidegger and Husserl for consideration in the helping professions and for specific use in education. van Manen (1990a, p. 50) discussed the phenomenological project as making “use of language in such a way as to make present to us what is inherently pre-linguistic and therefore essentially not transposable into a set of precisely delineated propositional statements”. To accomplish the project, he proposed a structure for hermeneutic phenomenological research. He sees the research as a dynamic interplay among six research activities and emphasises that these activities are not sequential.

- Turning to a phenomenon which seriously interests us and commits us to the world;
- Investigating experience as we live it rather than as we conceptualise it.
- Reflecting on the essential themes which characterise the phenomenon
- Describing the phenomenon through the art of writing and rewriting
- Maintaining a strong and oriented pedagogical relation to the phenomenon
- Balancing the research context by considering parts and whole (van Manen, 1997, pp. 30-31)

The beginning is a commitment to being truly thoughtful about some area of interest or concern and pursuing it to make “sense of some aspect of human existence” (p. 31). The aspect of human existence under scrutiny is sought in the lived experience of it – by exploring the experiences that people have of the area of interest. Further steps include reflective thoughtful examination of the area to bring into the fore the essential nature of the experience and then to write and rewrite the thoughts until a clear, crystalline essence of the thing emerges. In fact, van Manen asserts the

> aim of phenomenology is to transform lived experience into a textual expression of its essence-in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience (van Manen 1997, p. 36).

van Manen urges the researcher to maintain a passion for the area of interest and to resist the temptations to be led away from the question of interest. He also cautions that balancing the whole with the part within the research context is mandatory. This is a movement back into the hermeneutic circle. Having examined the particular, the universal is considered in light of the new understandings.

Conclusion

This chapter has explored in brief the rise of phenomenology through explicating some of the basic tenets of this philosophy. From its roots in Aristotealian philosophy through to a vigorous rebirth in Husserl’s writings and thought, to the modifications made by Heidegger, Merleau-Ponty and many other twentieth century philosophers, phenomenology has emerged in the early twenty-first century as a philosophical approach that appeals to those who wish to truly understand a phenomenon as it is lived.

Phenomenology is a philosophical approach to experience – but it has been developed into a method of approaching research on the experiences that we and other people have. This study is based on the philosophical grounding outlined in this chapter, and will use the research structure suggested by van Manen (1997). The following chapter discusses the methods used to complete the study as well as a brief discussion of the various roles assumed by the researcher.

Chapter 4 - Methods

Introduction

This chapter outlines the research design and methods used to obtain the data, manage the material gained, and analyse it. The roles of the researcher are briefly discussed.

The method chosen to undertake a qualitative research study is dependent on the question that is initially asked. Jackson, Daly and Chang (2004, p. 141) state that researchers are required to develop identifiable positions on the ontology (world view) that guides the study, the epistemology that provides a focus for the study and the methodology (or how knowledge is gained) to provide a design for the study. In humanistic qualitative research, the relativist ontology encompasses multiple realities and states that one objective reality cannot be proven. The interpretive epistemology permits the researcher to acknowledge and elucidate the experiences, including the values and beliefs, of their participants while being aware that “any gaze is always filtered through the lenses of language, gender, social class, race and ethnicity” (Denzin & Lincoln, 2000, p. 19). The research design assists the researcher to access the other’s perspective through a close association with the participant and the extraction of rich descriptive data. To gain access to the participants, the initial step is to consider the ethics involved in the research.

Ethical Considerations

The axiology (values and ethics) of a person underpins all of the actions and decisions made by that person. It is so interwoven with the psyche of the person, that untangling the threads would be a gargantuan task. Nursing ethics illuminate the value of the individual to the nurse and the unique relationship between the nurse and the individual – built on two sets of values that have developed over the two lifetimes. For the purpose of this study, the ethics surrounding the conduct of a research project will be discussed. Ethics in the context of a research project means to treat people in respectful and considerate ways. Stake (2000, p. 447) advises that because qualitative researchers are guests in the privacy of their participant’s spaces, they must be well mannered and maintain a strict code of ethics. Qualitative research studies rely on a relationship between the researcher and participant that is of necessity reasonably intimate and for this reason, ethical treatment of the participant is mandatory. A national set of guidelines to prevent any harm from coming to an individual participant has been developed for research on humans- a code of ethics. This research project complied with the ethical standards demanded by the National Health and Medical Research Council of Australia. Ethical approval was sought and gained from James Cook University Ethics Review Board (See Appendix 1). A brief outline of the ethical considerations taken for this study follows.

Participant Welfare

Participants in qualitative research risk embarrassment, exposure, and other risks to their personal circumstances. Researchers have a moral obligation to protect their participants or at least to warn them of possible risks to their wellbeing. The following steps were undertaken to minimise harm to the participants in this study.

Free and informed consent was obtained before the interviews. Participants were given a 'plain language statement' of the proposed interview, its purpose, demands, their right to withdraw from the project at any time, without prejudice and any risk to them that was involved (see Appendix 2). They were asked about their understanding of the project prior to being asked to sign a consent form (see Appendix 3) and were informed of their right to withdraw from the study at any time.

Confidentiality and anonymity were addressed by the use of pseudonyms whenever individual participants were referred to in the published material. Any identifying characteristics (name of town, station) were altered or omitted from any printed documents.

This research would be considered a Level One. Few side effects or post-experiment distress were anticipated, however, there are some potentially difficult areas (eg health carers not believing the pain is real, the memories of ineffective but trying treatments) that may have emerged during the interview and caused some discomfort to the participant. In such an instance, the name and phone number of a practicing psychologist at the Townsville Pain Clinic (Letters of request and answer available in Appendix 3) who had agreed to care for any participant who required counselling were supplied. Dr Kim Usher, Dr Narelle Biedermann, Dr Dawn Francis, and Dr Kim Foster supervised the project.

Data Protection

Consent forms with identifying signatures were kept separate from demographic information, tape recordings and transcribed data. Tape recordings were made of each interview. While in the field, the tapes were stored in a briefcase and kept with the researcher or locked in the researcher's car boot at all times. Tape recordings were labelled with a pseudonym and kept separately from the demographic information so that participants were not identifiable. A diary of each interview was also made. The book containing the diaries from all interviews was secured in the researcher's office. The consent forms, demographic information, tapes and later the transcriptions of them were kept in a secured filing cabinet in the researcher's office. These data will be kept for a minimum period of 5 years following completion of the project, then destroyed in a secure manner as organised by the university.

The researcher, for purposes of writing a thesis and for subsequent publications, assumed intellectual property/ownership of the data. This information was included in the plain language statement (see Appendix 2).

Recruitment method and justification

Qualitative research requires a different sampling method to obtain the informants or participants than does quantitative research. Because qualitative studies are interested in deep understanding of an issue or condition that affects people, asking the people who know about the issue is an effective approach. This is purposeful sampling. Participants were recruited to the study using a purposeful sampling strategy. According to Llewellyn, Sullivan and Minichello (2004, p. 228), a purposeful sample is used to achieve the most relevant participants who can explain the topic of interest. Participants for this study were recruited because they were a) homogeneous in the fact that they all lived in a rural area and could therefore be expected to illuminate that aspect of their pain experience; and b) had an intensity of the experience of interest (chronic pain) and could therefore be expected to help with the exploration of this experience. They all met the selection criteria of:

Experiencing chronic pain from any condition for a minimum of 6 months

Having no other concurrent medical condition (associated depression excepted)

Living in a rural area of Queensland

Between the ages of 18 and 55 years
English speaking

People who are interviewed are active participants in the research project. To acknowledge each individual's contribution, an executive summary of the project was given to each participant following completion of the project.

Several approaches to gaining participants were tried without success. Initially a two-step method involving an introduction via a local GP to the participant was attempted. Gauthier and Clarke (1999) report this method as being very effective. In this case, written and telephone contact with physicians in small rural towns in North and Western Queensland were made in an attempt to involve their assistance in identifying and approaching participants (see Appendix 4). Asch, Connor, Hamilton and Fox (2000) recommend the physician as the most appropriate health care worker because the participants were known to the physician. The physicians approached declined to assist.

Next, General Practice residents from rural areas in North Queensland were attending a staff development program that included a morning devoted to research. During this time a flyer appealing for their assistance was handed out to the group of 12 doctors from rural areas. This too, proved unsuccessful.

The next strategy used is termed 'highly aggressive' and is analogous to the direct to the consumer sales approach. It is supposed to be a highly effective recruitment strategy (Anderson, 2001; Boles, Getchell, Feldman, McBride, & Hart, 2000; Cosgrove et al., 1999; Johnson, Mebane-Sims, Hogan, & Stoy, 1995). An advertisement was placed in a weekly newspaper in a rural town, appealing to people who were experiencing chronic pain to contact the researcher, to no avail (see Appendix 5). The researcher contacted the ABC radio station in Mt Isa for assistance, and a 15 minute interview about the research project was broadcast on the CountryWide (ABC CountryWide, 1215h, May 25, 2006) program, and rerun later during the same week. During the final minutes of the interview, the researcher provided a contact number for anyone interested in contributing to the project. One appropriate participant replied, and two people who were older than the reference age of 55 replied. Information was provided to all three, and interviews were conducted with all of these people, although only the data from the one person who met the criteria has been used. The other two interviews were conducted first, and these people told that the information could not be used for the project, but permission was gained to treat these interviews as trial runs to determine the appropriateness and comprehensibility of the interviewing.

Then an approach to the regional pain clinic was made. Ethical clearance was sought and obtained from the Regional Health service, and the Director of the Pain Clinic, the Nurse Manager and the Psychologist were approached for discussion and explanation of the project. Their assistance was enlisted to identify appropriate participants who met the criteria for inclusion.

Patients who had chronic pain with postal codes in the relevant rural region were contacted by the pain clinic with a request that they participate in the research project. If they were interested, a plain language statement was sent to them by the clinic. In the statement, interested people were asked to contact the researcher to establish contact. During this contact, a suitable time and venue was arranged between the participant and researcher. The meetings were scheduled at a time and venue that were mutually convenient. One participant was obtained using this method.

Next, the researcher appealed to personal networks and subsequently obtained 2 suitable participants. This occurred when friends of the researcher gave their appropriate acquaintances the plain language statement, and asked them to contact the researcher to be interviewed. Two more participants were recruited through the snowball technique from participants already interviewed (as above). And finally, the two-step approach to a physician outlined above was again attempted with a neurologist in Townsville. He sent several information sheets to various rural patients, and eventually referred 2 people to the researcher. One of these people was subsequently willing to be interviewed. The total number of participants interviewed and whose data have been used is seven.

Data collection, management and analysis

Interviewing

Qualitative interviewing is an art (Minichello, Sullivan, Greenwood, & Axford, 2004). It is the art of facilitating the person to reveal inner thoughts about their own experiences that they may even be unaware they had. To accomplish this feat, the interviewer needs to employ all the skills of active listening; to encourage the participant to be reflective and be able to stimulate the reflexivity by being responsive to the meanings of the participant's words – and not just the words themselves (Jackson, Daly & Chang, 2001, p. 149).

A conversational encounter with each participant was arranged at a convenient place for the participant and within a mutually agreeable timeframe. Initially, demographic characteristics were sought including age, residence, disease process, pain levels and time the pain has been endured. This was used as an 'icebreaker' in order to gain the participant's confidence and reduce any tension for the participant. The conversation was very participant-oriented, beginning with a question such as 'Can you tell me what it is like to live with chronic pain here in (town name)?' However, after the patient had exhausted their story, words that the participant had used or innuendos were picked up and queried for clarification. If the participant was not especially articulate about the experiences, a semi-structured interview protocol was used to initiate the conversation, and the participant's leads were followed as they arose. The conversations were tape-recorded with the participant's consent.

Information on the environment, geography, economic situation and any other pertinent information that may have impacted on the pain experience was gathered during visits to the town and surrounding county-side (e.g. photos and feelings engendered in the researcher by the countryside).

A diary or log for recording of visual information (non-verbal communication, interpersonal interactions, contextual ideas) and the researcher's thoughts and insights gained during the interviews was written immediately following each interview and kept for use during analysis and writing. Photographs were taken as memory jogs of the geographical surroundings for use in the discussion of context in relation to chronic pain. These visual recordings and recollections made immediately following an interview assist the researcher to reduce the possible distortions of more distant recall and assist with the reconstruction of the interview when the analysis stage of the project is undertaken.

Data management

The tapes of each interview were marked with a pseudonym and the date of the interview. The documentation – demographic material, consent form and diary notes of the interview and any visual material was marked with the same pseudonym. The consent form, the only paper with the actual information about the patient's identity was then placed with the remainder of the consent forms for other participants and stored in a locked filing cabinet separate from the interview tapes, demographic and diary documentation and other visual material. The researcher transcribed the interview tapes. During the verbatim transcription of the interviews, additional material to enhance the meaningfulness of the transcription was added from field notes (pauses and laughter were indicated, tears, voice tones or interruptions were noted in the text of the interview). The transcriptions, diary, demographic material and visual material were also kept in a locked filing cabinet.

The verbatim transcriptions were arranged on the page so that wide margins on either side were created to enable handwritten notations about the content to be made.

Data analysis

The verbatim transcriptions were each read through while listening to the tape to resituate the researcher into the conversation. The interpretation process was begun by rereading the transcription (van Manen calls these 'anecdotes' according to Caelli 2001, p. 277). Identifying contradictions between the tone, hesitations and silences in the material and the words used began the interpretive process. Following this, each line of text was read for meaning, then larger, meaningful groupings of words were read for central ideas and meaning. Significant words used by the participant were noted in the right margin, and the left margin was used for summaries, notes, ideas, and questions. Hermeneutic phenomenological reflection (van Manen 1997, p.77) was used to try to understand the essential nature of the phenomenon. Writing and reflecting and rewriting the text was done to comprehend the meaning structures of the text – the themes. This term, theme, is used in this project to describe an aspect of the phenomenon that is essential to the nature of the phenomenon. Although it is a simplification of the aspect, it also exemplifies the essence of it and evokes a reverberation in those who have experienced the phenomenon. The 'process of recovering the theme or themes that are embodied and dramatised in the evolving meanings and imagery of the work' is what van Manen (1990, p.78) termed 'theme analysis' and he asserted that theme analysis 'gives control to our research and writing' as we attempt to describe a lived experience of the phenomenon. With themes we are trying to use the *particular* to explicate the *universal* (van Manen 1990, p.79).

Each narrative was analysed individually, then was reflected upon along with the narratives of the rest of the participants so that themes that recurred could be captured and written, to seek meaning and provide a focus for phenomenological description. A constant movement between the entire transcript (the whole) and the words being considered (the part) was utilized during the analysis of each of the transcript. This assisted to situate the parts of each interview within the hermeneutic circle. Each of the themes and sub-themes was named using the participants' words whenever possible to increase the transparency and thus the rigour of the research.

Rigour in a phenomenological research project

Rigour in qualitative research is an important aspect of the project because it assures the scientific world that the research is worthy of being termed 'science' (Streubert & Carpenter, 1999). Researchers want to demonstrate the validity of their interpretations and the clarity of their thinking, so that their findings and explications are worthy of being added to the knowledge base of a discipline. To do this in a qualitative research study requires just as much effort as does the proving of reliability and validity in a quantitative study.

Phenomenological reduction is the initial step in obtaining pure data as this permits the researcher to recognise their own biases and prior assumptions, so that they do not interfere with the data gathering process. This personal 'story' was written prior to any interviews and reviewed periodically throughout the project. Participant selection is another aspect of the rigour of the project. Participants self-selected or volunteered and had an ongoing experience of chronic pain, thus qualifying them as experts in their own experience of pain. Asking participants who were informed about the project to contact the researcher ensured that only those with a desire to share that experience and who were prepared to be frank and honest were asked to describe their experiences. Use of an open-ended question to initiate the 'interview' ensured that researcher bias did not cloud the data. An unscheduled interview permits the participant to explain their experience in their own words. Prompts and questions used during the interview were non-directive, used simply to open an aspect of the experience that was either stated or alluded to. Not only during the interview can the researcher influence the data, but even more danger lies during the analysis stage.

Every time a phenomenological study is conducted, and analysis and interpretation of another's private thoughts occurs, important information and nuances may be lost or misinterpreted. It is therefore imperative that the phenomenological researcher returns to the source with the written material for verification of its authenticity. Each participant was provided with a written copy of their narrative - the researcher's transformation of their interview material for verification that it truly reflected the participant's experience. Credibility is established when the participant confirms that the narrative is true to their experience (Jackson, Daly & Chang, 2004, p. 149).

Auditability according to Jackson, Daly and Chang (2004, p. 149) is demonstrated by the construction of conceptual themes directly from the participant's words. Each theme that is suggested in this thesis is constructed from the participants' verbatim transcriptions (after verification by the participant) and is exemplified by words and descriptions provided by the participant. Fittingness refers to a discussion of the constructed concepts in view of other works and literature (Jackson, Daly & Chang, 2004, p. 149). The constructed concepts are discussed along with the findings, which are participants' words in this study. Confirmability, according to Jackson, Daly and Chang (2004, p. 149) is achieved when the researcher is able to demonstrate credibility, auditability and fittingness.

Transparency and a verifiable paper trail reduce or eliminate any possibility of spurious data. Maintaining a log entry following every interview to record non-verbal communication and the tone or feel of the interaction, transcribing interviews verbatim, using the participant's words in written material are all examples of verifiable information and transparency. Rigour within the research is one of the major roles assumed when undertaking a research project.

Roles of the Researcher

The researcher has many roles during the conduct of a phenomenological project – and each facet impacts on the outcome of the research. When self funded research is undertaken, the researcher is not restricted by funding bodies as to the type or scope of research undertaken, but can pursue whatever researchable questions interest them. However, funding was sought and gained for this project. The aims and objectives of the research and of the researcher were congruent with those of the funding body so that there were no perceived restrictions on the project.

Researchers are first and foremost scientists. This means that they search for truth – or in qualitative studies which acknowledge multiple realities, they attempt to make some of these realities transparent to others in order to (in this case) improve understanding and thus nursing practice. This is undertaken to add knowledge to the particular discipline.

Researchers come from a variety of disciplines and professional backgrounds. This will influence how they view the world and what they choose to research about. This study is being undertaken by a nurse researcher with a wealth of life experiences – ‘the accumulation of lived experiences and the understanding and sense we may have made of these experiences’ (van Manen, 1997, p. 177). Nursing is a humanistic endeavour, and as such centrally locates each individual, and treats individuals as holistic beings. Pathic listening to conversation with the individual participant exemplifies not only the ‘caring attentiveness of the nurse’ (van Manen, 1999, p. 32) but also of the qualitative researcher. This orientation influenced the selection of a methodology for the study and the interpretation of the data.

Researchers in qualitative research projects become the instrument of the research (Janesick, 2000). They become partners with their participants to explore and elucidate a specific phenomenon. The researcher is the seeker of the knowledge that the participant is seen to have because of their unique experience. To accomplish this exploration and elucidation, the researcher undertakes a number of roles, each of which is explored in some detail below.

Initially, an understanding of the phenomenological philosophy is undertaken. Since ‘doing phenomenology’ is an exploration of experience based on the philosophy of phenomenology, an appreciation of its basic tenets must be developed to be able to explicate the impact of the philosophy on both the method used and then on the findings of the study. As well, the researcher needs to use a reflective stance to understand being a person in the world, their own *noesis/noema* of the phenomenon and then to appreciate the subtleties of being a person experiencing the phenomenon in a situated context (O'Brien, 2003). Thus the role of learner is also assumed.

Developing the thoughtful, phenomenologically oriented question (van Manen, 1990) is an essential first step in conducting a phenomenological study. The question arises from who the researcher is (a nurse) and is also involved with the ego of the researcher (thus the self-interest of chronic pain and rural living) because we are required to “interrogate something from the heart of our existence” (van Manen 1990, p. 43) and to truly do that we need to be absorbed both personally and professionally with the idea. Phenomenological questions are ‘what is it like’ questions – they search for the nature of the experience as it is lived by real people. Gadamer asserts “genuine questioning always involves a laying open and holding open of possibilities” (Gadamer, 1976, p xxi). And to this van Manen (1990, p. 43) replies that we can only keep ourselves open by an abiding concern, which makes the question possible in the first place.

Selecting the participants is another role undertaken by the researcher. The researcher must decide who can give the most informative data for use in the analysis. In this study, people who lived in a rural area of Queensland, who could communicate their experiences in English, who were adults without other disease or conditions that might interfere or influence the description of chronic pain were sought to provide the clearest and most usable information for analysis. Saturation or redundancy of information signals the completion of data collection (Jackson, Daly & Chang, 2004, p. 147). In qualitative research, there is no need to sample a significant portion of the population as in quantitative projects, rather the phenomenon under scrutiny is probed and studied until there is no new information forthcoming from participants about the phenomenon. If there is repetition of data, the data set is considered complete, so there is no absolute number of participants who inform a study.

Interviewing participants is a separate undertaking that requires skill to assist the person describing the phenomenon to transform their experiences into language (Streubert & Carpenter, 1999, p. 57). The researcher as interviewer is required to have or develop skills in interviewing that do not lead or suggest direction to the participant but rather demonstrate a willingness to listen to the story and the ability to assist the participant to both keep the direction on track and at the same time to be reflective. The interview is aimed at exploring what the experience means to the participant and gaining illustrations of that meaning – to

> recall the experience in such a way that the essential aspects, the meaning structures of this experience as lived through, are brought back and in such a way that we recognise this description…as a possible interpretation of the experience' (van Manen, 1990b, p. 41).

Analysis in a phenomenological study begins with the first interview, although according to O'Brien, "phenomenological studies are interpretive from beginning to end" (O'Brien, 2003, p. 200). However, during the analysis phase, the researcher is analyst who transforms the raw data that has been seen and heard into a fresh comprehension of the phenomenon. The researcher as analyst employs imaginative use of conceptualising the material into categories that eventually collapse into essences.

The researcher is a writer. Writing is inextricably linked with analysis in an attempt to capture the essential characteristics of a phenomenon – the essences - in a written document. Hermeneutic phenomenological writing is the heart of human science research and the creation of a phenomenological text is the desired outcome of each project (van Manen, 1990, p. 111). Streubert and Carpenter charge the researcher-writer to "synthesise and capture the meaning of the experience" (Streubert & Carpenter, 1999, p. 57) into written form without distorting or losing the richness of the data. This is accomplished by descriptive writing with an imaginative use of language (O'Brien, 2003). The writer know that this is accomplished when readers are able to give a 'phenomenological nod' to the material.

Conclusion

In summary, this chapter has addressed the methods of undertaking this research. The ethical considerations that are required in human research were briefly presented in relation to this project. Participant recruitment for the study was explained. The management of the data was outlined and the methods of analysis used to extract meaning from the raw data were discussed. The issue of rigour within a qualitative study was addressed by citing the methods used within this study. The various roles of the researcher were discussed. The following chapter introduces the participants in this study and gives a background idea of these people, as well as of the researcher. Chapters 6, 7, 8 and 9 are devoted to discussing the findings and the meanings and essences of the material collected from the participants.

Chapter 5 - Portraits

Portraits of the Participants

Brett

Brett is a 27 year old young single man who is somewhat out of condition and overweight, although not obese. He is living in the family home in a large rural town. His parents are both in the house during the interview, but have retreated to the far reaches of their home. They live in a neat and tidy brick home in a quiet neighbourhood on the outskirts of town.

Brett has had chronic pain from sacroiliitis and spondyloarthritis for 11 years and feels the pain in his back, neck and hips as a numbness or throbbing which makes him tired at its best and he rates it at a 10/10 on the verbal analogue scale (VAS) at its worst. He says fatigue is the one related symptom that is bothersome. He claims that rain, alcohol, and a high sugar content diet precipitate the pain. He takes occasional over the counter analgesics. He sits fairly still during the hour and a half of the conversation. When he does move, the cautiousness is apparent. He walks with a stiff looking gait.

Brett sits quietly at the kitchen table and ‘fiddles’ with a teaspoon. He rarely meets my eyes when talking and has a somewhat flattened affect, although he becomes animated when his family is mentioned. He mostly talks over my shoulder or to the wall across the table. He does not talk much without prompts and long silences do work to get some information. He volunteers that he belongs to the Jehovah Witness faith. Brett works part time as a delivery driver in a small furniture supply/manufacturing business. He does not have many ‘friends’ and does not have a partner in his life. He lives with his parents and is the only one of four siblings who remains in the family home.

Brigid

Brigid is a 55 year old divorcee who is living on a disability pension in a small outback town. She supplements her income with sewing and ironing. She lives independently with her pet, a quiet, happy terrier as companion. Her home is a council house with 4 steps up and is neat and clean, although sparsely furnished and with few mementos. She has a large table in the carport area, which is crowded with pots and tubs of very healthy looking plants. She is overweight, but not obese. She takes good care of herself and wears minimal makeup, manicures her nails, has her hair well cut and tidily arranged, and she dresses for comfort. Her facial affect is bright and alert and interested. She speaks with animation and needs no prompting to tell her story. She moves slowly and deliberately and moves her torso as a unit. She did not bend.

Brigid has lived with chronic back pain for over half of her life (29 years). The diagnosis is osteoarthritis of the hip, knee and shoulder. The pain is hot, burning, grinding and continuous. She was born with scoliosis and sustained a lower back injury as a young woman of 26. This has been exacerbated over the years. She has had spinal surgery (laminectomy x 2) when she was younger and she now has a spinal stimulator implanted (for about 9 years) to assist with the pain. Using this device, she keeps the pain at about a 3 when she is sitting, but it goes up to a 6 or 7 when she moves around. If the implant is not functioning, the pain is a 10. The control mechanism for the spinal stimulator is never far from her hand. She also takes Tramadol on a daily basis and her pupils are 1-2 mm during the conversation.

She had 4 children (after the onset of the chronic pain) but is no longer in contact with the 3 surviving offspring. She seldom sees her 2 surviving siblings. Tippy, a small terrier is her companion at all times. Brigid has a strong friendship with a woman in town whom she has made her executor. She has a male friend with whom she has a comfortable, non-sexual relationship. She maintains her independent mobility by using a scooter around town.

Carl

Carl is a 54 year old man whose hair is mostly white. He is slim and athletic looking with a ruddy ‘outdoors’ sort of complexion. He is cleanly shaven and his hair is wildly curly, giving him an unkempt look. He is dressed appropriately to the season and the outside chores he was doing. He is articulate and forthcoming, conversing easily and comfortably. He lives with his wife of 15 years. They have no children. There are several siblings who live at some distance from Carl. He is particularly close to one sister, and can talk to her. Carl and his wife reside in a very comfortable and relatively new house in a small town about 2 hours by road from a large coastal city. The house is immaculate, and Carl tells me he is the housekeeper and likes to keep things ‘where they belong’. Carl can no longer work outside the home and has had to give up his screen- printing business. He has also had to forego his sports and hobby interests because of the pain

Carl has fibromyalgia and has had it for nearly 11 years. He describes the pain he is currently experiencing at 6 on the verbal analogue scale of 0-10. He sits very still through the conversations we have and rests his arms and hands on the table. During our time together, he laughs a lot. He says he is basically a happy person and uses his personality tendencies to deal with the pain and fatigue.

Gary

Gary is 52 and he has fibromyalgia. He is a burly, bearded man with a weather-beaten face. He wears an expression of pain with permanent furrows in his forehead and deep vertical creases between his eyebrows. He talks comfortably and is often difficult to keep on track and to follow as his conversation is peppered with stories and anecdotes to illustrate his point. Gary is married, and his wife is also unwell, and on an invalid pension – with Gary as her designated carer. They have grown children who live elsewhere and who figured very little in the dialogues. He is not employed although he keeps up with the work of their 25 acres. He no longer grows vegetables or stock as just keeping the tree droppings cleaned up exhausts him.

Gary developed fibromyalgia nearly 7 years ago. It started with an attack for which he tells me the date. The fibromyalgia causes severe unremitting pain, which is currently at a 7/10 although it ranges from 5-9/10 on a verbal analogue scale. The pain migrates and today is in both arms, across his shoulders and in his lower back. Often his knees and toes are painful. He describes the pain as continual burning with acute stabbing sensations. He feels that work-stress precipitated the pain and often has anxiety attacks with sweating, vomiting and palpitations as associated symptoms. He also experiences what he calls brain fog – confusion, inability to concentrate and memory difficulties. He avoids social gatherings, shopping, loud children, strong light and wind as these aggravate the pain.

Diane

Diane is a stocky, young looking 45 year old woman who is cheerful and smiling when we meet. She is attractive and well groomed. Her thick, brown hair is clean and shiny and she wears it loose and wavy. She wears little make–up. Her clothing is appropriate to the occasion – slacks, print blouse and cardigan with sturdy shoes. Diane lives in a Queensland style house in a small town about two and a half hours from a large regional centre. She uses a cane to walk, and moves slowly and awkwardly. Her movement looks painful. Diane is divorced and has a teenage daughter who is 15. Her parents live in the same town and are able to assist her when she is incapacitated. Diane was a Registered Nurse and worked in Oncology units in the city prior to the pain.

Diane has lived with pain for at least 9 years. She says the pain was there long before she was diagnosed, but she kept rationalising it as a result of overwork. Four of her vertebral discs are degenerated and she has osteoarthritis in her large joints (hips, knees). The degenerated discs have caused neuropathic type pain with crawling sensations, alternating hot and cold sensation as well as a burning, grinding pain along the sciatic track. The pain radiates up into her lumbar back area. She has also developed bladder problems, tremors in both legs, and numbness in her right foot most of the time and sometimes in her left foot. The pain is precipitated by prolonged standing, or sitting, or by twisting. It increases when she is tired. On the day of the interview, she reported her pain at a 6 on the 0-10 VAS. At its worse, the pain is an 8 and it never really gets any better than a 3.

Diane uses at least one stick (cane) to walk, and usually two. She sometimes retreats to a wheelchair for days or even weeks at a time when the pain is relentless.

June

June is a 49 year old woman who looks older than her years. Although she was expecting me, the house was reasonably untidy and she was not tidied up, either. Her hair was not washed, nor had it been combed or arranged. She wore no make-up. Her nails and her fingers were stained with nicotine. She was overweight and dressed in stained and obviously old T-shirt and shorts and thongs on her feet. She moved slowly and deliberately and moved her body as a unit. She smoked cigarettes continuously during the interview. A small border collie was a constant companion.

June is married, and has never worked outside of the home. Her husband works for mining companies and can be away from home for several days at a time. June’s 3 children are grown and flown to distant parts of the state, although the youngest still comes home for a few days’ visit occasionally.

June fell off a potato harvester in 1988. She damaged vertebral discs and the pain has increased over the years. It radiates throughout her back and legs and she describes the pain as sharp and shooting, with either cold or burning needles sensations. The pain causes her fatigue, nausea and vomiting. When we had our conversation, she stated the pain was 9.5 and she was teary. I offered to come back another time, but she wished to press on with the interview. June says that the best the pain has been in the past week is a 7/10 and the worst was a 10. Remaining in one position for any length of time, driving or sitting in a car are extremely difficult and aggravate the pain. Moving around helps to ease the pain.

June’s husband was near to hand during the entire conversation, despite requests to have private words with June. He was not at all supportive of his wife and made derogatory comments when she answered questions or related anecdotes. His intrusiveness and denigration were difficult to contend with.

Leah

Leah is a 42 year old woman. She was neatly dressed with minimal make-up. She looked younger than her stated age. She moved cautiously, easing herself into the chair at the hotel where she came for the interview. She moved restlessly throughout the interview, guarding her right arm and supporting it with her left. She did not move her neck during the interview but turned or inclined her entire torso as necessary. She was often teary and her voice choked frequently.

Leah was a bookkeeper in her family's company prior to the accident (a rear-end collision where her vehicle was the one hit), which caused the pain. Her parents have abandoned her since the accident and do not even enquire about her now. She says that, although she was on her way to work, and the claim was legitimate, the family would not permit her to apply for worker's compensation because it would affect the company's insurance premiums and she now only has an invalid pension. She is in contact with her siblings, who offer moral and some psychological support, although, not monetary assistance. She lives in a stable relationship, and her partner is reasonably well paid, although she too, is suffering from a debilitating condition and cannot support Leah as effectively as she desires. Leah raises and shows pedigree dogs and now, they fill her days.

During the accident, Leah had cervical disc damage that caused neuropathic pain up into her neck and head and down into her arm. The pain is fierce, throbbing at times, and shooting, burning at other times. She has weakness and loss of sensation to her arm and hand, and using the arm and hand cause a terrible increase in the pain in the shoulder and neck. She has throbbing headaches nearly constantly. Her visual analogue on the day we talked was 6-7/10. She says it seldom goes below a 4 or 5 and frequently she experiences a 10/10.

Portrait of the Researcher

Introduction

Phenomenological studies demand that the researcher acknowledges and then sets aside or takes account of their own experiences and background before they approach the participants and the resulting data that is under scrutiny. Kluckhohn (1949, cited in Strasser 1963, p. 7) tells us “the scientist of human affairs needs to know as much about the eye that sees as the object seen”. Crotty states that phenomena are “essential structures of reality” (Crotty, 1996, p. 31) revealed “in and through the person’s subjective perceptions, thoughts and feelings” (Crotty, 1996, p. 32).

Moustakas (1994) asserts that phenomenological studies are rooted in questions that direct the researcher and that the researcher is personally interested in the topic. He states (p. 59) that the puzzlement is autobiographical, making memory and history essential dimensions of discovery in the present and extensions into the future.

The purpose of the following explication is to permit the reader to see the position of the writer in relation to the topic. The autobiographical interest is apparent and the memories and history are outlined. Since preconceived ideas, understandings and constructs taint the comprehension of the phenomenon, this description demonstrates that researcher is aware of the background influences and is attempting to ensure that any biases are interfering as little as possible with the interpretation of the material. This section is devoted to explicating my background and involvement with the key concepts of the phenomena under study – chronic pain and rural experiences.

Country girl

I was born and raised in a country town in western Canada. There I was immersed in the sense of community I have since come to associate with rural living. Following my education and some experience in larger centres, I returned to ‘small town’ living, and practiced as a registered nurse for 7 years in an agricultural community of less than 4000 people. I appreciate the sense of involvement and care that are the hallmark of small rural communities, while being mindful of some of the drawbacks. I have summarised my own ideas, garnered from my years of experience there, about rural living in the paragraphs that follow.

Community is an important concept in small, rural towns. Neighbours are friends, and friends are willing to help whenever the need arises. There is no sense of isolation or alienation and as long as you conform to the expectations of the district or town, you are accepted and cherished. People who need help are extended it without a counting of the cost, because it is understood that this is a reciprocal arrangement.

History is unbroken in a rural district. Children grow up to inherit the family business – be it farm, store or service. This is changing, although the change is slow. Increasing access to education, travel and experiences of all types has broadened the availability of opportunity for country children. Often, they return to the country with a new perspective and sense of commitment to the rural town. So, there is a deep sense of belonging and continuity that in itself is sustaining. Shared local understandings increase these feelings.

Geographic distance does make a difference in the country. Travel has become more common, but taking 3 hours out of the working day for a visit to the doctor still is not done unless the symptoms are overwhelmingly frightening or incapacitating. The necessity to complete the daily work (especially if there is livestock involved or during the planting and harvesting seasons) is ingrained. This becomes a strong inhibiting force to adequate or even appropriate use of health care services – many of which take a great deal of time in travel, waiting and in the service itself. Most country folk are self-employed with little or no ‘health care benefits’. When they become ill, there is a direct cost in money not earned because of time lost. Single person businesses cannot afford to close – either economically or as a community service since others depend on that service. It is becoming more common for one partner, usually the wife, to take off-farm employment in the nearest town as a guarantee against the downturn in rural income. This makes it even more imperative for the farm-working partner to remain on the farm to complete the necessary daily round of duties.

There is little anonymity in a small rural community and this impacts on the delivery and the experience of health care. Concerned neighbours (as well as anyone with their eyes open) know when people come to town for health care, and undoubtedly, someone in the café or on the street will ask specifically about the visit to the doctor that was just completed. Evasions work to a point, but since the community is small, and there is often little to discuss, it is usually less traumatic (i.e. rumours are often more horrific than the truth) to answer rather than evade the question. The rumours are rife whenever there is a whiff of tragedy, and this fact of daily life makes it reasonable that rural folk maintain a level of honesty about most aspects of themselves, including their health, to avoid becoming grist for the rumour mill.

Health carers are part of the community and if they are to be accepted, they need to conform to the community standards. Hard work (e.g. cheerfully doing ‘overtime’ or coming in to relieve on a day off) is an expectation. People in the country work hard and expect it of others, making this work ethic a community standard. Confidentiality is a major concern for both patients and health care workers. It only takes one loose tongue in the doctor’s office or the hospital to destroy the trust of the community in the ability of the system to maintain their privacy. Health carers are under scrutiny both within and outside of their professional positions. Friends and neighbours expect advice about their health and answers to their health concerns from nurses, usually across the back fence or at social/sporting gatherings. Failure to comply or inaccurate advice given too often makes the nurse vulnerable to the poor opinion of the town. There is a need to guard one’s professional and personal reputation since there is no anonymity in a small town. Publicly, the moral standing of the nurse is also a consideration.

GPs are the only physicians that a small town is able to sustain. Sometimes there are visiting specialists, but they have not earned the respect of the country people and often do not understand the influences that motivate and constrain their country patients. Country living is not to everyone’s taste. There are often not professionals such as physiotherapists, occupational therapists and other specialised allied health care professionals who are readily available in the country town. Without medical and other specialists, the health care of the rural population is left to the health care professionals who choose to live and practice in the country setting.

Professionals who chose to live in rural areas are often from the rural sector. This choice has an impact on the health care professional. Unless they are extraordinarily motivated, their level of expertise diminishes with the passage of time and with the increase in knowledge available to the health professions. They become experienced in a range of medical situations but expert at nothing. The generalist nature of their practice, although honing a range of important diagnostic and implementation skills, precludes the development of expertise in any one area. Nor would this expertise be expected or utilised since these practitioners care for people with a whole gamut of diseases, disorders, conditions and traumatic injuries. However, the isolation from other practitioners and the nature of their work does mean that their ability to treat any specific condition or disease is limited to a generalist level.

To overcome this limitation, patients are referred to specialists in the city. In many cases, this means a flight or a lengthy bus or car trip, an overnight (at least) stay in the city and a return trip from the city. This takes the farmer or towns-person away from family, support networks, home and work for a lengthy period of time. If possible, people prefer to stay at home, and at great inconvenience, attend specialist clinics on an out-patient basis. For instance, when my brother attended the cancer clinic for radiation treatment, a 5 to 6 hour round trip was needed. He was too ill to drive himself, but friends and neighbours rallied. Over the 20 days of treatment, 9 different people made the trip once or more. They became involved in his care, and felt they were ‘doing something’ – a tangible manifestation of their concern - to help their friend in a desperate time. He saw and felt the care and support, and benefited from staying at home and from being with his friends for those hours.

Chronic Pain

My experience with chronic pain began when I was a child. I suffered my first migraine at age 11. From my eleventh birthday, for the ensuing 30 years, I experienced severe common migraines on two or more days every week. Many of these were totally incapacitating. Specialists in the city tested me for years, without results that were helpful. When I was in training, I was re-tested, given several different treatments and when nothing worked, was told to just live with the pain. I did this. It interfered with work because I was not alert. Not only was the pain distracting, but many of the medications prescribed (e.g. Phenobarbital and Benzodiazapine) made me very drowsy – but did not relieve the pain nor prevent it. After a few years, I determined that no medication really helped much except for Acetyl Salicylic Acid and Acetaminophen, which took the edge off the pain and allowed me to get on with living. These were the only treatments I took, apart from occasional doses of Morphine from the Accident and Emergency Room when the pain became unbearable. When it was unbearable, I felt like I was starting to disintegrate and that if the pain was not ‘taken away’, I would implode and become nothing. Outside of these relatively infrequent (fortnightly to monthly) episodes, I was determined that I would do everything I could to ensure that the pain would not alter me or change my life.

I did not take sick days very often, limiting my sick days to one or at most two per month. Work was a means of coping with the pain, which seemed to recede with the distraction of doing things. I stayed in bed only if I was prostrate with pain or actually vomiting. I went to work; at times with so much pain that thinking was a chore and moving was an agony. My social life suffered more than I permitted my work to be affected. I became fairly socially isolated as I caught up with my studies or housework or later, devoted the pain free time to my family. Social activities could be abandoned, family and work could not.

These experiences with pain made me particularly sensitive to patients’ complaints of pain and I read what I could find about pain assessment and management. I tried out new assessment and management techniques for controlling pain in my patients and in my own pain experiences. I advocated for patients with pain. Since I began teaching nursing, pain management has always been one of the most important aspects of my teaching interest.

When I was in my early forties, the migraines started to change. They were no longer as severe, did not last much more than a day and came less frequently. I became cautiously optimistic that pain would not be a lifelong companion. This hubris was quickly squashed, when I contracted an arboviral disease called Ross River Viral Disease (RRVD). In me, it manifested as severe small joint pain. Initially, I thought I had overdone the gardening over the weekend. Soon though, my wrists, ankles, fingers and toes felt like they were on fire. The pain limited the use of these joints – for a while, I had difficulty in walking. The physician I consulted assured me that this would abate within 6 weeks. All of the literature discussed the 6 week limitation. I waited patiently, being unable to drive the car, pick up a cup of tea without using both hands, cut my meat or peel the vegetables for dinner. My family pitched in and made life bearable. The 6 weeks came and went- with no relief of the pain. The physician did not want to hear from me – the trajectory of RRVD was a 6 week one, and he did not know what to do. Other physicians were consulted to no avail. My memory of that year is hazy. When 12 months had passed, I still was limited in the amount of use I could have from these joints. Overuse or becoming tired meant that I would endure excruciating pain for days. By the time I had had RRVD for 18 months, the pain was manageable at a dull ache. Still, excess use or tiredness would flare it into severity for days.

I decided to look at the natural history of RRVD from an epidemiological viewpoint in able to make sense of my experience. I enrolled in a Masters degree by research. I designed a longitudinal descriptive study and sent questionnaires to people who had just been diagnosed with clinically diagnosed RRVD. I followed their progress for 2 years, asking them to complete a questionnaire every 6 months. I found that many of the participants experienced similar unrelieved pain that diminished slowly over time. Sixty – two percent of the 81 participants still reported significant pain (enough to interfere with activities of daily living) 2 years post-diagnosis. In the meantime, other researchers had found similar pain experiences in patients with RRVD.

Since the RRVD has resolved (I experienced flare-ups, although with diminishing frequency and intensity for over 6 years), I have been relatively pain free for several years. I continue to experience frequent (2-3 times weekly) headaches, but again, the intensity has diminished to the point where the headaches are a nuisance rather than the enemy they were in my younger years. I am still surprised and pleased when I awake without pain.

Conclusion

My experiences of living in a small rural town and with chronic pain have shaped who I am. They have brought me to the point where I want to explore these phenomena more and in a disciplined manner – hence this study. The next four chapters present the findings from the conversational interviews with the seven participants, along with discussion about the findings substantiated from earlier research and other relevant literature.

Chapter 6 - The country style of life

Spatiality

> Studying chronic pain patients means that each must be situated in a local world. That world must be described and the description must include an account of the experience of pain in the wider context of experience of the family, workplace and the community (Kleinman, 1992, p. 173).

Introduction

Space is one of the existential themes of phenomenology (personal communication, M. van Manen, December 1997) which, when inhabited and experienced becomes more than a void inside a geometrical boundary (Freshwater, 2005). Space is imbued with meaning and gives meaning to experience.

Space encompasses the personal spaces we inhabit and the communal spaces we share as well as the vast sparsely-populated distances that rural people are used to. Space is an important theme when discussing the experience of chronic pain in small rural towns. Being born into or living in a specific context for a long period of time means that the person only has the horizons that are available within their family and the context of their community. Their world – the language, culture, perceptions, knowledge, meanings and traditions – is constituted by the local world. In this case, the local world is a rural area. The participants in this study shared insights into the communal spaces, the rural context and their own personal space during our conversations.

On the concept of ‘Rural’

The term ‘rural’ has healthful and stress free connotations. We associate an Arcadian life, with healthful living, open space and freedom from the crowding and pollution of the city with the term ‘rural’ (Buys, Roberto, Miller, & Blieszner, 2008). Sadly, the reality is often different. Living in a rural area of Australia is detrimental to health. Rural Australians enjoy poorer health than do their urban counterparts. The further from the city (i.e. the more geographically isolated) that people live, the poorer their health is. The Australian Institute of Health and Welfare (1998) demonstrates this with statistical indicators of both increased morbidity and mortality for rural people and for remote people. Rurality in this day and age is described as stressful because of environmental and economic hardship, limited resources (Hays, 2002), because of out-migration of the younger generation to cities where work is more readily available, to the disintegration of the social systems that have sustained the rural inhabitants for generations (DeLeon, Wakefield, & Hagglund, 2002). Services are being withdrawn, and with the loss of such amenities as banks, schools and hospitals go the people who sustained these services – the professionals are withdrawing to larger and larger centres (Wagonfeld, 2002). Without these services, retirement from the farm to the small town is less attractive – and the rural elders are forced to larger centres. The vicious cycle gathers momentum as the population in the rural town diminishes. Rural living has become more difficult.

The participants in this study lived in or near towns with ARIA index numbers ranging from 3 (moderately inaccessible) to 8.6 (remote). “As the index of remoteness based on distance increases, access to the variety, quality and range of goods, services, facilities and opportunities decreases” (Peach & Bath, 1999, p.25). This statement, although made in 1999, remains generally true. Since the adequate treatment of chronic pain is that provided by a multidisciplinary team (Loeser & Turk, 2001) and these teams are mostly available in urban and regional, adequate and appropriate treatment of chronic pain decreases as the distance from main metropolitan areas increases. Self-management of the pain becomes the primary strategy (Tollefson, Piggott, & Fitzgerald, 2008). The participants in this study have told the researcher that there are few services that are easily accessible to assist them to live with their pain. Thus, distance from pain clinics and ready access to pain specialists and other services causes difficulties for the rural person who is living with chronic pain.

Distance is the biggest problem

Chronic pain usually prevents free mobility, and geographically constricts the person’s space to their hometown, and sometimes to their own home. Traveling in or driving a car any distance presents great obstacles to those who live with chronic pain, intensifying the pain experience and destroying any pleasure or excitement that could be associated with being away. Diane, who lived in one of the ‘moderately accessible’ towns using the ARIA calculations, says: *I think in general, the biggest* *problem is the distances you have to travel for treatment, for tests, even for medication* (p. 2, L34-35)

She goes on to describe the difficulties that increase her symptoms of pain when she does drive a long distance and states that: (I) *round up a parent or a friend or someone else to go and collect my medication for me. Every hospital visit, every Doctor's visit everything involves traveling and I can't sit on the bus, I can't get up the steps, the seats slope the wrong way. And most places, it's a two or three- hour trip to anywhere for x-rays, tests, the hospital, whatever. So everything becomes such a major production and I think that's probably the hardest thing is knowing that there's no shortcut around things* (p. 3, L43-51). Not only do the actual distances daunt Diane, she added that even when she was driven, the nearest appropriate facilities were…*A few hours away on bumpy roads up and down hills* (p. 3, L62-63).

Travel to centralised medical facilities for treatment and diagnosis is problematic for those living in rural communities (Bourke & Sheridan, 2008; Keleher & Ellis, 1996). Travel takes time and costs a great deal of money – both in actual terms and for some, in loss of work time/wages, child care, and inconvenience. Public transport is often not readily available to the rural person. Although many states in Australia offer the rural person compensation for travel and accommodation expenses during illness and hospital visits, many rural people do not access this support because they are unaware of its existence or because it is quite inaccessible (Keleher & Ellis, 1996).

June, who lives in a 'moderately accessible' town finds travel to the city extremely difficult: *You've got to stop, hop out, back in the car, keep going, make sure I've taken medication and that before I go so I can get down and back. Sometimes I get really bad- Dr* (GP) *has got to ring up another GP so he can get me an injection to get back home again* (p. 5, L128-133).

Brigid, who lives in a 'remote' location according to the ARIA classification, also finds road travel difficulties: *It's the jarring, though. Even on the HACC bus, I can't go up to* (next towns) *on the HACC bus with them because it's just too much on my back. It's just too much* (p. 11, L327-328). [note: HACC (2008) is an acronym for Home and Community Care which is a Queensland program providing services to persons with disabilities and the frail elderly to assist them to continue to live in their communities]

Although she is much happier to take advantage of the Royal Flying Doctor Service*:* *I was flown to* (larger town) *and then I was flown on to* (large regional centre). *Um, then I was flown home, back to* (town). *So yeah, pretty good – the flying doctor service is really good* (p. 13, L400-401).

Brett, who lives in an ARIA designated ‘moderately accessible’ town, has found that he can manage the distances involved in a 2-3 hour journey if he really needs to: *I just adjust the seat to where I feel comfortable over a long period of time…If I need to pull over the side, and have a nap, I do that* (p. 5, L106-108).

Gary lives in another ‘moderately accessible’ area and he adds another mental and emotional dimension to the distance difficulties, saying that long distances are: *Very hard because its hard enough to go from here to* (big regional town) *and not be mentally challenged because of the extra people on the road, the traffic* (p. 14, L456-458).

Maintaining independent mobility in the rural area is mainly reliant on the ability to drive a car. The isolation that results from no longer being able to drive a car is just too great for many people to contemplate and they endure more pain to enable them to maintain at least a minimum level of independent mobility. Leah lives near to a ‘moderately accessible’ town and finds that she must adapt her driving style to accommodate the shoulder and neck pain – *If I drive, I drive from the bottom so that my hands are basically on my legs and I can drive. The most I’ve driven is about 35 minutes in one go then I just can’t drive anymore. I just physically cannot do it* (p.4, L73-75). Leah is adamant that her world is not just her property and house. She says *no-one can drive me because we don’t have anyone else you know and* (partner*) has to go to work so there’s no other way. You’ve just got to do it. There is no option* (p.4, L84-86). She just ignores the pain to maintain some semblance of mobility and independence: *Driving in, I just go “yeah I’m really sore but I know I’ve got to go to town” and just drive* (p. 4, L78-79).

In contrast, Branston, Rogers-Clarke et al. (2000) found that geographical location did not influence distress levels in well women who lived in rural areas and, used alone, is by no means directly related to well-being. With the added complexity of chronic pain and its deleterious effects on mobility and independence, geographical distance again becomes a negative challenge to overcome. Brigid maintains her independence within the town she lives in. She has a scooter, which she drives around town (on the sidewalks where there are any) with a basket for her small dog. Brigid says: *She comes uptown with me on the scooter, you know. She sits on the basket in front. She goes every Sunday* (laughs) *During the week, she doesn't go because I'm usually in a hurry – I just go straight up and straight back you know. On a Sunday I take my time – we call in and see a few friends - pick the mail up* (p. 9, L257-261).

Living in a small town

Rurality is a concept that is not only defined by geographical distance. Kulig, Andrews et al. (2008) add that community characteristics such as lack of infrastructure including facilities like public transport, educational and leisure amenities, limited health resources both human in the form of physicians, nurses, allied health personnel and specialists, and technological in the form of medical equipment help to define the rural community. These attributes were all apparent in the small country towns in which the participants lived. Kulig, Andrews et al. (2008) also cite the nurse as the frontline health care provider, however, participants in this study did not find this was so. Carl for instance found that he had little to do with health care professionals other than his GP (Carl, Field notes) and June cannot utilize the services of the Blue Nurses because she is not on a pension and cannot afford to pay the full price (p. 6, L155-158). Brigid only interacts with the nurses when she needs to be hospitalized, and then the nurses are 'agency', are in the district for 6 weeks, and do not know how to help her because of the spinal stimulator she uses to control the pain (p.13, L402-407).

Another defining characteristic of rural is the character of the people who live in country areas. Smith (2004, p. 12) outlines the foundation of the characteristics of the county persona, as do Hegney, Pearson and McCarthy (1997). These authors attribute many of the traits of the country character to the isolation and the need to adapt to the situations. The traits outlined in the introduction (pragmatism, ingenuity, resilience, self-reliance, independence, strong social support, hard work, and stoicism) are also cited in the literature from other developed countries with large rural populations (USA, Canada). However, it is prudent to keep in mind that rural people are individuals and these traits cannot be extrapolated to imply an aggregate ‘rural personality’.

The ‘rural character’ is further shaped by such forces as working in primary industries (or their support services). Occupational difference is one distinguishing characteristic between the rural dweller and their urban counterpart. In rural areas, primary industries (agriculture, grazing and mining) are the largest employers of labour along with the support of service industries such as farm implement sales, mechanical repairs and feed and fertiliser retail outlets (Hays, 2002) as well as the more general support industries and services of food, health care and education which are all concentrated in the small rural towns. The dangers inherent in country jobs, environmental exposure and frequent long distance travel increases occupational risk. On top of this, occupational stress grows from the combination of self-employment, dependence on the weather/climate, the extension into marginal lands and the economic decline of the rural sector (Hays, 2002; Wagonfeld, 2002). These indicators of rurality affect the experience of living in a small rural town and must be borne in mind when considering the entire existential essence of spatiality..

Carl talks about having moved from the city and how the move has helped him to deal with the pain: *I think the country sort of style of life as in the peace and quiet, not so pressured by people coming all the time…it’s helped a lot* (p.15, L513-515). And again: *The wide-open spaces and scenery help with serenity and peace. These reduce tension* (Field Notes, Carl). With these thoughts, Carl raises an important aspect of the differences between the rural and urban experiences. Crowding in cities involves psychological stress (Altman, 1975) and people must endure noise, intrusion into their personal space, becoming an unknown, impersonal cipher in the mass, as well as face unfamiliar sights, sounds and smells and generally increased stimulation. The cognitive and emotional inconsistency encountered by country people who visit the city increases their physiological response to the altered environment with elevation of the blood pressure, increased hormonal output and muscle tension (Altman 1975). This author also asserts that the more time the person spends in the crowded situation, the more distress is apparent. Noise in particular stimulates the tension effects with increased secretion of cortisol (Stokowski, 2008). Psychological and physiological tension increase pain and cause increased fatigue (Nicholas, 2008), providing a biomedical explanation for some of the ameliorating effects of relaxation (Schaffer & Yucha, 2004) and of living in the country.

Small towns are safe and comfortable.

Participants found that living in a rural community involved the experience of being wrapped in the security of familiarity, trust and mutual respect.

Brigid: *If I didn't live in* (small country town), *if I lived in* (large regional centre*), I wouldn't handle the pain as well as I do out here. Because in* (large regional town), *I'd be too scared to go anywhere. In* (small country town), *I know I can go all over this town – at midnight- and not be hurt* (p.16, L489-492). *And you ask why I live in* (small country town) *when I can go down the street and leave my doors open and not have anyone come in? I'm not ALLOWED to have a life out here – I've GOT a life out here* (p. 16, L494-496).

Brigid raises the issues of trust that develops within a community. Members of a rural community develop a personal knowledge of most of the members of that community (Lane, 2004) either directly or as a friend of a friend. This knowledge of the interconnectedness of the members develops a kind of community feeling of trust and respect, which in turn demands an interest in fostering the well-being of the community. People protect each other in county towns and are aware of strangers. An example of this was when I went to the local police station to determine the directions to Brigid's home prior to our first interview, the constable phoned ahead to ensure that Brigid was expecting a visitor, then he followed me to her home and waited until I had been greeted before driving away.

In this context of rurality, it is not only trust that develops, but also social solicitude. Diane describes this when she explains that the grocer tucks a box of her favorite biscuits into her order when she emails her grocery list into the store, and emails back to her '*We've got some of your favorite biscuits in, so I put a box in for you'* (Diane, p.7, L243-244) and the neighbours collected her daughter from school and cared for her when Diane was taken to hospital (p.7, L257). In another example, Brigid 'looks after' her next-door neighbour, who is elderly. She reads and writes for him because he is unable to do these things for himself (Brigid, p.8, L233-235) and she does a *lot of cooking for elderly people* (p.3, L69).

Brigid is one of several severely disabled people in her small town who are assisted to mobilize with the use of scooters. We discussed some of the difficulties of this and she related a story about one of the town's residents who *just drove where he liked, and everyone would just go around him. He thought he could go anywhere and people would let him* (p. 9, L268). She says *people are helpful and friendly* (p.9, L279). The shopkeepers *have put buzzers outside their shops – for people on scooters – the newsagent, the food shop and the chemist* (p.12, L353-355). These stories reflect a caring and concern about more vulnerable people that arises from the interdependence of geographically isolated people who develop rich traditions of mutual support and similar helping social values. The relative isolation of small towns has fostered these traditions.

Cordes (1985) outlines the conservative nature of attitudes of rural people, and states they are generally on the issues of morality, religion and political philosophy. The strong influence of traditional social values that have arisen because of the homogeneity of the values systems in small centres can be applied to health behaviours. Examples of positive health behaviour might be conforming to immunisation schedules. Negative health behaviours are seen when 'shame, fear and stigma keep rural residents from seeking help for problems that are deemed socially unacceptable, such as mental illness, human immunodeficiency virus infection, acquired immunodeficiency syndrome, and domestic violence' (Hudnall Stamm et al., 2003). These same behaviours can impede people from seeking assistance for the invisible and the chronic illnesses such as pain, because of the negative stereotyping of 'bludging' and of the value placed on hard work.

Hard work (Smith 2004) is a hallmark of country people. Hard work is needed in the harsh occupational and environmental climate of the rural dweller. Holmes (1981, cited in (Pashen et al., 2002) attributes the hard working rural person to self-selection, as those who are not prepared to work hard and thrive in the harsh environment tend to leave it. The loss of his capacity for hard work due to his chronic pain makes Gary feel guilty - *Because I knew that I could work sixteen-hour days and now I couldn't do a six-minute day* (p. 14, L444-445).

Hays extends the idea of hard work with the statement that “rural people expect to work hard and do not respect those who will not” (Hays, 2002, p. 51). As well, because hard work is such a valued commodity, anyone who is receiving a pension is viewed with some suspicion. Brett demonstrates his own aversion to being seen as a bludger and to go on the ‘dole’: *Even that 4 years where I couldn’t do anything at all, I never actually took the step to actually go on the Disability Pension just because it was like taking the last step which was over the crest sort of thing. I just mentally felt that way so I never did it. And I think I had pretty good reasons to be on the dole but I always hated it. To take that extra step was just seemed to be like closing the door on everything else* (p. 11, L 303-308).

Carl, who does get the disability pension (although he does not believe it is sufficient to live on) worries that others think *‘Jeez, you don’t look sick – why are you on a pension? Bludger!’*(Field notes, Carl). Pao-Feng (2004) concludes that financial hardship predicts distress in older people with chronic pain. Financial hardship is common in the country areas as the socioeconomic levels are lower (Bourke & Sheridan, 2008) and doing without or using a system of bartering to ensure essential needs are met is common. Gary, Carl and Brigid all reported that these were frequently used. For example, Brigid sews and pots up cuttings for friends and neighbours in exchange for transport, or for assistance like changing the battery in her scooter. On the day I visited, Carl was ‘gifted’ a dozen pumpkins as he had agisted some goats for a few weeks. Gary ‘lent a hand’ to a farmer to gain the use of his truck for a weekend. Worry about where the next meal is coming from adds another difficult dimension to the pain experience.

Despite these drawbacks to living in relative isolation, the residents of small towns appreciate the favorable aspects of country living. Peace and quiet, beautiful and serene surroundings and conversations punctuated with the insistent sounds of crows in the fields near the house, anchor people to the town. In this context, the fast paced life of the big city can be repellant to rural dwellers. Gary, for instance, used to live in Melbourne and drive a cab there, but now prefers to stay in the small rural town where he and his family have lived for several years: *But just now I don’t like going to the city at all actually* (p. 20, L478). He illustrates his preference by relaying an anecdote about going to the city and being confused and irritated by the traffic, and the confusion of the excessive stimulation and the difficulties with driving and parking in the city (p. 20-21, L680-707).

Carl also has difficulty with driving in the city and discusses his move to the rural town a decade ago: *Moving out of a situation where you so easily can get tense – like driving- start-stop driving, traffic. Now see, that's using your legs and foot pedals all the time. You can end up with ankle pain which will creep up into your knees which creeps up into your hips and that and once it's in your hips it's really severe* (p. 2, L37-43). These ideas again reinforce the tension that rural people can feel when they are obliged to venture into the unfamiliar territory of the large town or city.

Small towns do, however, have drawbacks and June finds that because of the difficulty with travel from the chronic pain, she has had to forego her hobby of ceramic painting. She is unable to source supplies without driving to the city: *I used to do ceramics and that, but see, that's another one – you can't get ceramics and that out here and there's no kiln. If you want to use the kiln or to buy pieces and that and your paints and that, that means you've got to go to* (city) *or wherever you can get your pieces and that. That's the only other thing I got into was ceramics because, night times when I had bad nights, I used to just paint them and do them up and that* (p. 9, L210-218).

The lack of facilities and resources is inherent in the small rural town. Population sizes do not permit capitalist enterprises of the size and variety available in large regional centres or cities. This lack forces the rural town person to travel to the city for any out of the ordinary purchases. Unfortunately, this disadvantage affects most people who live in small towns, although with the increase in Internet usage and sales from Internet sources, this disadvantage is slowly being eliminated. Internet facilities are available in most parts of Australia, but are generally more expensive if standard access is unavailable and is often less efficient in the rural areas (personal communication, Helpwizards Ltd. 11.10.08).

Retreating to private spaces

Private space is exceptionally important when living with a chronic pain condition. At times, severe chronic pain can be overwhelming to the normal adaptations we make to life and to our capacity to cope (Sherman, 2005). A private space is somewhere that the participants retreated to when ‘things’ became too intense and they needed undisturbed space to themselves. It could be home, a room, or their bed or chair – somewhere they felt they could be themselves and not have to put on a face for the world – or even for their friends and families. Arendt (1998) says that this private refuge is somewhere in the world that a person can hide and be protected against the public; a private space that shields them from intrusion by others (van Manen & Levering, 1996). Often this physical area becomes a sanctuary from the world of pain and of dealing with the pain in public.

Brigid: *If I’m sitting down in the lounge chair and say, knitting, I’m quite comfortable* (p. 1, L23). Brigid has an established comfort area in her home, as do most adults. Each of us, given a choice, will gravitate to one specific area where we feel comfortable and secure. Often ‘our’ chair or space is surrounded with the things we need and use, our books, writing materials and leisure activity materials. This chair and these familiar and used articles engender a feeling of calm and contentment that help to ease the day’s troubles and give us pleasure.

Brigid uses her sewing room as a refuge: *But I’m lucky, see. I just go into the sewing room and hide* (p. 8, L227). Here she is able to hide from the heat of the summer, the world and even the chores that await her in the rest of the house. The comfort this disengagement offers assists to relax her, reduce muscle tension and de-escalate the pain experience.

Diane also talks about her private space. *If I’m having a really crap day then I just go back to bed and I’ve got my music and I’ve got my stack of library books* (p. 26, L 1049). She also uses the recliner with an electric hot pad where she retreats for a rest between tasks (p. 22, L860-870). Relaxation is an important pain control strategy and relaxation is made more effective by being in a private and comfortable place. The private space can be seen to help reduce the emotional component of pain as the familiar and comfortable surroundings help the person to cope with the events of the day as well as the pain more effectively (Schaffer & Yucha, 2004). People feel safe and more in control in well-known home territory.

In this respect, Gary referred to ‘going to bed’ or ‘jumping into the bed’ a lot during our conversation (p. 2, L39; p. 3, L42; p. 4, L97; p. 6, L190; p. 7, L216, 227; p. 9, L277; p. 10, L316; p. 11, L338). Gary was able to gain a sense of security and to relax (Moore, 1984) as well as reduce the physical and psychosocial efforts required to live his life when retreating to his own bed. *I just said to* (wife) *"Going to bed" and all I could do was put the cup down, turn and walk off like a little old man and just get onto the bed like that and just lay there. And it takes twenty minutes before I can actually sort of can relax again*. (p. 6, L165-168). He equates being in bed with being able to relax. Relaxation is known to ease pain by reducing muscle tension and reducing the hormonal response to pain (Schaffer & Yucha, 2007).

Gary also sought refuge from others when he had to drive into town: *I'd rather just sit in the car and watch the world go by and try and deal with my pain* (p. 8, L243-244). People who live in or near small country towns expect social interaction from nearly everyone they meet in town (Lane, 2004). For these participants, avoidance of interaction, especially with mere acquaintances was a protective mechanism for the individual living with their pain. This consideration is especially pertinent in a small country town where the townsfolk have expectations of a leisurely chat when they encounter those they know. Small talk with a near stranger or peripheral friend requires concentration and active input from each of the participants and this is very difficult for someone living with chronic pain.

Carl discusses his relative paucity of socialisation and says *I don't mind the quiet life out here. As I said, we've got a nice mixture of people coming to visit us now and it gives me headspace to cope with* (pause) *and it allows me the time to drop all my guards and go "Ew, I'm not feeling well", you know. It gives me that bit of time where I can sort of, I suppose, maybe think about yourself if that doesn't sound selfish…You need that you know* (p.13, L435-442). In this context, Carl's 'selfishness' can be understood as a necessity, rather than an indulgence. Dealing with constant pain requires a great deal of energy, as does socialisation. The body can be overwhelmed by energy demands if both occur over protracted times or at frequent intervals.

Privacy to be oneself and to not have to put on a face or front for other people is an important consideration for those who live with chronic pain. Carl says it is so helpful to live in the country and to stay at home, because *You don't have to look or act happy* (Field notes, Carl). Keeping up appearances is energy consuming and the energy is required for dealing with the pain. The privacy gives them the space to be themselves, to be miserable if they need to be. Diane exemplifies this with:.*I'm probably not going to really see anyone, I'm just going to lie at home and be miserable…eventually it wears off – a bit* (p. 26, L1059-1060).

Conclusion

The lived experience of the existential essence of spatiality is individual and shapes our life experience, our values and beliefs, and influences the culture we develop. These impact on our how the other essences, temporality, corporeality and relationality are experienced. The country style of life certainly affects how chronic pain is experienced. This chapter has explored themes of rurality, distance, living in a rural town, safety and comfort, and retreating to private spaces. Time in relation to living in a body that is enduring chronic pain is explored in the next chapter.

Chapter 7 - This is my life now

Temporality

Introduction

Temporality is one of the existential themes that van Manen (1997b) uses to discuss the lived experience. Our knowledge of the passage of time permits awareness of mortality and this gives meaning to all we do. Merleau-Ponty discusses the elusive nature of time. He identifies the intimate relationship between time and subjectivity that arises from our experience of the three dimensions – the future sliding into the present and slipping into the past – that are carried along by lines of intentionality tracing out in advance ‘the style of what is to come’ (Merleau-Ponty, 1962b, p. 418). Heidegger comments on temporality and says that “the past and future cannot be understood if they are thought of as mere appendages around the present moment”(cited in Moran, 2000, p. 223). This presentation of the intimate entwinement of past, present and future, with each informing and being informed by the others permits us to understand our subjective existence using a historical approach.

Time is a subjective construct that in our society, we mark by named periodicities – minutes, hours, days, months, seasons, years, decades. This construct is shared within a culture or society in order to standardize our experience of temporality. Flaherty explains that “our experience of duration is thought to change as we step from one realm of social reality to another, or as the immediate situation mutates into a new form of interaction”(Flaherty, 1999, p. 28)and on the density of experience that fluctuates in relation to the self and situation. To a greater or lesser degree, we are aware of the passage of these units of time. We may experience the passage of time in an idiosyncratic way

Flaherty (1999) outlines the paradoxes that are inherent in the perceived passage of time and account for the variation between normal, accelerated and extended time passages that seems to exist. He illustrates each of these with examples of lived experiences. The initial paradox is that time is perceived to pass slowly “in situations with abnormally high or abnormally low levels of overt activity” (Flaherty, 1999, p. 21). The second is that we perceive the same interval of time as passing slowly while it is in the present, and of having passed quickly in retrospect (in our memories). And the final paradox of the perception of time is that some busy intervals are perceived as passing slowly, while others speed past.

Chronic illness distorts the standard perception of the passage of time. Synchronously perceived time passage is not generally noted or remarked upon. But either the protraction of duration of time or its acceleration brings the passage of time to our attention and it takes extraordinary circumstances to do this. Flaherty states “any form of suffering is capable of provoking the perception that time is passing slowly” (Flaherty, 1999, p. 43).

I am different to what I was

For most of us, time flows seamlessly along a continuum from past to present to future. Our past shapes our present, which in turn molds our future. We are able to return to earlier times via our memories, and meaningful occasions create special moments in time (births, deaths, marriages) which we refer to as markers in our lives, enabling us to bracket periods of our time continuum for consideration and for ease of discussion with others (for example ‘after Dad died’, or ‘before we were married’). Friedman (1990, p. 28) calls this the ‘inference model’ of the remembrance of things passed. For each participant, the time continuum has been marked by the onset of their pain experience. There is a ‘before’ and an ‘after’ the onset of the pain, with the acknowledgement that their lives had changed dramatically following the pain. The former pain-free self is gone and life has turned around - with all that is involved in accepting the permanence and reality of this change

Participants described the experience of chronic pain as including the need to give up many things, and essentially develop into a different person who is now able to undertake only a fraction of the activities of the ‘before-the-pain’ self. The present has become an impoverished country without the freedom to grow their identity as they would wish or as they had envisioned it ‘before-the-pain’. The immersion in the reality of the present is underscored by remembrance of the past and the fear of the future.

The temporal discontinuity between the ‘now’ and the ‘then’ is mourned as a “loss and to be met in the way one usually meets irretrievable losses – by accepting that what one has loved is gone beyond recall” (Vasalou 2008, p. 306). This grieving process can be protracted. Acceptance of the change into the person of the present is slow to develop and there is frustration and anger. However, usually, the discontinuity of the “out-of- reach past …does not constitute an ever-present object of thematised, reflective dismay” (Vasalou, 2008, p. 296) and is viewed with a pragmatic, though regretful acceptance.

Carl tells us *Before this happened, I was a very active person, very active, probably even overactive, you know* (p. 3, L93-95) and again: *All the things I really enjoyed doing have been taken out of my life. You know, I’ve accepted that, like I used to surf all the time and I was in theatre and all of this sort of stuff but it was just too much for me so I’ve given it all away* (p. 9/10, L 308-312). ‘Giving it all away’ is a recognition of the self-imposed (or pain imposed) limitations that are now necessary in order to live in any sort of comfort. Carl has had his diagnosis of fibromyalgia for many years, and the acceptance of his life as it is now possible has grown through that time. This permits him to focus on maintaining an as near to normal lifestyle as he can. Nicholas (2008) styles this as one of the tenets of pain management.

Brett is very aware that he has changed. *I can’t go out jogging and that sort of stuff…*(I’m) *Different to what I was*. (p. 2, L49) and again *what I was back then to what I am now is completely different* (p. 2, L32-33). Brigit contrasted her current life with her ‘before’ life in which she worked very hard and did a lot of volunteer work: *And I look after myself more. And I don’t pamper myself and I don’t feel sorry for myself. I get on with life but I don’t overextend myself anymore. I’m not available to run back and forwards doing things for so and so. I’ve cut all that out. No, you can’t just ring me up and have me drop things and go and do what you want, you know* (p. 15, L463-467).

This passage demonstrates all of the ‘can’t do’ things that she once enjoyed doing for people. Her frustration at the changes she has had to make is apparent. *Now, now, I’ve got to be a real lady – I’m not allowed to do anything* (p.15, L458*)…I get so frustrated. It is so frustrating* (p. 15, L460). Brigid has had to adapt her self-image to one of a more idle, less involved, less doing person. Again this realisation has been long in coming and she has caused herself a lot of pain and grief by trying to battle the pain to continue with her ‘old’ lifestyle for far longer than was wise. She says *I just got on with it. I’ve done a lot of heavy work…driving tractors, school bus, dressed down a sheep. ‘N I only hurt myself more and more with every year that went by*…(p. 15, L454-456).

Diane was a Registered Nurse and worked with oncology patients. She says *I loved it – that was the hardest thing was giving up work* (p. 2, L32-33). She compares herself to the women she used to socialize with: *But ten years down the track, I am the only one of those women who doesn't work* (p. 5, L178). Gary says *I've had 57 jobs, I've joined the Army, I've done a lot of things in a lot of places and sort of, sort of have always been a hard worker and when you get hit with pain and can't do your work, well, that tends to mentally eat at me as well* (p. 4, L115-118).

The difference between the 'before the pain' person and the 'after the pain' person can be seen in these participant's words. Vasalou (2008) discusses these discrepancies and suggests that the person is often dismayed and made anxious by the differences that are perceived because they indicate a fragmentation of self and a disintegration of personal identity. This separation of present self from past self is difficult to accept and requires the person to explore the discontinuity and self-doubt it engenders for the present and the future. The disparities between before-the-pain and after-the-pain have been hard to accept by the participants and still produce longing in both voice and facial expression as the past is spoken of.

Self identity is shaped and influenced by our experiences and is a work under construction all of our lives – it is who we are. Our identity will be altered by very negative experiences such as severe pain states. This evolution occurs as we try to adjust in response to our experiences, and to adapt to the constraints imposed by something outside our control. Vasalou (2008) proposes that a lack of control over factors influencing our self-identity is predictive of instances of future action, thought or words that are inconsistent with our past or current value systems. These are therefore anxiety provoking. She states "discontinuity between past and present …is situated in the perspective of a present that doubts itself on account of its failure to instantiate the qualities considered to be definitive of one's being" (Vasalou, 2008, p. 295). Sherman (2005) warns that anxiety about the future can derail agency.

Gary is proud of his past accomplishments. *When we first moved here we had a beaut veggie garden. We sat down one night there and we had nine different veggies on our plate that we'd grown off the land and we used to breed our own dairy goats, have, their own dairy fed milk and breed our own pigs and we used to feed the dairy goat* *milk to the piglets and have them on grain ration. And the man over at* (Name) *Pig Factory here in* (Town*) said they were the best piglets he'd ever seen* (p. 19, L642-648). People define themselves by their activities, and distinguish themselves from others by their action (Arendt 1998, p.176). Work is seen as essential to life in that life's necessities are acquired through work or labour, and although most of the participants received Disability pensions, they all recalled 'before the pain' halcyon days when they earned their own money, and sought avenues for increasing their income. Brett, who did not receive a pension, although entitled to one, was *working full time and the doctor actually told me to* (pause) *that I should cut back on work* (p. 3, L53-54). He had to move back with his family of origin partly because *rents in* (town) *are extremely high - I couldn't afford it by myself* (p. 6, L163-1640). Rental properties in small rural towns, and especially those near mining operations, are often scarce and thus demand a high monthly rent.

Carl says that *finances are a burden with us. We have our good moments and we have a lot of lean moments, you know. Though I'm thankful for the pension, I 'm very thankful for it, you can't live on that* (p. 10, L 340-343) and although he is unsure that he can manage the pain, he wants to undertake a part time job *because I'm a doer and I want to do something and I'd like to contribute financially to the family instead of just doing housework all the time and stuff* (p.10, L 328-332). In Western society, our labour is exchanged for the necessities of life, making labour one of the most important facets of an adult's existence and is required for contentment (Arendt, 1998). Our labour comes to define us as people, and the loss of the ability to labour for wages is a devastating blow to self-esteem. Clancy (2004, p. 66) outlines the centrality of labour in the Australian consciousness and points to terms like 'hard Yakka' and 'hard slog' as defining admired traits.

Brigid takes in sewing jobs as well as doing ironing as paid work. She says *not a week goes by that I don't get 2 or 3 jobs* (sewing)…*As I said, it keeps me busy*. *And my friends say it keeps me out of trouble* (p.14, L436-437). For her, work not only brings in a supplement to her income, but occupies her hours and helps provide her with distraction from the pain. Carl (field notes) concurs that keeping his mind active helps him to cope with the pain.

Gary, who was an artist and art teacher before the chronic pain onset says *it comes back to the artist in me being creative and wanting to create. Because I feel good when I create* (p. 15, L497-498). Carl, too, needs to feel he is contributing to the household. He does the housework, files the taxes, takes care of the bills and does the yard work, although he says he feels guilty that he cannot contribute financially (field notes Carl).

This is my life now

The endurance and acceptance of pain is a different developmental task for each person. It is a positive change that grows out of the experience of living with the pain and coming to terms with it. Acceptance is time consuming and waxes and wanes even after years of living with the pain. It differs from trying to control the pain and from fighting it (Benner, Janson-Bjerklie, Ferketich, & Becker, 1994, p. 247) and leaves the person more comfortable with themselves and more able to engage in a meaningful life. Acceptance is an "attitude characterized by attempts to change personal circumstances to meet the demands of the environment, whilst disengaging from ineffective attempts to control the environment" and further characterize it by "living within the present and …decoupling of present experience from the tortuous rehearsal of a past that cannot be changed and a projection into a future that cannot be known" (Risdon, Eccleston, Crombez, & McCracken, 2003, p. 376). These authors report that acceptance of chronic pain produces a more successful adjustment to the situation and reduced depression, anxiety and disability.

Diane has lived with chronic pain for 9 years and she says *I guess over the years I've come to accept that this is my life now and you just have to make the best of it, you know* (p. 6, L206-208). 'Making the best of it' is a shift away from futile attempts to find a cure for the pain and a move toward recognition that the pain may not end. According to Corbin's (2001) Trajectory model of chronic illness, this is a linear, time related shift. Achieving this understanding is not easy and does take most people a great deal of time. Those who live without chronic pain state they cannot understand the concept (Risdon, 2003). Curing a chronic pain condition is unlikely and chasing a silver bullet only exhausts and discourages the person as one after another intervention brings no relief or at best, a fleeting remission of the constant pain. Nicholas (2008) asserts that complete pain relief is usually not attainable with the present knowledge of treatments. Refocussing on other life issues reduces the pain's potential to 'overpower life' and is a central feature of accepting the chronic pain (Risdon et al., 2003, p. 383). Is refocusing attention away from the pain even possible when the pain can be so overwhelmingly consuming? At times, the pain dominates all attention and there is nothing but the pain.

Paterson (2001) suggests that chronic illness is not defined by a linear trajectory, even if regressions are included. Instead, she concluded from a metastudy that there is a shifting perspectives model of chronic illness. By this she means that the person who is chronically ill focuses on either the wellness of themselves as an entity or on the illness aspect of symptoms and limitations. These two perspectives are either foreground or background in the daily life of someone with a chronic illness. The perspective can shift, sometimes very easily, from wellness to illness and back again. Shifting of the perspectives is caused by such events as changes in symptoms, treatment failures or good support and realisation of the changes followed by a mental shift toward wellness or illness (as relevant).

Diane reiterates: *Then at some point you have to accept that you're going to have days like that* (having a bad day and just going back to bed) *where you're not going to accomplish anything and to accept that that's life* (p. 26, L1052-1054). With these words, Diane demonstrates another cornerstone of acceptance of the chronic pain which is living in the present and not needing to avoid or change the pain (Risdon et al., 2003) but living as normal a life as possible within the constraints imposed by the pain. This echoes Heidegger's (1927/1962, p. 63) thinking about *Daisen* (the being-in-the –world) in that an individual makes their own lives – their choices - against the backdrop of their history and hoped-for future but within the limitations that are imposed on them and constrain their choices.

Carl says *I've been diagnosed ten years ago so I'm on top of it a bit…its taken me a long time to get to this point now* (p.15, L532-33). Carl recognises the temporality in the acceptance of his pain state and in fact, told me that Gary, his friend and another participant in this study might be 'a bit teary' (Field Notes) because he has not had his pain as long, implying that acceptance of these circumstances takes a great deal of time. Acceptance of a chronic pain state is not dependent on the sensory or experiential aspects of the pain but on the chronic pain's effects on self-identity, on the social roles it permits and on what the pain allows the individual to undertake and accomplish. Vasalou (2008, p. 303) outlines the "practical standpoint from which we regard ourselves as agents" to undertake the "making of oneself as the same person…to see personal identity as a task" (p. 304). In other words, people are the creators of their own identity within the limits of their control over self. This reiteration of the importance of self-identity in living with chronic pain is a recurring theme throughout the participants' statements.

Things will not improve

Coming to the realization that the future does not bring a guarantee that pain will go away, and that their lives will be affected far into the future, is a searing realisation for many participants, and one that took years to come to. Brigit has lived with chronic pain for 30 years and was relating her younger years and the heavy work she had to do on the farm (fencing, tractor driving, dressing beasts) for survival - *Well, they just had to be done* (p. 15, L454). She realised that the work and thus the damage she had endured would only increase with the effects of aging. The heavy manual work involved in farming places extraordinary physical demands on many people living in rural areas. *I only hurt myself more and more with every year that went by. I was doing more and more damage. And the older I get, the worse it gets* (Brigid, p.15, L456-458). In these statements, Brigit acknowledged her own part in causing and exacerbating the pain and her understanding that the future holds only more intrusive and debilitating pain for her.

Gary, who has a diagnosis of fibromyalgia, says *I'm never going to get out of this* (the severe pain). *This is just going to contort me and twist me and just leave me* (like this) (p. 3, L67-68). Gary is in essence, crying out and sees his body as betraying him. He has not lived with the chronic pain as long as Brigit, Diane or Carl and has not developed a level of acceptance that permits him to reduce the influence of the pain on the way he lives his life. Brett is trying to come to terms with his future and feels that he can research *the worst-case scenarios* (p. 8, L212) for his diagnosis and then, in the short term, at least, can *still do all these big heavy things yet pay for it later on with pain* (p. 8, L213-214).

Diane says about becoming dependent: *That day will probably come again. There's no doubt that … I'm going to hit bad patches in the future where I just need that level of help* (p. 12, L441-444). In the past, the pain has relegated Diane to a wheelchair and a return to dependence on her aging parents who are still able to assist her. Diane has slowly gained a degree of equanimity in the face of ongoing bouts of dependence due to fluctuating pain levels, and although she sees that the pain will not improve or go away, and her dependence may increase, she has developed a level of acceptance. *Having lived through that period in my life where things were pretty well as crappy as they could possible be, it is like "Well, I've survived the worst. If I end up back in the wheelchair, I end up back in the wheelchair" I know I can cope with it because I've already done it once, sort of* (p. 7, L226-230). Although she is accepting, there is a note of fear of the future and worsening pain in her voice as she says: *I'll wake up one morning and I can't get out of bed* (p. 5, L150). *Of course there's always that fear in the back of my mind where I think that this is the time that it's not going to get better by itself* (p. 5, L153-154).

Uncertainty is a constant when a person is dealing with a chronic illness – either as the person living with chronic illness or as the family member. Chronic illness removes the structure and continuity of self. Weiner and Dodd (2001) discuss the dis-integration of self that occurs because of bodily malfunction. The self can no longer complete tasks over time – tasks that give definition to the self and had been planned from past to present to future. These authors discuss the disintegration of the self and how the elements are interrelated and begin to fail because of malfunctioning of the body. The intrusion of the illness separates the person of the present from the person of the past and alters the person of the future (Weiner & Dodd, 2001, p. 185-6). The change in temporal predictability – people's use of the past to make decisions in the present to affect the future – are altered, as are their conceptions of duration, pace, frequency and their sense of time (Weiner & Dodd 2001, p. 187).

Not only is time measured in past, present and future, we also live our lives from day to day, hour to hour and minute to minute. These shorter measures of time can be very elastic, passing in a blur of activity, creativity or intellectual pursuit, or they can drag by in boredom, routine or endurance of anxiety and pain. Flaherty (1999) attributes this disjunction in temporal perception (that is, the lived experience of duration of time and the passage of time on clocks and calendars) to the different circumstances that people find themselves in. He includes emotions and states of consciousness within the circumstances.

Seligman (2002) discusses the gratification of being totally immersed in an activity and demonstrates how time is suspended when we are engaged in a gratifying activity. He suggests that to attain this state, the task must be challenging, requiring skill and concentration with clear goals and immediate feedback and we have a deep effortless involvement with a sense of control and with a loss of our sense of self. Then time stops (p. 16). These time warps are apparent when what seems like a few minutes later, several hours have passed. Carl and Gary are both artists who have had to give up their professional work, but who both told me that when they create a piece, they ‘lose themselves in the work’, although when their concentration lapses, they are tired and they pay a big penalty for it in pain (Field Notes, Carl and Gary). Although the escape from the pain, even for a little while, helps each of them to reconcile themselves to this life with chronic pain, both are very aware that the pain will be with them for the rest of their lives.

Fending off the boredom, which brings on rumination and adds to feelings of depression, is an important aspect of filling in time. Our perception of time is controlled to an extent by the busy-ness of the hours so that our experience of time passing is accelerated. Brigit says *I try to keep my day that full on that I haven’t got time to sit and feel sorry for myself* (p. 2, L53). Our temporal perception is positively biased when our attention is engaged and the following words of Diane demonstrate her awareness of this occurrence. Diane, about undertaking some retraining in Diversional Therapy: *I wanted a job or career or something to keep me occupied intellectually* (p. 10, L345). Carl talks about ‘doing things’ in spite of having to endure pain afterwards and attributes this to the need for *keeping your mind occupied* (p. 9, L289) and that *it’s also to fill time* (p. 9, L292). He clarifies this when he says: *If I wasn’t ‘doing’, I’d get, you know* (pause) *boredom only leads to thinking again about how you feel and then you can get depressed about it* (p. 9, L299-302).

Preventing the extension of the perceived duration of time by occupying the brain is supported by neurobiological research that demonstrates that time is not a single entity but “a diverse group of neural mechanisms that mediate” our temporal judgments (Eagleman, 2008, p. 5).

Nicholas (2008, p. 461) summarises the literature around pain management and comments on the usefulness of several facets of ‘attentional techniques’. He concludes that reconceptualising the pain as an unreliable signal of tissue damage (to reduce fear), developing a non-reactive observation of the pain (to reduce negative emotional engagement) and to determine what activities can be undertaken despite the pain (to assist with lifestyle changes) are as important to the person dealing with chronic pain as is simple distraction.

Negative emotion and suffering elongate time (Tipples, 2008), and the hours drag by, seemingly interminable, something to endure. Gary explains that sometimes, managing pain in relation to time is difficult to deal with: *Yeah, one day at a time. You get through that day, go again* (p.18, L581-582). These words underline the chronicity of the pain, and hint at the importance of time to our lives. The end of personal time will occur with each individual's death and our own mortality is generally so painful to contemplate, that we ignore it. This leaves us perceiving time

Pace of life in the country

Another aspect of time is the perception of the slower pace of life in the rural towns in which the participants live. Friedman (1990, p. 111) described the differences in time pressure between large and small towns in the United States of America, and concluded that small towns experience a slower pace of life. He suggested some reasons for the reduced time pressure – generally older ages of his subjects, lower incomes, semi-skilled occupation – all of which occur more frequently in a small rural town than in the cities.

Brett says *I would prefer to have this sort of pain here in this little area because if you spent a week or so out here you'd be like* (pause*) the pace of life is a lot slower than it is in the city and I'm sort of grateful for that* (p.10, L283-286).

The pace of life has some influence on participants' pain perception because of the stress levels that are produced by the over stimulation of the fast pace in the city.

Brigit extols the virtues of the bush and very forcefully says *That is my idea of peace and tranquility and quiet. I hate the bustle. I went to* (regional city) *there. I couldn't stand the cars, the people. I think when you are living with chronic pain, you just want to be left alone. You want to live a quiet life – no hassles. Just do your own little thing and that's exactly what I do* (p. 7, L200-203). Participants all commented on the slower pace of life in the country. There are several factors that contribute to this perception. The rhythm of life in rural areas (and thus in small rural towns) is generally less dependent on regulated timeframes (such as time to start work), but is usually spread out over the entire daylight hours. Many country folk are their own boss, and home life and work life are intertwined. The work in the country, although hard, is often not rushed. Not ‘working to the clock’ reduces stress levels, travel time is non-existent or short because of not having the challenge of heavy and rush-hour traffic, road rage is infrequent as there is little traffic to contend with and people tolerate the foibles of those they know socially. There is less noise from traffic, from building sites and from people.

Carl explains his family’s move from a larger coastal town to the small country town where they now live: *I think it also helped me mentally cope with it because I don’t feel I’m under so much pressure, I think. I started getting very, I suppose, angry living down the towns and cities. It was an emotional thing starting to happen, but living with it* (the pain*)…The country was just a more peaceful place. The serenity doesn’t get you uptight and when you get uptight your muscles lock and once that happens, it* (the pain) *starts working* (p. 3, L47-56). Gary says *so the peace and quiet of the country lifestyle is great. I can hear a chainsaw way off, I can hear a dog barking way off, I can tolerate that but I can’t tolerate noisy neighbours and noisy cars …not when you’re actually laying in there in bed trying to get some sleep or some quiet* (p. 4, L93-97).

Because of the relatively small populations in rural towns, there are fewer people-to-people exchanges each day, and many people have known each other for a long time, reducing the stress of interacting with strangers. This alters the encounters from the impersonal ones found in the urban areas to at least partially social contacts, and produces a comfortable, familiar interaction. Running an errand or going for the groceries becomes a social event. Gary says that prior to his illness, he and his wife were known as ‘*the Have-a-chats’* (p. 8, L236) because they took the time to chat to all of their acquaintances they met in the street or during their business exchanges when they visited town. Brigid agrees: *When shopping – Have a bit of a yarn to everyone. There’s always someone that’ll pull you up. “What are you doing?” “What have you been up to?” “Where have you been?” …you can’t help but trip over people you know* (p. 6, L164-166).

People are known as individuals in the shops and interactions between shopkeeper and customer are neighbourly – acknowledging the value of the person in the town. The shop keeper knows that the numbers of his customers are limited and treats them as valued individuals, and the people of the small town also realize the contribution the shop keeper makes to the community and generally treat him with respect. As well, trust and respect develop in two sided mutual relationships (van Manen, 1997, p. 32) which deepen over time, contributing to a comfort level and reduction of anxiety.

All of these issues contribute to the 'slower pace of life' in a small town that is appreciated by its inhabitants with chronic pain. And thus, living in a quiet rural setting is a comfort or a benefit for these participants.

Conclusion

This chapter has developed some ideas about the life-world existential of temporality and has illustrated these ideas with the participants' words. The theme of 'I am different to what I was' demonstrated the differences participants perceived to have developed in their lives from the time they first encountered their pain. 'This is my life now' looked at the acceptance and accommodation to the chronic pain state that the participants had made. 'The pace of life is slower in the country' was a theme common to many of the participants and in general, they appreciated the reduced time pressure of life in the rural arena. The following chapter explores the life-world existential of corporeality – living in a body that is enduring chronic pain in the context of the rural area.

Chapter 8 - Some days are better than others – living within the body with chronic pain

Corporeality

Merleau-Ponty describes the body as “the vehicle of being in the world” (Merleau-Ponty, 1962, p. 82). This philosopher suggests that the body is experienced as a phenomenon because the consciousness and the body are experienced as one and are equally relevant to existence. It is the way we experience the world, and in the healthy person, active awareness of the body and its state of being is not usual – movement and sensation/perception are thoughtless. With the advent of ongoing pain, the body itself becomes a focus of attention. This unfamiliar territory which the person needs to will into action to deal with the world is seen a being “homeless in one’s own body” by Raheim and Haland (2006, p. 753). One of the participants (June, Field notes) demonstrated this gap between body and self by referring to herself in the second person (you) throughout the interview when she was discussing her body and its reaction to pain. She reverted to first person when talking about family. Osborne and Smith (2006, p. 218) discuss this separation of the self (I) and the body in pain (it) associating the flawed body with feelings of “exclusion alienation, rejection and powerlessness”.

Chronic pain seems to be an alien entity that invades the person’s body to alter their life. Negotiations to coexist with this relentless state/thing are fruitless. The entity takes over every aspect of the person’s body – bringing every movement and even every contemplated movement into sharp and implacable focus. It affects all of life, altering, removing and ending important and even essential facets of identity and self-esteem, corroding function and self-efficacy and grinding down mind and motivation. Facing the reality of living with chronic pain means coming to terms with the probability that their life would not revert to it’s former state and that the condition could actually deteriorate. Health related Quality of Life (QOL) indicators for people living with chronic pain and attending a multidisciplinary pain clinic dramatically demonstrated a lower QOL in addition to severe pain, than even patients who are dying of cancer and experiencing pain (Fredheim et al., 2008). This chapter addresses the efforts of the participants of this study to come to terms with the corporeal changes that have occurred and to integrate these into their lives and expectations.

This is an insider’s perspective as the concepts discussed arise from the interviews with the participants.

Difficult to name – all there is is the pain

Pain is difficult to describe and participants became relatively inarticulate about the actual sensations and about its effects on them. Leah tried to verbalise her pain, her cheeks streaming with tears, and came up with: *The pain is -- - - that’s when I know - -- - I have burning pain. That’s very- - - that pain is just - - - - really, I can’t do it. That tells me - - - -that’s it* (p. 4, L75-77).

Describing something as intimate and overwhelming and subjective as pain is a Herculean task and words fail. The words that are available for describing pain are pale and insignificant compared to the sensations the body is feeling, and the agony and anguish it is causing. Van Manen (1990, p. 113) terms this the “epistemological silence” where the unspeakable cannot be named. June says with a tight throat and choked voice:

As soon as a bad part of the pain starts coming, you just start clenching your teeth and you just--- going into a sweat – all there is the pain (p. 2, L279-281).

Participants became very frustrated with their inability to adequately describe their pain. Visual Analogue Scales and the words of the McGill-Melzack Short Form to describe pain were completely inadequate, although these are the most frequently used pain assessment tools. Because the pain is such a central part of their lives, it assumes an incredible significance, as does its description to others. Scarry (1985) suggests that physical pain, unlike any other state of consciousness, has no other referential content. It is not ‘of’ or ‘for’ anything and it is precisely because there is no object that pain, more than any other phenomenon, resists objectification in language. This resistance to language is essential to its nature (p. 5) and is demonstrated by the efforts of Leah and June. Carl calls it *the hurt everywhere syndrome* (Field notes, Carl) and listed a number of descriptors before he gave up trying to describe it. Strandmark (2004) attributes the destruction of this ability to communicate to suffering. She believes suffering arises when there is no autonomy over the pain and powerlessness to influence its existence is felt.

Assessment of chronic pain is a more demanding task than assessment of acute pain (Breivik et al., 2008, p. 21). In part this is due to the difficulties described above and requires the pain assessor to be assiduous in their questioning during the pain complaint description and the history gathering to determine not only the nature of the pain but also its impact on the person's quality of life.

Although describing the pain to someone who has never experienced it is difficult, if not impossible, giving the pain-condition a name is very important to most of the participants. This has to do with many factors – understanding what is happening to them, verification and validation of the pain as real, reassurance that the pain does not signify a fatal illness, having something concrete to tell others. Davis, Glynn and Kadry (2003, p. 82) add that patients often believe that a diagnosis must be made before a condition can be adequately treated. Sullivan (2004, p. 438) explores the patient's expectation of receiving a diagnosis and prognosis and asserts that when the patient is given these, there is functional improvement and symptom relief within a couple of weeks, and conversely, without a diagnosis, patients do not do as well.

Gary offered *No one could really tell me what was happening to me* (p. 3, L70). Treating the symptoms of the pain was not enough for Gary – he needed to be able to label what was going on in his body. Without a label, the pain could be related to anything, and pain generally indicates tissue damage. With ongoing and severe pain, one imagines that the damage to the body is increasing and any damage could be increasingly permanent. Merleau-Ponty (1962, p.144) states "the body is our anchorage in the world". It becomes an existential conundrum if that anchorage is crumbling from an unspecified process that we cannot know or name. Labeling that process reduces the unknown and presents a focus for what is happening. It becomes something tangible and rational thinking about the problem is then possible. With a label, anxiety and fear of the unknown are corralled and are more able to be controlled.

Labeling the pain requires diagnostic tests and frequent visits to first the GP and then (usually) to a specialist physician. Brett describes the process of diagnosis as protracted. The doctor sent him for innumerable tests and then: *I went through a number of different diagnoses before I got the – before they gave it a name that sort of matched* (p. 7, L177-178).

All of the participants described the processes of diagnosis that they had to endure, often over months if not years. Over this time, anxiety and fear increase, questions asked go unanswered, the person doubts themselves and the system. This protracted process can be corrosive of the trust developed between the health care professional and their patient. Carl says he was diagnosed *About 11 years ago. But obviously, there was a building up period towards that* (p. 1, L11). *I went through 12 months of tests, different types of tests and he* (a previous GP) *couldn't find anything wrong and in the end he said Í don't know what's wrong with you blahblahblah" And by that time you started thinking 'Oh, am I making this up, you know.-No, its for real, its for real'* (p. 3, L67-73). He tells of nearly having a mental breakdown before the diagnosis because he was so worried about what it was and was very happy when he was diagnosed because *it was not just in my head* (Field notes, Carl).

This dichotomy between the perception of ongoing pain and the validation of a condition by an authority is disturbing to the person. Participants need to have the medical authority name the condition so that they are reassured that the pain is not psychogenic. Strandmark (2004) asserts that one of the most difficult health care problems occur when people suffer but have no disease (i.e. a societally recognized and objectively observed pathological process).

When he went to a rheumatologist, and was given a definitive diagnosis, Carl says*: But I was really happy because for 2 years I'd been wondering whether it was starting to become a psychological sort of thing because you think "Well, they're not finding anything wrong with me, but I know*" (p. 3, L89-92). Later in the interview, Carl returns to the importance of having *a name for it (*p.11, L373). *Once they diagnosed what it was and I could read what it was, it seemed to lift a big burden off me – just to have a name, that's all it was, you know…To have a name for it was something and I think once that happened, I was sort of, not on the road to recovery, but on the road to understanding what was happening*" (p. 11, L369-376) and he felt that he could cope with the situation once he knew what it was.

What's wrong? What's wrong? The meaning of pain

However, naming the condition does not explain it. Davis, Glynn and Kadry (2003) found that 77% of patients at their specialist headache pain clinic were not satisfied with a diagnostic label, but wanted an explanation for their pain. These researchers postulated that this concern is related to the expectation that a good doctor should explore the problem sufficiently to provide a satisfactory explanation rather than just treat the symptoms only. Many of the participants in this study had pain conditions that are poorly understood as physiological entities. Understanding what is occurring in the body is an initial step in accepting and adapting to the condition. Long term living with a painful condition often intensifies a search for a cure or at least a meaning for the pain and this hunt can dominate the person's life (Risdon et al., 2003).

Deary (2005) elegantly describes a non-hierarchical, non-biomedical model of illness that seems to fit as an explanation of chronic pain extremely well. He suggests that, rather than a specific pathophysiology or trauma in the past producing symptoms, there is an ongoing interaction between physiology, behaviour, beliefs and culture that serves to produce particular symptoms in individuals (Deary, 2005, p. 219). This seems to be intuitively, if incompletely, understood by some of the participants as they seek an explanation of the pain. Gary describes his search for understanding of what was happening and suggests that something that happened in his past caused it: *There's some nights where you can't move your hands here through the pain. You can just feel it burning …I was actually arrested some years ago now and when the police put the handcuffs on, they put them on so tight that six weeks later, both hands were jet black from the handcuffs. And I don't know whether that's part of the problem in the arms. Why does it only go to here, the pain? Why doesn't it come all the way here?* (p. 5, L140-146). And again *It was all part of the heavy duty lifting I did. I was a garbo for eight years so I think you know all that lifting and turning – your body's not designed to do that, I don't think* (p. 5, L 149-151).

Richardson, Ong and Sim (2006) tell of people searching for information within their own biographies to assist them to understand the cause of their pain and define the meaning it has for them. Gary describes a hectic lifestyle of heavy labour, long hours and little sleep prior to the onset of the pain and feels that this might underlie the pain as well. *I did that for years and years and years and years and just too many years and all of a sudden just, I think the body's gone 'Nah – we're not going to do this anymore'* (p. 6, L187-190). He also says *I went to the gym quite frequently when I was younger. I do have thoughts of 'Did I do damage back then to the muscular system?' Because it is a system and we're not bulletproof. So whether all those years* *of strain – no pain, no gain- it could all been strain…and all of a sudden it locked down. Because we're pretty resilient as human beings and then years later, a stress breakdown and whoah, everything comes back* (p. 20, L669-675).

Understanding the condition and being able to attribute it to a cause assumes a great significance for most people, because in our society, only real diseases are legitimate in the sense that the biomedical perspective is dominant and gives credence preferentially to objective anatomically/pathophysiologically demonstrable disease. Although Edwards (2005) reinforces the physiological underpinning of chronic pain citing variation in central nervous system processing affecting pain sensitivity and pain modulation, chronic pain causation is often considered to be at least partly psychosomatic (Sullivan, 2004).

Individual and health care provider frustration mount when a 'real' disease cannot be found (Sullivan 2004, p. 437). Hampton (2005) reports that although this attitude is entrenched in the medical establishment, new studies that demonstrate pain memory as a significant factor contributing to chronic pain experiences point to cognitive behavioural therapies as the way forward in treating chronic pain conditions. This brings pain back to being 'unreal' and 'all in your head'. People of the western, Anglo-Saxon cultures are reluctant to consider and accept that the basis of pain can be other than physiological.

Benner, Janson-Bjerklie, Ferketich and Becker (1994, p. 226) describe their findings of moral shame and responsibility being attached to conditions that the individual can 'control'- that is, the person has some responsibility in causing (i.e., psychosomatic). Their phenomenological study was about asthma, however, these findings apply equally to the patient with chronic pain. These authors suggest that the perceived failure to control the body with the mind is experienced as a threat to autonomy and is felt as responsibility, shame and blame. These intense feelings add to the burden of the chronic pain patient.

The disagreeableness of having their real pain attributed to a psychological problem requires the interviewer, the nurse and any helping professional to ensure that the contact they have with the person is pathic and marked by a caring attentiveness (van Manen, 1999). This would enable the individual to express their beliefs about their pain, and their possible dismay about its causes.

Gary returns to this theme of naming the condition and describes the day he was given a diagnosis, when the doctor says: *"…and with the other symptoms, so I'm going to make a firm diagnosis" But it took three years. And I did walk out of there with a little bit of a spring in my step and probably the first person I saw, I went "I got fibromyalgia!*" (p. 9. L296-299). Having a name for his pain meant he could tell others what was crippling him and moving him out of his usual social roles. He phoned his children and one son sent him a book on the condition. He returned to the understanding of the condition later with. *And I remember making a statement to* (wife) *one day. I said "I'm so sick of being sick, trying to answer what's wrong, what's wrong?" This was only 18 months, two years into the diagnosis. So, I'd been diagnosed – great- then I could read the book, but reading the book was harder than I'd ever anticipated* (p. 11, L344-349).

People who live with chronic pain need to understand the pain. Often 'intellectualizing' or information seeking about the pain experience is used and everything available is read about the pain condition – so giving it a name is essential for this form of coping to occur. Livneh (1999) discusses coping strategies in relation to chronic heart disease, and suggest that the cognitive strategy of intellectualizing/information seeking is a very effective strategy to foster psychosocial adaptation to a chronic illness. The person in chronic pain also gains a sense of control over their pain condition if they can approach it on a cognitive level. This in itself assists the person to reduce the negative emotional impact of the condition. The web is a growing source of appropriate information with various interest groups hosting websites about specific conditions. However, several participants in this study had either no access to the Internet because of disinterest, lack of money to purchase equipment or had very limited access because of their geographical situation. Thus their information seeking was limited to what the health care provider was able to supply or to information from families and friends (Gary told me the book he received was entitled 'Fibromyalgia for Dummies').

Pain is invisible - but it really does hurt

Diane: *It's always difficult with something that's not externally visible* (p. 24, L954-955)

You feel like you want to sort of have a little sign tattooed on your forehead that says "It really does hurt" you know (p. 24, L981-982). The invisibility of pain contributes to an apprehension that the changes in social roles and physical capabilities will be seen as an attempt to gain advantages such as reduced work requirements, sympathy and so on. Because the pain cannot be seen by others or measurably demonstrated by the person who is living with it, the burden of living with the chronic pain has an added psychological encumbrance. Since chronic pain cannot be seen, there is discomfort in claiming benefit, even if that benefit is at no one else's expense. We are meant to be self-sufficient creatures who control our selves (bodies and minds) and take responsibility for ourselves. When this invisible invader prevents us from taking these responsibilities, we feel guilt and shame and we feel that others do not understand what is happening to us.

Leah says about a friend who lives with chronic pain: …(She) *understands what it's like because it's something that no-one else can see* (p. 10, L234). Her ability to discuss the pain with someone who understands at a deeper level than most of her friends is a relief to her and permits her to discuss the pain without apology and with the comfort of being believed and completely understood.

Paul demonstrates his own incredulity that the pain cannot be seen: *It felt like someone had put a hundred pound sandbag down and was tearing at the flesh, tearing the flesh off here* (indicating forearm) *and I was laying in bed going "OK, that's how I feel" but I'm looking around and - nothing wrong with that arm* (p. 6, L173-175). The invisibility of the pain makes it seem incredible that it can be happening and makes even the person experiencing the pain doubt their own sensations.

Breen's (2002) review of three decades of chronic pain literature from nursing, psychology and neurobiology demonstrated that prior to the mid to late 1980s, chronic pain without discernible pathophysiology was believed to be psychogenic. People with chronic pain disorders were thought to be misinterpreting psychic distress and expressing it as a physical manifestation. This belief has persisted in many health care professional's minds and almost certainly in the collective mind of the people (Deary, 2005). Deary (2005, p. 214) captures the dichotomy that many people living with pain feel – is their pain real (in the sense of having a definable, physical cause) or is it imaginary, and thus unreal? Faced with the specter of being either mad or a fraud, the participants were relieved when they found out that their pain condition had a medically acceptable name, and they were not making it up. Gary expressed this when he was told the diagnosis of his condition: *Because then I knew I wasn't a fraud. I knew I wasn't a fraud, that there was something there they could actually put a name to, you know, and I thought, "How many people just don't continually go to the Doctor to find out the actual thing of it?" They go and they go and they go – "Oh, I'm not going again"* (p. 5, L154-158).

Having a definitive medical diagnosis validates not only the person's legitimate claim to the intangible pain they are experiencing (Parsons et al., 2007) but also, to an extent, to their assumption of the sick role. The sick role is a behaviour that is deemed appropriate if one has met established criteria (especially sanction of a medical diagnosis) and entitles the sick person to release from many of the roles and expectations of society and family. In our society, being legitimately sick over time also entitles the person to financial assistance, which assumes enormous importance when people are unable to work for their income. The doctor is the gate-keeper of the sick role. However, the sick role has obligations as well. The person must do everything in their power to get well, and to follow the prescribed treatments. With chronic pain, these obligations are usually impossible to meet, and the individual returns again and again to the doctor for an explanation.

Once having gained a medical diagnosis, and no longer needing to struggle to continue in various societal roles, the participants could relinquish these roles and retreat to home and comfort. Having a diagnosis is not all that is needed. Pain is both private and invisible and as such is not available to be seen (or studied in the scientific manner), and people who live outside the intimate circle of confidence cannot see the immediate and long term effects of the pain on the individual. The behaviour of the person in pain is assessed by the societal members as appropriate to the situation or exaggerated for gain. Moral judgments about those who do not honestly fulfill their societal roles or expectations are made. The group rules are being flouted (Sullivan, 2004, p. 433) and the person is categorized as a malingerer. Mendelson and Mendelson (2004) explain that this concept of a subjective complaint not accompanied by demonstrable organic abnormalities has been with us since the time of the ancient Greeks, when a soldier's attempt to elude war duties was punished by death. The societal group's displeasure with someone who is thought to be malingering is often conveyed to the person living with pain, no longer with a death sentence, but verbally or in more subtle ways.

Diane, as a relatively young woman within the social set she finds herself, doesn't feel like a fraud, but she does think that others view her as a malingerer: *I think there is definitely a perception that people who complain of back pain are malingerers. You know if you don't have a limp or a bandage, then there can't be too much wrong with you. And I think for people like me who are relatively young and have had pain for years, that that idea becomes more and more deeply entrenched you know* (p. 22, L897-901).

Although she feels very certain about the pain she is experiencing, she is aware that hearing about pain means entertaining doubts about it (Scarry, 1985). And Diane feels embarrassed and worries about her inability to help and to involve herself in community activities. *It's very difficult because you find yourself in a position where you're apologising all the time "No I'm sorry I can't lift those tables up and move them", you know, "no I'm sorry I can't spend all day standing beside the urn handing out cups of tea, no I'm sorry I don't carry cartons full of second-hand books" and those sorts of things and when you're younger than the rest of the group, there's an automatic presumption that you are going to be more active and stronger and more able to contribute and it can be very difficult sometimes having to keep backing off all the time saying "No, look I'm....yes I am better than I was at the moment and frankly I want to keep it that way, so really heaving around cartons of old CWA magazines is completely out of the question, sorry" and that can be difficult* (p. 4, L126-140).

June tells a story about how she denigrated an acquaintance who was complaining of chronic pain before she had experienced it and says: *Its not until you go through it yourself can you understand what other people go through and I understand what she was complaining of now* (p. 13, L293-295).

Because the pain is invisible, and difficult to describe, some of the participants had difficulty believing the diagnosis. Brett: *It took me just as long as them* (the doctors*) to believe it. You know you sort of, the idea that something is wrong that can't be fixed up…it took me a while to come to the realisation* (p. 8, L202-205).

With the realisation that there is no cure for the pain, adaptation and acceptance of the situation are required. Acceptance and lack of pain-related anxiety foster the person's adaptation to their situation and this in turn provides them with increasing ability to cope with the pain (McCracken et al., 1999). The process of adaptation to a chronic pain disorder is usually protracted and volatile, with frequent retreats from the reality of the chronicity of the pain.

This struggle towards adaptation is sometimes not won completely by the individual. June is still hoping for a cure after living with her chronic pain for many years. She says *I will be glad to get it operated on and see if they can fix it up, because the first thing I'm going to do as soon as I get mobile again I'm going fishing* (p. 10, L234-237). For her, the pain is a dominant force in her life. Hope seems to be relatively unrealistic in June's case, as she has undergone several surgeries without much effect. Kautz (2008) suggests that believing in the seemingly impossible is a good strategy for survival because hope assists to prevent powerlessness. So, like all of us, she clings to hope for the future.

June is teary when discussing many aspects of her life and emphasises what she is unable to do. This produces the antithesis to hope – despair. Strandmark (2004) outlines the self-image of worthlessness and suggests that this develops when the individual is unable to meet the demands of society, their family and friends and their own expectations. Australian society, and certainly the rural ethos emphasises a rugged individuality as a desirable trait. As well, being a female also engenders a learned response of being the caretaker of the family and community worker (Musshauser, Bader, Wildt, & Hochlietner, 2006). Individual egotism and standard development creates the expectation that we can shoulder all of these responsibilities and still attain a satisfactory level of productivity within our lives. When all of these ideal expectations cannot be met, an individual who feels worthless within herself, her place in the family and in the society develops (DuBois, Tevendale, Burk-Braxton, Swenson, & Hardesty, 2000). June feels entrapped by her body's inabilities, and this is affecting treasured parts of her life. *I tried a bit of gardening. I had to wait for* (son) *to come home, wait for an hour and fifteen minutes for him to come home one day. I got down and couldn't get back up, so I had to sit there and wait for* (son) *to come home to get me back up out of the bloody yard, out of the garden. I haven't tried that ever since then* (p.15, L344-3350).

Risdon et al. (2003, p. 376) claim that turning your back on finding a cure and learning to live with the pain is a core task of rehabilitation during chronic pain. This is a difficult undertaking and often requires a great deal of time before the hope of a cure or magic treatment is allowed to die. Some people are never able to relinquish this hope. Most of the participants of this study were well on the road to adapting to their lives of living with the pain. This is demonstrated throughout the next sub-theme.

Balancing the pain

Balancing normalcy and chronic pain is precarious. Persevering with activity while minimizing the pain and fatigue is often a finely drawn line, and overdoing activity plunges the person into, sometimes, days of pain and enforced rest. On the other hand, not remaining active is destructive to the soul. Keeping the balance is a lesson that must be learned in adapting to the pain.

Part of accepting the pain is normalizing life events as well as possible. Working through the pain and transcending its limitations permits a more normal lifestyle. Most of the participants in this study pushed through the pain to accomplish daily tasks and to engage in carefully chosen activities. Sofaer-Bennett, et al. (2007) termed this 'keeping going' – perseverance and included keeping occupied and social activity when they described it in a grounded theory study. Although their study participants were over 60 years of age, these authors' findings mirror what the participants in this study were saying. An Australian example is provided by de la Rue and Coulson (2003, p. 6), one of whose participants talked about shearing and the resultant back pain and said 'well, I had to learn to live with that …so I just went on…you just cope with things'.

Brigid demonstrates this perseverance with: *As to housework I do all my own housework – it might take me 3 days to get the whole place mopped out and vacuumed out* (laughs) (p. 3, L82-83). She does her own ironing, and takes in ironing for pay: *No I can stand, with the implant going, probably for 10 minutes. Then I have to sit, get up and do another couple of shirts, you know, then sit again* (p. 14, L429-

430). Her philosophy is: *What's the good of whingeing about it? I'd like to say to people out there in chronic pain – get off your butt. Do something with your life. Occupy yourself and keep going. Even if it means pushing yourself. If you want to pull the pin, sit in a wheelchair or sit in a lounge chair, that's fine – go ahead and do it. But you'll only sit there, suffering* (p. 16, L480-484).

Brigid exemplifies the resilient attitude of most of the participants. They are facing the adversity in their lives with strength and often a grim sort of determination and persistence in the face of great difficulty. Gary recognizes that the persistence is one of his strengths: *For me, persistence is power. If I can be persistent, I'll win in the end. I just won't be beaten but this has certainly given me a good nudge. I'm not going to be knocked out of it. I've got too many things to do, I think. It's taken me fifteen years to build this house out of stone…and it's been one rock at a time* (p.16, L526-529). And again: *Yeah, one day at a time. You get through that day and go again* (p.18, L581-582). Gary is in an unfortunate position. They live on a small rural property, and he feels *it's up to us to maintain it* (p. 2, L34). His wife is also unwell and cannot undertake physical work, and Gary says: *so it's up to myself to do it. I don't trust myself with chainsaws and tools like that, so I just use a rake and a stick pick* (p. 2, L36-37).

And in the beginning, the persistence proved to be one of his weaknesses: *Well, it was an effort to walk to the toilet from one end of the house to the other let alone clean up an acreage, so it just sat there and sat there and sat there for ages until I had enough and finally worked through the pain. But I'd go for an hour and then I'd be back in pain for three days after one hour* (p. 3, L46-50). Diane keeps plugging away at the chores she needs to do. She describes a typical day of getting her daughter ready for school, doing dishes, washing and housework interspersed with periods of rest: *It sort of takes me all day to do things in short bursts* (p. 22, L 876). June manages her work in a similar way: *I can still do some* (housework) *but I've got to do it, sit down, get up and do a bit more, sit down or lay down* (p. 1, L16-18).

The drive to complete a task is tempered by a sound and hard won knowledge of the limitations imposed by the pain. The expectation of a negative event, such as increased pain, helps us to prepare for its impact and strengthens us to deal with the distress. With experience we learn to circumvent the negative results of overexertion and to respect what can and what cannot be changed, what can and cannot be undertaken. Sherman (2005) indicates that self-agency and the development of autonomy begin here. O'Loughlin (1999) in her phenomenological study of a person with chronic pain found that the limitations to function were often more frustrating and difficult than the pain itself. We normally take for granted that our body will do what we want it to, and respond to our needs and desires with no complaint. When this does not occur, when pain levels interfere with our control and desires, we become angry and fearful that we will not be able to control our body again. These negative emotions surface as frustration, and especially in the early period of adjusting and adapting to the pain. With time, we develop a sort of contract with our body to do what we can within the parameters set by the pain, and to acknowledge that the pain does abrogate our control.

Brett says: *I know my limitations…I keep myself paced out make sure everything's in place …take the breaks if I ever need to* (p. 3, L63-66). The pacing is a recurrent theme of most of the participants. Birkholtz, Aylwin and Harman (2004) describe pacing as an aim of pain management that shapes self-efficacy (i.e. if activities are undertaken and cause no increase in pain, then the person feels themselves more able to attempt the next activity). This is an extremely important concept in maintaining an as near to normal lifestyle as is possible. These authors describe the effects of reducing participation in activities (escalation of the pain, deteriorating fitness, social isolation, catastrophising and rumination) as well as the effects of overactivity (leading to episodes of severe pain and exhaustion), suggesting that pacing is the best solution. Pacing permits the person to engage in periods of valued activities (moderate levels), interspersed with short rest periods with the aim of increasing the time spent in pleasurable activity. Pacing sounds like a very simple strategy to employ. However, it is not easy to stop activities that you feel need to be completed or that you are enjoying before the pain becomes intrusive.

Carl was asked about over activity bringing on the pain and answers: *Yes, or lack of activity can bring it on. You've got to get that balance. If you don't do something, it can end up hurting just as much as if you do too much.* (p. 2, L20-23). Birkholtz, Aylwin and Harman (2004) agree with this, stating that breadwinners and those who do not 'want to give in to the pain' (p. 448) are most often caught in this trap. They contend that muscle exhaustion leading to extended recovery time is the culprit. They suggest activity pacing using a 'quota-contingent' approach is effective for both under- and over- activity. Certainly being aware of limitations is an important first step. Gary explains: *you know that if you don't stop there and then, you're going to be in bed another day longer that you want to be and the whole idea is "get off that bed"* (p. 16, L522-523).

Diane exceeds her limitations and pays for the extra stress on her body: *I really enjoyed the art workshop over the weekend, but Monday Tuesday and Wednesday, I was just in bed. I didn't do anything for 3 days, I was just buggered. But I don't mind that – it was worth it and I knew that it would happen, I knew that that's what I would be like, so I made sure that I didn't have anywhere that I had to go or anything that I had to do. I live my life according to the pain* (p. 22, L877-883). The awareness of what activities really do contribute to quality of life, the preplanning necessary to undertake them and the willingness to put up with the increased pain and fatigue subsequent to the over-activity are evident in this statement. Kautz (2008) attributes fatigue in part to dealing with the negative emotions that often accompany chronic pain such as anxiety, pessimism about the future, memory loss, feelings of powerlessness and worthlessness. A previous persona of strength and competence has been overwritten by the pain experience, but the earlier life shows through and haunts the person living with chronic pain.

Leah demonstrates the 'over activity' (Birkholtz et al., 2004) side of doing and perhaps this is because, of all of the participants, she has been living with and adapting to the chronic pain for the shortest period of time (just under a year at the time of interview). She says *I always feel like I've a lot to catch up on or make up for. "Today's a good day – I'll do as much as I can". Silly, but it's – sounds silly, but it's, - I don't know. Then usually, the next day's not so good* (p. 8, L179-183). Later in the interview, she says: *And sometimes you just have to do things. You don't have that choice. So, you just do them* (p. 12, L293-294). Her feelings of well being are bound up with a sense of control and self-agency.

These examples of the participants' responses to their bodily experiences of chronic pain point to the concept of resilience. This concept has been proposed as a trait of country people (Jacelon, 1997). Gillespie, Charboyer and Wallis (2007) have recently developed a model of resilience that incorporates many of the ideas discussed above. They contend that there are antecedents required to develop resilience (adversity, interpretation of this adversity as traumatic, cognitive ability and a realistic world view), attributes that define resilience (self-efficacy, hope and coping), and consequences of resilience (integration, control, adjustment and growth).

Taking analgesics is another part of keeping the balance. Analgesics are a staple to someone living with chronic pain, although most of the participants disliked the side effects and tried to limit the use of the drugs. Diane demonstrates the dependence on analgesics that develops with this: *It becomes like a comfort blanket, doesn't it? You have to have your pills. Even if you haven't used them in a year, you'll still make sure you've got a bottle in your handbag and one beside the bed and one in your travel case wash bag for the little time you're away – always- because you need to know that they're there just in case you need them* (p. 14, L490-496).

Leah says *I've got my drugs with me. They're – I've got different ones. Tramadol and other ones to take to counteract different things* (p. 2, L41-42). Although they offer some relief from the pain, several comments indicated that there were problems with using analgesics. Gary wondered if the medications he was taking were doing any good at all. *The painkillers. There was a time there where I was taking 5 and 6 tablets in a dose thing. And I didn't know what I was taking in the end. "What's this one? What's this one? What's this one? What's this one?" and you don't know if they're actually working or placebos or what* (p. 9, L285-289). Brett has chosen to stop taking analgesics for pain relief – using them for sleeping. *I actually don't really take much in the way of pain relievers… I just mentally blocked it out if you want to call it that. Worked through it sort of thing. If I take them it's to sleep but that's about it. I don't take them for pain relief. I probably should, but I figure it comes up so often that it'd be pointless - there'll be not much affect any more. I prefer to stay away from them or whatever* (p. 3, L73-81). Brett has used a mind over matter approach to his pain and feels able to live with it to a level of tolerance.

Diane was a Registered Nurse working in Oncology prior to developing the chronic back pain, so perhaps naturally, we discussed drug therapies a lot. She had encountered a series of disastrous events (illness plus treatment problems), which she referred to and then said: *Then sort of every time something else would happen, they would up the Oxycontin by a couple of doses and up the antidepressants and up the steroids and you know, I just – I think eventually at the end of it I was just awash in a* *sea of chemicals* (p. 21, L841-846). She described numerous side and toxic effects of the drugs she was taking that are still plaguing her despite no longer taking any of the offending drugs. She spent several days in the Pain Clinic dealing with her dependence on medications of various sorts, saying: *I was actually hospitalized and weaned off all medication that I'd been on because at that point, I was on quite a lot of morphine and I was on high dosages of antidepressants and I was on high dosages of steroids and all sorts of other things so they weaned me off all those things and a lot of the symptoms disappeared then* (p. 6, L 214-220). Her voice and demeanor indicated how proud she was of this accomplishment. She continues a few minutes later: *I know if I get back on the merry-go-round that it will be too tempting…because it just feels so wonderful when the pain goes away. You know its easier - its easier to have the pain all the time than it is to have the pain go away and come back* (p. 13, L484-489). We discussed the use of analgesics and the terrible effects they can have on the body if used inappropriately. She recounted a story of one of the patients she had met in the Pain Clinic who was obtaining drugs from several different sources and medicating herself. Diane then says *I think the problem is that you get so tired of being in pain that you just don't care anymore, you know. You will literally do anything, take anything, try anything. I think I've now just got to the point where I'm so cynical about the whole business that I just grit my teeth and put up with it instead* (p. 14, L512-416).

Now that she has weaned herself off most medications she has turned to food as a comfort source. She says *OK, if you have to choose between Morphine, Prozac and biscuits, it's like, "Oh, well, Tim Tams is the winning combination" (*p.16, L588-590) and, demonstrating her humorous outlook on life, *And wonderful though meditation can be, you know nothing beats a Hot Chocolate and two Tim Tams when you're feeling sorry for yourself* (p. 16, L595-598).

June realizes that she will need to come off the medications she is currently taking if the operation she is waiting for is successful and she is dreading this. *Now, that's another battle I'm going to have to look at is coming off the tablets and that because I've been on them for such a long time – the withdrawals*. Then she lists the medications, both narcotic and non-narcotic and says *Well now, they just upped – because the pain's getting that bad and I'm losing feeling and that they've put me on Morphine mixture* (p.3, L69-76).

Brigid has found that analgesic medication by itself is insufficient for her needs and has had a battery powered spinal stimulator implanted for several years. During interviews with her, the control was either in her hand or right next to it. She says: (I turn)*…the stimulator off at night to prolong the life of that thing, but …this morning, I was forced to put the turner* (control) *on and take 2 panadol and of course I'm still on the tramadol 150mg slow release* (p. 2, L37-39). She has found that she needs the stimulator plus the analgesics to have the confidence to perform necessary tasks and to cope with the pain (Nicholas, 2007).

Leah's plight was different from other participants. She had not been prescribed any treatment for her pain nor given any prescription or directed to any over the counter medications. She was angry about this and relates: *But for the first – it was* (a friend) *that got me to ask the Doctor to give me Tramadol Slow Release for the night and he said "Oh, that's a really good idea". Like, you've got no idea – I was on no pain management at all for at least 6 months. More actually – probably about 7 months. We just happened to come across one. I had to go to the hospital in* (small country town far from her home) *and get some Panadeine Forte and he was a locum because the doctor was away and he was a chronic pain specialist and just couldn't believe that I was just banished (*p. 2, L43-51).

The aim of pain management is to permit the person to resume and then maintain as normal a life style as possible (Nicholas, 2008). Taking analgesia is a passive coping strategy that is used to try to achieve that aim. However, the people in this study have found that taking analgesics is a double-edged sword. The side effects and consequences of taking strong opioid-like drugs are disagreeable or dangerous and once the person determines that the analgesic is not the panacea to reduce or remove the pain, they usually move away from complete reliance on the drugs for help. Analgesia does take the edge off the pain though, and assists the individual to utilize the more active coping strategies more effectively to achieve an acceptable Quality of Life. The use of analgesia for breakthrough pain, i.e. flare-ups of pain to a severe level over the usual moderate level of pain, (Taylor et al., 2007) was an important management strategy for many of the participants.

Keeping busy is another important strategy for keeping the pain somewhat at bay. Hoffman, Meier and Council (2002) found that people with chronic pain living in rural areas had fewer environmental distractions that did their urban counterparts. They suggest that attention focused internally increases feelings of pain and that various forms of distraction, especially stimulating endeavours will assist to reduce these. The participants have found this to be true and often use distraction in the form of busy-ness to keep the pain levels more tolerable.

Diane says *Because I am not in the workforce and I'd go crazy if I just stayed at home staring at the walls all day, I sort of belong to community groups…CWA, Choir and RSL Women's Auxiliary…But the only people available for me to socialise with are in their 70s and 80s. There isn't anyone else available for me to socialise with because they are all at work* (p. 6, L182-201). Brigid says *And I'm always doing something. As I've said, I have to keep my life pretty full on to be able to handle it* (p. 8, L231-232) and *I've got to be doing* (p. 15, L459). Leah says she keeps her mind busy with other things so she doesn't think about the pain or her prognosis and says: *The worst thing I think is that you can't do any one particular thing for long. Like, I'd like to play with my photographs because I love photography and I can't sit in front of the computer for too long* (p. 12, L282-283). June finds that she cannot remain in one position for long either and moves about the house in search of somewhere that doesn't hurt. She moves from bed to lounge to chair to walking in the hall to the kitchen chair most nights (Field notes, June).

Carl brings up another facet of 'keeping busy' which is significant for him. This is the satisfaction that comes from doing a job, and completing it. *It's very gratifying to have finished something. You know it might take you longer. It still gives you that buzz in the head that 'Oh, I've started it, I've finished it and it looks good' whatever it is you're doing, whether its baking a cake or mowing the lawn, you know, it's so gratifying* (p. 11, L352-357). Keeping busy and satisfaction with completing a job introduce the psychological side of the experience of chronic pain.

Mind over matter - the scary mental side of things

Brett calls the fears that he is going crazy *the scary mental side of things* (p. 5, L117). He asks *Am I making this up? …Is it a really big deal? …It's something that's going to be mind over matter?* (p. 8, L216 – 220). Heidegger (cited in Moran, 2000, p. 241) suggests that this may not be a psychological state, but “the way the world appears” a way of being ‘attuned’ to the world. Because our selves, our bodies, our being-in-the-world is the greatest concern any individual has, when something does not feel right, we ‘worry’ it – like our tongue does with a broken tooth. We compare what is going on in our selves to what we know historically, intellectually and interpersonally and try to come to a rational conclusion. Sometimes, we rationalize our fears away and can regain a sense of comfort. An example might be a young female feeling chest pain, who considers a heart attack, but then remembers that she had heartburn when she last ate the same meal she just completed, and that there are none of the other symptoms of heart attack happening to her, and that she does not have any of the risk factors. Of course our ability to rationalize can also lead us into great trouble. Consider the same scenario in a middle aged, obese man who has never had heartburn – he may well have something serious going on, and may need to get help quickly – difficult to do if you dismiss the symptoms as harmless.

Losing our mind is a deep-seated fear – to lose our mind is to lose ourselves. We believe from our culture inculcation, that with madness, our self-control and self-esteem would drop, we would be vulnerable, we would embarrass ourselves and our families, and we would be incarcerated along with other mad people. Insanity has always set people apart from the community, although sometimes, rather than as an affliction, it has been viewed as a God-given gift in other cultures and at other times. Relationships with others are disrupted by insanity and the general community does not have the skills or patience to understand and assist their members who become mad. Fear, helplessness, distrust and suspicion develop when the behaviour of the mad member cannot be understood or controlled, or when their behaviour becomes violent or aberrant. Gary also says he worries about losing his mind. He says about spasms in his neck *Well, I’ll just try and get rid of that thought because maybe it’s only a thought – but I know its not* (p. 10, L308-310).

Diane says *its sort of really a matter of mind over matter* (p. 13, L484). Mind over matter is a term used by several of the participants. Our minds are powerfully in control of our physical bodies, and we know from experience that we can will ourselves to do extraordinary things, beyond what we could normally accomplish. Somewhere, we find a small reserve of energy to complete a task when we feel entirely worn out. Or we do amazing feats of courage or strength when called on by circumstances to intervene to prevent disaster from befalling others or ourselves. Jahn and Dunne(2001) have suggested a complex model of the working of the mind over the somatic body using an anomalous route through the unconscious mind, and Carl demonstrates this with his attitude to the constant pain he endures: *Let's put this in perspective – I've got pain – but others have a lot worse- I've got it pretty good* (Field notes, Carl). He says he tries to *think of the positives* and *use his brain to pick himself up* (Field Notes, Carl).

The Brain Fog

Diane says *I was having problems with my memory and I mean I literally – I would be having a conversation on the phone and get to the end of the sentence and not be able to remember what the beginning had been about and at the end you know and at that point I was a complete mess. And most of that's gone now. Some of it hasn't like I still have problems with my memory, not as bad as it was but I still have some* (p. 21, L846-853).

Gary tells us *I just couldn't understand the brain fog with the pain* (p. 3, L77) and demonstrates that with *Reading the book was harder than I'd ever anticipated…They put little tips with hands and faces and all this sort of thing and I'd read this one, read this one, read this page, read two pages. Next day 'Where was I?' I know the bookmark's there but it didn't go in* (p.11, L348-349).

Leah has both memory troubles and cannot put her thoughts into words. She says *Like we have dogs, and where I started picking up that there was that sort of problem was that – like I know every dog and I know them very well is - I actually started to forget types of dogs I couldn't remember what they were. And that's a really big thing for me* (p.1, L6-10). And *I can't remember if someone has told me something* (p.6, L140). She tells a story about replying to emails and ends with *Like, usually I end up confusing the other person more than when we started. So that's – now I'll just ask* (partner) *to reply to them because I just can't do them* (p. 6, L128-130).

Inability to concentrate is a hallmark of constant pain. Wade and Hart (2002) demonstrated that attentional impairment is associated with the suffering stage of chronic pain processing (rather than the initial intensity and unpleasantness stages). They link the attentional impairment to the two prominent aspects of the suffering stage of pain processing which are the negative emotional (fear, anger) and the ideational (interference in lifestyle, self-efficacy to manage/reduce pain) aspects and suggest that this suffering may proscribe the capacity of the neural structures to attend to things outside of the suffering. Short term memory difficulties and memory loss (Kautz, 2008) arise from this inability to attend to the tasks at hand, increasing the person's misery and significantly reducing their quality of life (Dick & Rashiq, 2007).

Wade and Hart (2002) assert that there is a strong link between attentional abilities and depression because of the effects on the neuropsychological function. Munoz and Estevez (2005) support this describing the emotional distressors of depression and anxiety as the most important factors in memory loss in patients with chronic pain. Hampton (2004; Hampton, 2005) outlines the activity of stress related hormones on the impairment of memory.

Memory loss is incredibly distressing to anyone. Normal daily functioning is impaired.
Quality of life diminishes. A review of literature in relation to perceived memory loss in the absence of objective memory deficit in older adults demonstrated that Quality of Life, well-being and life satisfaction diminish (Mol, Carpay, Ramakers, Rozendaal, & Jolles, 2007). Some of the dimensions that were affected were anxiety levels, cognitive ability, increased depression, reduced locus of control, and difficulty in adapting to change.

Depression

Although most of the participants did not claim to be depressed, several of them were on antidepressant medication. Leah and June both were teary at times throughout the interviews and certainly appeared clinically depressed and were both on antidepressant medications. The concomitant occurrence of depression with chronic pain is both common and not unexpected because these two conditions share pathophysiologic pathways (Gallagher, 2002). Each of these conditions exacerbates the other, and much research has been done over the years to demonstrate which is causative. Currently, the thinking is that both occur simultaneously as a result of the activation of the same neuropathological pathways (Gatchell et al., 2007).

June admits to feelings of dejection and of being suicidal in the past saying: *I was just tired of carrying it* (the pain) *around* (p. 4, L110) and *I just give into it* (p. 4, L111). Her depression is palpable in the interview and her facial expression is lacking in affect, she is teary when discussing the pain, her relationships, her immobility and the future. She says *we don't even go out anymore* (p. 6, L171) when asked about her social life. Leah too is often in the grip of depression. *I don't want to be on anti-depressants and that's all they do is, you know, they put you straight on a pill and that's it- here take this- and you've got to be on it for months and months and months. I don't want to do that. I would just rather have my ups and downs than do that. You have your good days and you have your bad days. So you go 'Oh well today is a bad day. I'll wake up tomorrow and it'll be different'* (p. 6, L114-120).

Gary says *I'm so sick of being sick, trying to answer what's wrong, what's wrong??* (p.11, L345) with tears in his eyes and a sob in his voice. He too has had suicidal thoughts *Actually when I went there* (to the doctor's surgery) *I had heavy suicidal thoughts* (p. 3, L61) and he leaves his pain behind with sleep *I really really look for my sleep and when it first happened, as I said, fifteen hours on the bed we'd go* (p. 6, L189-190). Depression is a close and constant companion to about half of the people who live with chronic pain. Others seem to deal more positively with the unrelenting pain.

Todres and Galvin (2008) discuss the evocative use of poetic language to help to convey the lived experiences of the participants. The following is a poem that I believe helps to express these dark feelings.

> I find oblivion in sleep
>
> Sometimes the black dog rages through me, surging and breaking on me,
> tearing and savaging my will, my hopes, my thoughts, my self.
>
> Mostly though, it creeps around me, curling in imperceptibly until it blankets
> my soul. Crushing me between despair and apathy: denying joy or pleasure,
> smothering desire, tarnishing colour, weighing down motivation and sapping
> energy until it is only my own will that permits me a semblance of reality.

> I find oblivion in sleep
> I do not need to fight when I am asleep
>
> Waking is a nightmare. Bone weary, heavy headed and heavy hearted, I gather the tatters of myself and rise to struggle through another day.

Depression is ubiquitous in the modern world with 5 % per annum of the Australian adult population succumbing to a major episode of this debilitating condition (Fanker & O'Brien, 2008) and perhaps a greater percentage experiencing a dysthymic disorder [6% in the USA] (Klein, Shankman, & Rose, 2006). Suicide is more prevalent among males in the rural areas and although depression does not seem to be increased from metropolitan statistics (Caldwell, Jorm, & Dear, 2004), Australian Institute of Health and Welfare (AIHW) (2001) suggest that the association between suicide and depression is indicative of increased levels of depression in rural men. Although all of the depression in rural Australia is not due to chronic pain, chronic pain affecting 20-40 % of the adult population can certainly be a contributing factor.

Conclusion

This chapter has explored the existential corporeal theme. It has demonstrated and discussed the sub-themes of describing the pain, giving it a name (diagnosis), finding an explanation, pain is invisible, feeling like a fraud, believing the diagnosis, persistence with chores, keeping the balance, taking analgesics, the scary mental side of things including brain fog and depression. The effects of chronic pain on the body will be similar in whatever context the person finds themselves. Some of their reactions will have been shaped by their rural culture. In the next chapter, the existential theme of relationships will be explored and more effects of living in a rural area will be illustrated.

Chapter 9 - Relationships in pain

Relationality

Relationality is the fourth existential found in phenomenological reflection. Relationships are elusive to pin down but are essential to living a full life. Developing a relationship with another "allows us to transcend our selves" (van Manen, 1997, p. 105). This search for a transcendence of self is carried out by all human beings to bring purpose and meaningfulness to life. The epitome of the search is a relationship with ' the absolute Other, God' (p. 105).

Relationships are essential for most people. Relationships are based on reciprocal interaction and communication over time (van Manen, 1997, p. 325). They are dynamic and require energy and commitment to establish and maintain. In return, good relationships sustain and nurture. Poor relationships drain and defeat.

Interpersonal support when you are in chronic pain is crucial to your ability to cope with it and over time adapt to it. Consider three concentric circles surrounding the self. Immediately outside the self is the significant other – a very few people who are privilege to intimate knowledge of the self. Significant others, and especially spouses play a leading role in assisting or hampering the person to manage all of the difficulties inherent in living with a condition like chronic pain. The next, intimate circle of family and close friends support the person in various ways to maintain normalcy. Friends and neighbors outside this intimate circle act as support networks to form a cushion to soften the blows and make the person's life more bearable. In the rural area, this circle is large and longstanding (Bushy, 2008).

Health care professionals are in a unique position that forms a spearhead across the circles. They are given access to the self, initially based on their ascribed characteristics of expertise in an area. However, there is no reciprocity in this relationship, and the Teflon coated professional must maintain the expert status or find some other avenue to develop an ongoing relationship with the person. If the 'expert' persona or a different connection is not found and maintained, trust is lost, and the relationship becomes apathetic if not antagonistic.

This chapter explores the experiences of the participants within their relationships initially with their significant others, then with their intimate and close circle and with the wider circle of friends and neighbors. Some of the participants talked about the importance of their relationship with God, so this too is included. There is an especially long look at the relationships that develop (or not) with health care professionals.

Silence on pain

Most of the participants said they would minimise the extent of their pain when talking to even close family members to avoid upsetting or burdening their significant others (Girdhari & Smith, 2006, p. 190; Kugelmann, 1999). Chronic pain impacts on even the closest relationships. The person's attention is consumed by the pain and making it though the day leaves little energy to expend on maintaining or strengthening relationships. Exhaustion and unrelenting pain corrode hope (Kautz, 2008). Cognitive ability is affected, causing change in relationships. Chronic pain interferes with the physical relationship- physical intimacy is often avoided, and sexual interactions are curtailed or eliminated because of the ongoing and debilitating pain, fatigue and depression. As well, some of the therapies for pain management contribute to deterioration of relationships. Pain drugs and antidepressant medications can alter personality and thought processes, changing the person and the relationships they have with others. Living within a relationship with a person with chronic pain becomes an extremely wearing burden on the close other as the chronic pain person's roles are assumed increasing time and energy required to get through the day. Pain becomes a constant source of conversation, causing the other to 'turn-off' and reducing psychological connection if not actual contact with the person because there is nothing that can be done or said.

Family environmental factors and interpersonal relations impact substantially on the health status of the individual (Ferrer, Palmer, & Burge, 2005). In a qualitative study of people living with chronic pain and their families (Smith & Friedemann, 1999, p. 547) found these themes emerged: emotional distress, distancing from family members, inability to share difficult feelings, intense mutual involvement with family members and identification with others' problems, family isolation from the community and attempt at healing. Each of the participants in the current study has demonstrated different themes found by Smith and Friedmann, although not all of the themes, and to varying degrees and often not articulated as such. The power of fear (of future pain and deterioration) is ameliorated by support from family, friends and a caring health care professional (Sherman, 2005).

Diane says: *I don't tell her* (15 year old daughter) *about the pain. I don't want her to worry and I don't want her to then decide that she won't do things because she thinks she should be home looking after me, you know* (p.11, L378-381). There are several reasons for this – and each bears a relationship to the others and either impacts on the pain or the pain impacts on the concepts. Stoicism, privacy, autonomy and dignity are intimately bound together to protect the individual from the outside world. Brigid says: *I don't want anyone feeling sorry for me and I don't want anyone thinking, you know, I'm worse off – Its something I live with and I don't ask other people to live with it, especially friends* (p. 3, L66-68).

Stoicism, privacy, dignity and the silence about pain have been addressed in fictional literature by such methods as Proulx's character from *Brokeback Mountain*, Ennis Del Mar, who poignantly says "but nothing could be done about it and if you can't fix it then you've got to stand it" (Proulx, 2006, p. 318). This statement demonstrates a stoic attitude to life's vicissitudes. Stoicism arises from previous experience, cultural mores, and religious traditions. Currently, the concept of stoicism is distinguished by the denial, suppression and control of emotion (Wagstaff & Rowledge, 1995, p. 181) in relation to a range of (usually negative) emotive situations that results in a type of fortitude to endure and a concealment of the extent of negative effect on the individual. Yong (2006) also found a type of superiority entwined with the fortitude and concealment. Stoicism both helps and hinders an individual's ability to deal with their disease condition.

The word *stoic* has come to mean unemotional or indifferent to pain, because Stoic ethics taught freedom from passion by following reason. Stoicism is a philosophical standpoint of accepting and enduring with courage that which cannot be changed. Becker (1998) says the ancient Greek philosophers of the Stoic school of thought believed that virtuous people would be content, whatever their circumstances, because their virtuous life contributed to nature's unknowable purpose. This perspective arose in western philosophy from the Greek ideas of the immutable nature of the world and man’s ability to use reason, wisdom and self-control - the maintenance of equanimity in the face of life's highs and lows - getting carried away by neither. Acceptance of things as they were was seen as the epitome of maturity and the natural order. The Roman philosophers refined this thinking to promoting a life in harmony with the universe over which one has no direct control and through which self mastery is achieved (Becker, 1998).

The Christian tradition recognised the futility of man’s attempts to influence the natural world, and elevated a stoic type of acceptance of events, although the Church eschewed the pagan roots of Stoicism. Neostoicism (arising in the 16th century) is a practical philosophy which holds that the basic rule of a good life is that the human should not yield to the passions, but submit to God. Especially, in a religiously upright life, suffering was accepted and elevated to the status of a trial of the individual’s worthiness in God’s eye. Accepting what life gives you without complaint was considered to demonstrate a trust in God and the individual’s worthiness (Lipsius, 1584). In the 16th and 17th centuries, Neo-Stoicism was seen as “the appropriate philosophical framework for a well-lived Christian life” (Brooke, 2006, p. 387).

A strong link to religious belief was seen in previous generations in rural areas. So the quiet endurance of adversity and setbacks with courage and grace is a rural cultural expectation (Heenan, 2006). It manifests itself in many areas of the rural person’s life. People who dwell on the land often have a stoic approach to adversity because of the connectivity of their land and livelihood to the weather, over which humans have no control. This country culture expects individuals to just endure their circumstance with out complaint (Heenan 2006) and stigmatises those who do not adhere to this more with labels like ‘wimp’, ‘quitter’ and so on.

The Stoic philosophy also encompasses the concept of working together for the common good – another concept adapted to Christian beliefs, and one that is strongly held in rural communities. Diane feels that she has to apologise for her inability to contribute to the various committees and functions she attends because as a relatively young woman, there is *an automatic presumption that you are more able to contribute* (p. 4, L133-134) than the older, frailer-looking members and workers.

In the case of ongoing pain, stoicism is expected by the individual and is used to control the fear of being overwhelmed by the negative emotions aroused by the ongoing pain that is being endured. Stoicism has been divided into the concepts of reticence and superiority (Yong, Gibson, de Horne, & Helme, 2001). Brigid doesn't talk about the pain even with her closest friends, although she says: *friends who are very concerned …can tell by just looking at me* (p. 3, L62-63).

Reticence implies a reluctance to speak of the pain. One of the recurring themes from the participants is the reluctance to let others know just how much pain the participant is enduring – and it seems that the worse the pain is, the more reticent the individual is. For instance, Carl has told all of his family of origin that he has this painful condition (by sending them the brochures the doctor gave him), but downplays the magnitude of the pain on a daily basis, answering the inevitable 'how are you today' with "*oh, well enough*" (p. 9, L272) and not mentioning the pain specifically. Diane says *You hurt all the time and you worry it's going to hurt worse…But what can you do? People don't want to hear it, they don't want to know that you're more miserable than they are, I think a lot of the time – you know* (p. 25, L1019 – 1024). Brigid agrees with this*: I do keep it* (the pain) *to myself, I don't believe in burdening other people with my problems* (p. 11, L236). Brett *doesn't really talk about it much.* (He) *only ever told the ones that really had to know* (p. 8, L222-223). Girdhari and Smith (2006, p. 190) suggest that this downplaying of the pain levels is an effort to not worry their support systems and perhaps avoid loss of independence.

Diane, when asked if she discusses the pain with her parents says *no, and pretty much for the same reason* (as with her daughter – avoid burdening them) *actually. You know if you're going to be miserable most of the time, it is easier to just be miserable on your own* (p. 11, L410-412). This aspect of reticence in interesting - being miserable on your own requires less energy expenditure because you do not have to be nice or put on a front to protect the other person from your pain. There is also an element of cautiousness inherent in the reticence. With ongoing pain, relationship strain is a very real possibility, and highlighting or indeed talking about the pain, even to close others emphasizes the alteration in relationships (roles, responsibilities, altered future plans) that the pain has wrought. As well, people who live with chronic pain fear not being believed, even by their significant others because of the invisibility of the pain. Guilty feelings on the part of the significant other arise because they feel impotent in alleviating the pain; or for taking time out from care giving for themselves, they feel angry with the person who is living with chronic pain for not contributing to the relationship or the family, for being self absorbed and for changing their future. So the person living with chronic pain is reluctant to discuss their pain with their significant other.

Diane also brings another aspect of reticence to the fore. She comments on the oblique references people make to her health with*: I think there's a difficulty - people have-there's a-Australians I think have a real reticence about asking personal questions in general and I think part of that extends to they look at me and they can see that I'm not having a good day - whether it's that I'm frowning or I'm sort of limping or you know I'm back to two sticks instead of one or whatever. But they won't come right out and say "Do you have a lot of pain?" They will say "Oh you're not looking very well" or "Oh you look tired" or something like that and I know really what they mean is "You must be in pain today" but that's never what they say* (p.10, L358-368). It is as if there is a tacit agreement that pain as a topic of conversation is avoided. The person in pain avoids talking about it because bringing it to the foreground makes them focus on the pain and this intensifies the sensation and suffering (Paterson, 2001). The friend or neighbour who is enquiring about the health of the person in pain is concerned enough to ask, but feels reluctant to define chronic pain as a legitimate topic of conversation. Because chronic pain has a negative connotation in our society, which has been derived from a past pockmarked with: blame for the person who is living with chronic pain; notions of dependence on medication; worthlessness; powerlessness (Strandmark, 2004); social isolation and a definition in terms of the psychogenic origin of the pain (Gatchell et al., 2007), and stigma of chronic illness (Millen & Walker, 2001), this reluctance to name the health problem is understandable. There is also a disinclination to intrude on private matters, and to probe where you are not wanted.

Gary doesn't tell his wife how much pain he has because then *she doesn't have to worry about anything* (p. 9, L280-281). Saving their significant others from the worry associated with the pain is an important finding. A type of self-protection is inherent in keeping the pain to yourself. Since the other person cannot do anything to ease the pain, telling them about it only makes them feel bad or inadequate (Douglas, Windsor, & Wollin, 2008; Spillers, Wellisch, Kim, Matthews, & Baker, 2008), which in turn increases the misery of the person living with chronic pain. Carl, as others do, often hides the extent of the pain from his wife, stating that he does not want to burden her (Field Notes, Carl) and: *but most of the time I don't talk about it. Because you're in pain all the time, so it's sort of just getting used to it* (p. 8, L260-263). This protectiveness is not selfless in other ways. Telling people about the pain invites pity and altered expectations from the other. This is difficult to deal with when the person in pain is attempting to cope with the pain and manage their life in as near a normal way as possible.

The other part of stoicism that Yong et al. (2001) refer to is superiority. In this case, superiority is a type of pride that engenders strength to endure the pain. '(P)ride necessitates self-sufficiency and an unwillingness to appeal for help beyond the self" explains Fike (2007, p. 141). This is a cornerstone of surviving pain with self intact. Self-sufficiency, self reliance and independence are hallmarks of rural people (Bushy, 2008). Gary demonstrates this type of pride in a very poignant way. Gary says *I hope no one comes down to say g'day today, I really can't handle it, you know And people will walk past "G'day mate, how you going today?" – "Yeah, yeah, good thanks, real good"and I'm at 8 ½* (on the VAS), *yeah, real good!!* (p. 11, L372-376).

Independence and privacy contribute to, evolve from or are closely related to stoicism. Both of these concepts are amply demonstrated in the participants' interviews. All of the participants stated that they finish the job no matter how long it takes. Brigid, for example, states it may take her 3 days or more to clean the house (p. 3, L81), but she accomplishes it. This is an internal driver to demonstrate to themselves their own efficacy and certainly acts as a motivator to get up and do things, not sit around and feel sorry for themselves. She says: *I don't want to ask anyone to do things. I could have a HACC cleaner but I don't want to. Not until I really can't do it. I suppose I am just very stubborn because as long as I can do it, I'll do it* (p. 3, L86-88).

Gary says: *I'm the only one that can do it. You can't ask your neighbour to come over and pick up your sticks, so therefore, it was up to me to battle mentally, knowing that they'd be dropping all the time; they drop and drop and I'd have to get back there an pick them up* (p. 3, L43-46). Gary struggled with the work on his land, seeing it as his responsibility to look after the land, to pick up the twigs and limbs that have fallen from his trees (p. 2, L34), and as his wife is also an invalid, he had to rely on himself to do what he considered to be right.

Diane recalls when she was wheelchair bound and did not have her independence. She says: *when I didn't have it at all, I hated it. I hated not having independence. And the thing I hated the most was never being able to do things by myself. Because I was in a wheelchair, I couldn't get anywhere on my own. You know, if I wanted to go to the shops, I'd have to have someone to drive me and then I'd have to have someone to push me around. And sometimes, I'd need two someones, because I'd need someone to push me and someone to push the trolley, or hold the clothes or carry the basket or whatever, whatever, whatever, you know* (p. 12, L421-431). Independence is important to maintaining self esteem. Independence is based on self efficacy or the ability to undertake and complete a task to your own satisfaction.

Diane has a different take on her attempts to maintain independence: *I sort of have the feeling that I want to wait til things get really bad before I impose on their time any more, you know, like there's a sense of not wanting to empty the favour bucket* (p. 12, L417-420). This statement underlines her knowledge that her condition will worsen in the future and she will need more help. Maintaining as much independence as possible, now, while she still feels able to mostly help herself, gives her a greater sense of confidence about asking for assistance when she really needs it. Other participants also wanted to 'save' asking for assistance until they felt they really needed it. June says of asking her friends and neighbours for assistance: *you don't like to call them because when you really do need them you don't feel as guilty as asking them then to give you a hand* (p. 6, L67-170). Asking for assistance is problematical for most people because in our culture, and especially in the rural areas, rugged, independent individualism is an expected and valued trait (Bigbee & Lind, 2007). Our friends and neighbours seem to be so involved in their own busy lives that asking them for help in accomplishing mundane chores or personal goals is seen as increasing their burdens, and we feel guilty about doing so. Guilty feelings arise when we believe that we have not met our own expectations or fulfilled our responsibilities. This negative emotion is produced when our actions do not accord with our beliefs and values (Spillers et al., 2008). It is very uncomfortable and can be a very strong motivator to ensure that our actions stay inline with our beliefs.

There is also an element of fear of rejection in this quote from June. Because the person living with chronic pain cannot meet their own expectations of independent action, they are also fearful that others will have similar expectations, that if not met, will cause the other person to avoid or shun them. This leads to a self-imposed desire to both have and prove their self efficacy

Inability to continue to participate in family, work and social life and understanding the effect this has on family and friends leads to a sense of guilt. There is guilt at being unable to assume normal (or previously held) role responsibilities, and especially intimate roles. *We don't have a sex relationship in the marriage because* [of the] *pain* (Gary, p. 12, L400). Social obligations and outings can only be spontaneous because of the unpredictability of the intensity or the constant presence of the pain. June says *so I don't just screw up my social life, I ruin everyone else's* (p. 6, L172-173) when the pain forces her to cancel planned social activities. Avoidance behaviour (activity, social outings, leisure activities) is considered maladaptive because it reduces both physical and psychological functioning (Samwel, Evers, Crul, & Kraaimaat, 2006, p. 245) further eroding the person's ability to undertake normal activities.

Mingled with the guilty feelings is a sense of grief at the loss of abilities and productive roles, for example, Diane rued the loss of her nursing career – for self-fulfillment, as well as for income (p. 2, L32), and Carl grieved over the loss of his art career, surfing and theatre life (p.10, L299-203). Loss of the ability to be financially independent was also apparent for most of the participants, exemplified by Carl who *says I just would feel mentally better, you know, I suppose, earning some money for the family, for* (wife) *and I -, rather than the way it is* (p.10, L337-339). Tsai (2005) purports that financial hardship is strongly associated with distress and depression in her study of elders living with arthritic pain. The participants in this study were very cognizant of their financial status – all of them bar one lived frugally on the pension, and expressed difficulty in reconciling themselves to the loss of their breadwinner or supplemental income role and the resultant level of poverty. All commented on the distress in their lives because of their financial strait.

Privacy – you don't have to look and act happy

To each person, privacy is very precious as it keeps outsiders from seeing what goes on in our undisclosed lives and from browsing in our souls. Arendt (1998) names pain as one of the intimate parts of our lives and it is thus assigned to our private selves.

Thought on privacy had its roots in ancient Greece when men developed a life outside of their natural association with home at the life-sustaining centre. Initially, this was the political life, the life of freedom and persuasion, wherein man became a communal being with duties and rights which opposed his kinship ones (Arendt 1998, p. 24). During Roman times, the social life and therefore society was carved out of the home-life. Arendt (1998, p. 38-39) argues that the privation (from which the word private derives) of the individual of the conformism (rules) of society and the freedom of the political life is the underlying meaning of what we understand to be privacy today. This takes privacy back to the intimacy of the hearth and the individuality of the person. Spierenburg (1991) writes that family as we understand it – the nuclear unit of husband, wife and children – has been refined from a household of a man and his dependents (including apprentices, servants, boarders, wife, children, elderly parents and others) during the past 3 centuries. This smaller group of people has fostered the development of intimacy and the concept of privacy.

Privacy is a deeply held tradition in 'Western' cultures and has been until recently, a presumed right (Cowan, 1969) and is now upheld in law (Kloss, 2001). Privacy is 'central to all types of stable interpersonal relationships' (Ingham, 1978, p. 55). Young (1978) claims privacy as a 'facet of human nature' (p. 2) and quotes Brandeis (1890) who claimed privacy to be 'the right most valued by civilised man' (p. 2). Young further espouses that privacy is of a person who is able to live with values and make moral decisions, and has rights and duties conferred by personhood.

The definition of privacy is difficult, and subjective. It is more easily felt than described and is usually recognised by its emotive characteristics. However, despite the difficulties, various authors have described it. Young philosophically discusses a range of issues and concepts such as moral good, moral right, 'being let alone', personhood, and the violation of this right that results in the inability of the person to be 'captain of his soul' (Young, 1978, p. 33), all packaged together in the word 'privacy'. Rhodes (2006, p. 325) defines privacy as the freedom from unwanted intrusion which includes social, psychological and physical elements. Schoeman sees privacy as a “culturally conditioned sensitivity that makes people more vulnerable than they would otherwise be to selective disclosures and to the sense of comparative inferiority and abject shame” (Schoeman, 1984, p. 1) because of lack of awareness of the veiled lives of others. He claims that the concept of privacy is a recent one, brought about by social transformation that resulted from technological innovation. However, Murphy stressed that privacy is “recognised and institutionalised in all societies and is essential to the maintenance of social relationships and the sense of self”(Murphy, 1984, p. 37) and described cultural mores to create and maintain privacy. Young (1978, p. 16) agrees with this when he states that societies have their own forms of privacy, although they vary considerably from the contemporary Western norm of the concept. Cowen (1969, p. 10) concurs and concludes that without a sense of privacy, a person cannot develop in any meaningful way into an individual.

Privacy protects what is personal and intimate (van Manen & Levering, 1996, p. 66) and protects against undesired intrusion by an outsider (p. 73). By maintaining privacy, a person retains control over information about self, the intimacy of their own identity and who can access their body sensually (see, touch). It is a matter of control, autonomy, dignity and respect for personal identity (p. 74). The intimate and thus private sphere of our lives is developed through the processes of learning and adhering to social rules to avoid some sort of punishment (p.114). The social rules are pervasive and Diane suggests that *Australians I think have a real reticence about asking personal questions in general* (p. 10, L359-360). Gary, too, found that friends were unwilling to approach him, and says that after he got sick *I avoided them* (friends) *but there was avoidance from them too, because they – I was just quiet, hunched over, obviously in pain* (p. 8, L238-239). And again, *they’d go back across the road and you’d go ‘Oh, sweet. I didn’t want to talk to you anyway’ Maybe they just saw me coming and they went ‘Oh, pain, we’re going away’. They don’t want to hear it* (p. 8, L258-260). There was sadness in Gary’s voice when he said this, but often, this type of enforced privacy is welcomed because it permits the person living with chronic pain the space to be in pain in peace.

Ingham (1978) discusses the four functions of privacy – maintenance of personal autonomy, the opportunity for emotional release, self-evaluation and the provision for limited and protected communication. . Autonomy permits the individual to retain a sense of personal identity by keeping specific thoughts and judgments to ourselves. This autonomy is mandatory for us to preserve our sense of uniqueness and 'even of worth' (Ingham, 1978, p. 45). Brigid says *Like the friend who sat beside me, she kept saying are you all right and that annoys me. I don't like people feeling sorry for me and I don't want anyone thinking, you know, I'm worse off. It's something I live with and I don't ask other people to live with it especially friends* (p. 3, L66-68).

Space is a part of privacy that is a necessity to feelings of personal autonomy, and personal objects require a secure place free from prying eyes. The other functions of privacy also require or at least are assisted by personal space

Ingham's (1978) discussion of the function of privacy as opportunity for emotional release is particularly appropriate for this thesis. He postulates that people are not permitted by social norm to demonstrate emotions when with they are in company (with the exception of specific others). Diane demonstrates this with *People don't want to hear it, they don't want to know that you're more miserable than they are, I think a lot of the time, you know* (p. 25, L1021-1023). The masking of our emotions for any period of time is draining of psychic energy and being able to relax our guard and display emotions such as anger or grief with an emotional response such as crying is a relief. Relaxing our emotional defenses is not limited to strong or negative emotions, but can be simply relaxing and taking the opportunity to be ourselves, rather than putting on the 'face' or social role that we adopt in company. Carl summarises this with *you don't have to look and act happy* when discussing living in the country (Field notes, Carl).

Self evaluation is usually a solitary occupation where the person steps back from interaction and determines the meaning and veracity of his actions, thoughts and feelings, and can compare his state with previous ones or with that of others. This function occurs during times of stress and change and is linked with self-confidence and the stability of interactions with others.

Finally choosing to discuss information, feelings, and judgments with those we select is a function of privacy. Diane says there are a few friends she is willing to disclose the level of pain she is enduring to: *Yeah, some people I would (*tell*) a lot more to* *than others. You know some friends …I've known for a long time now, I'll just come right out and say "Look, everything's hurting today, I'm having a horizontal day. I'm just going to stay in bed in the electric blanket. Sorry*" (p. 10, L371-375)

Support and comfort

Family plays an important role in the health of its members, and never more so than when there is an ongoing, chronic condition like pain. The health related beliefs and behaviours held by the family impact on either diminishing the pain problem or in exacerbating or nurturing the problems (Jamison & Virts, 1990). These authors suggested that people with chronic pain who perceived their family as supportive reported lower pain intensity, less reliance on medication, greater activity levels and greater return to work. The social support offered within such families reduces the stress of living with chronic pain and its emotional consequences such as fear, anger, depression, low self esteem, helplessness, isolation, demoralization and increase their ability to cope with their pain (Jamison & Virts, 1990, p. 286). The closest others (James & Large, 1992), mainly, but not exclusively, spouses and partners, supply the greatest support, and are the people, other than the person living with chronic pain, most affected by the ongoing pain.

There are a large number of factors that change in a relationship when one of the members is living with chronic pain. Roles change, and often the role responsibilities are shifted onto the closest other (for example, financial responsibilities, child rearing, house and yard work) with that person assuming the altered responsibilities as well as their own. For example, June says her husband comes *home late of a night and then turns around and cooks his tea* (p.1, L32-33) and has had to do the shopping when she has a bad day (p. 5, L145-146). Social isolation often results when outings are cancelled because of the pain, and the closest other is reluctant to leave the person living with pain alone with the increased levels of pain.

Brigid says *I have no family support* (p. 5, L135) but she does have a significant friend who is her *next of kin – no relation – she's my next of kin, she's on my medic alert card, she's on my organ donor card, my will, my burial and my bank* (p. 6, L171-174) who has become Brigid's defacto family. This friend has provided comfort and support for years.

Diane has a daughter and her parents live close. The parents help out with *driving and going to collect my medication for me* (a roundtrip of 5 hours) (p. 3, L43). Diane says *I'm fortunate that my parents live nearby so they're available to sort of pick up the slack* (p. 9, L294-297). She is very conscious about turning to her parents for help, though. *There's no doubt that, you know, I'm going to hit bad patches in the future where I just need that level of help so I always have this sort of theory with my parents that I should be holding those favours in reserve for when I really, really need them. And too I guess I'm also conscious of the fact that they're entitled to have lives of their own an that my brother and his family deserve their fair share of my parent's attention as well* (p. 12, L442-448).

Turning to our parents for help and assistance is more natural than to our children. Even in adulthood, parents are seen as sources of succor and material assistance. Children are to be protected. Her daughter helps Diane to look after herself, but Diane says *I'm very anxious that she doesn't become my carer. That's not her job. Her job in life is not to sacrifice elements of her own life to look after me and I'm prepared to sort of move a lot to make sure that that stays that way. I think it's very unfortunate when children become their parent's defacto parents at a young age* (p. 8, L285-290). Women tend to put their own needs last because they have learned that their children's needs are absolute and can rarely wait (Bondas & Eriksson, 2001, p. 837). Diane protects her daughter from reminders of her mother's pain. *She understands…Mostly now she will organise that herself and fortunately, most of her friends parents understand that the reason I'm not reciprocating with the whole driving kids to things is because I'm mostly too tired, especially at night* (p. 11, L395..401-404). Diane's attitude is not unusual. Parents are reluctant to impose on their children's life. Gary says that they have their own lives to get on with about his grown-up children (Field notes, Gary).

June on the other hand, is in a very difficult relationship. Although she said nothing about her husband, he remained with us during the interview despite being asked for privacy. He disparaged June's pain "Bloody sook – it wouldn't even hurt me" (June, p. 13) and "He (son) gets sick of hearing about it (the pain) and ignores it. I suppose it's the best way of putting it. I do it myself at times. I get sick of hearing about it myself at times and I just – it goes in one ear and out the other and you pretend to listen" (June, p. 7). This difference in perception of the pain levels and lack of support, mirrors findings in a quantitative study suggesting that the non-congruence of perception leads to increased anger and fatigue, poorer psychological and interpersonal wellbeing and a lower quality of life (Miaskowski, Zimmer, Barrett, Dibble, & Wallhagen, 1997). On the other hand, the perceived frequency of talk about the pain was found to not influence the satisfaction of the relationship in a questionnaire based study (Newton-John & Williams, 2006).

In June's case, her vulnerability was exploited by her husband's denigration of her pain – leaving her feeling worthless, alienated, shamed and guilty. Of all of the participants, June had the least positive demeanor, slept very poorly, and stated that she was frequently nauseated and worried about the pain a lot. Catastrophising (ruminating about the negative possibilities of the pain) increases the fear and causes hypervigilance, and avoidance of activity, which results in withdrawal from positive reinforcing behaviours such as socialisation. Ultimately, this contributes to depression (Boersma & Linton, 2006) and reduces the social support network. June's husband also demonstrated a very negative attitude to June's attempts to cope with the pain, belittling her attempts to distract herself from the pain, or to try different alternate management strategies such as massage.

Other participants who were in partnerships or marriages had obviously supportive, but not over-solicitous partners who talked about the pain (Newton-John & Williams, 2006). This type of support is empowering, allowing the person living with chronic pain to tap into their own reserves of inner strength and fortitude.

Pets are part of the family support system as well. Brigid, Gary, Leah and June all have dogs as companions. June has a young dog that is much cherished and she says *they give you that much bloody support and comfort, they do* (p. 8, L208-209). The unconditional love offered by a dog or other pet can increase self esteem and reduce the loneliness of being by yourself for most of the day. As well, Brigid has a beloved pet, Tippy, who is integral to her 'family', providing companionship and comfort. Tippy lives with Brigid, and accompanies her to town on the scooter … o*n Sunday, I take my time – we call in and see a few friends* (p. 9, L260). Leah has several purebred dogs that she shows, and their care and attention keep her busy and a bit distracted from the pain. And Gary says he *went and got a little dog and she's just about the best mate at the time…so that's kept me – oh no, it gave me something to be* *responsible for, I suppose as it's a living animal* (p. 8. L245…250-251). Halm (2008, p. 375) undertook a best evidence review of animal therapy, and concluded there were positive and beneficial effects of living with animals. These were physiological effects (improved haemodynamics, decreased anxiety and lower neurohormone levels), psychological effects (emotional attachment, distraction, sense of control), and social effects (the snuggling contact, bridging communication, company late at night, connecting with and touching the outside world). These effects help to ameliorate the pain experiences and thus provide support to the person living with chronic pain. Strandmark (2004, p. 138) states that a close bond with animal companions helps to decrease vulnerability and permit improvements. However, Johnson et al (2008) found that there was no measurable benefit to the participants in their control trial pre-post test study she undertook, which randomized therapy dog visits for adults undergoing non-palliative radiation therapy. They did find that the patients who were visited by therapy dogs perceived their health and well being to be more improved than the controls in the post test. These participants were being treated for cancer, and the dog-visitors were not their own pets/companions, so the effect would be less positive for them than if it had been their own pets visiting. Pets are part of the family for many people, and as such would be expected to provide a level of social (contact, unconditional love and 'being there') interaction and have a positive impact on the happiness of people living with chronic pain.

Friends outside the family circle are also instrumental in providing support for the person living with chronic pain. Generally, this is structural support as opposed to the functional support supplied by families. Both geographical proximity and the intimacy of the ties affect the support given. Lack of strong support networks is associated with increased experiences of pain that interferes with activities of daily living in middle and older adults (Peat, Thomas, & Croft, 2004). Sometimes, when family is not available as in Brigid's case, friends become more important in respect to the support supplied and maintaining those networks becomes vital to maintaining wellbeing and coping with the pain. Resilience, an innate capacity that is strengthened by supportive relationships (Benard, 2007), increases the individual's ability to deal with the various adversities encountered by living with a chronic pain condition.

Social withdrawal is a frequent result of chronic pain. Energy and effort are required to ‘put on a cheery face’ and maintain established relationships, or establish new ones. There is often significant withdrawal into even the intimate family circle. Brett says he no longer has *a big circle of friends* (p. 8, L 221). This reduces the available support network for both the person and for their significant other (Douglas et al., 2008). In turn, the person’s ability to manage their pain and cope with the difficulties of every day life is undermined when their social network diminishes.

Self-transcendence was important to some of the participants in this study who turned to their relationship with God for succor and comfort. Brett, especially, found comfort not only in prayer, but within the religious community to which he belonged. Religion offers the person a strategy for managing the emotional effects of living with chronic pain (Dunn & Horgas, 2004) as well as a social support network of like-minded people. Brett demonstrates this with *We’re sort of fairly strong in the religious side of things. I think it’s one of the things that keeps me mentally sane. It’s really never crossed my mind so much to ask to get the pain taken away and that sort of stuff. Not really something I thought about praying about enough. But being in the spiritual – that’s sort of helped at least on the mental sort of side of things* (p. 9, L265-270).

Rolley, Chang and Johnson (2008) suggest the comfort and uncertainty of spirituality connects every part of life, but, like chronic pain, is different for each person. These authors suggest that spirituality is a relationship with self and also transcends self, gives meaning to life, holds hope and defines our world-views.

Wachholtz, Pearce and Koenig (2007, p. 311) quote an unknown author “Pain is inevitable; suffering is optional” during their discussion of the effects of spirituality on the person living with pain’s ability to live well with the pain. These authors suggest that spirituality and religious faith offer support to the person living with a chronic illness and are more often than not associated with a more positive outcome. Rippentrop (2005) agrees that religion and spirituality have a salutary effect on chronic pain, but is cautious in this proclamation since her review found that religious/ spiritual views change over time, and that some of the studies did not support the improvement in health outcomes. On the other hand, religion and spirituality is one aspect of a person’s quality of life that is not affected by the continuance of chronic pain (as is mobility, independence, other relationships) and thus might assume a greater importance in the lifeworld of the person living with chronic pain.

Leaning on someone else's strength and believing in a higher being can be very comforting when dealing with chronic pain over a long period as the following poem demonstrates:

Footprints in the Sand

One night I dreamed I was walking along the beach with the Lord.
Many scenes from my life flashed across the sky.
In each scene I noticed footprints in the sand.
Sometimes there were two sets of footprints,
other times there were one set of footprints.
This bothered me because I noticed
that during the low periods of my life,
when I was suffering from
anguish, sorrow or defeat,
I could see only one set of footprints.

So I said to the Lord,
"You promised me Lord,
that if I followed you,
you would walk with me always.
But I have noticed that during
the most trying periods of my life
there have only been one
set of footprints in the sand.
Why, when I needed you most,
you have not been there for me?"

The Lord replied,
"The times when you have
seen only one set of footprints in the sand,

> is when I carried you." (Stevenson, 1936/1984)

The downside of this 'leaning' on God is that it is a passive method of coping and as such increases the deleterious effects of the pain as opposed to more active coping measures which increase functionality. Dunn and Horgas (2004) suggest that this result arises when people defer to God and place the responsibility for coping onto Him (p. 24) as opposed to taking responsibility for themselves. The participants in their study generally used a collaborative approach, sharing the responsibility for coping with God.

A religious upbringing can influence the meaning and impact of chronic pain and thus the ways that are used for dealing with the pain. Brigid spent many of her formative years in a convent school – praying *on my knees while I was growing up* (p. 4, L105). Her outlook on her chronic pain is stoic because she sees the chronic pain as an endurance test set for her by God. Brigid says *I'm here because God set it for me. He'll take me when He's ready* (p.16, L468-4690). There is comfort in this view of the religious aspect of chronic pain as well, because the individual believes that a loving God would not send an affliction that the person could not tolerate, reducing the stress of the pain and providing them with the strength to carry on. Leah says *You are dealt in life only what you can deal with* (Leah, Field notes).

Diane has a strident view on this as she scoffs at this belief. *I think it's a sort of a tide-over from that sort of Calvinistic "suffering is next to Godliness". You know, almost that there's something sort of morally weak if you admit to having pain…And I think that's a really deeply entrenched attitude that there is something lacking moral fibre if you admit to being miserable* (p. 25, L1001-1004…1010-1012). Galvin (2002, p. 113) suggests that chronic illness is viewed as a sin because health is an individual responsibility and ill health occurs when faulty lifestyle choices are made, making illness a personal moral failure. This view blames the victim for their circumstances, and Galvin argues the view has replaced divine retribution and is embedded in the power relations established by the scientific hierarchy. She further suggests that this view needs to be replaced by an acknowledgement of the lived experiences of the chronically ill.

A proclivity toward spirituality seems to have some basis in brain physiology. There is evidence from a Positron Emission Tomography study of 15 healthy males that serotonin binding receptors in the brain are inversely correlated to the self-transcendence character trait, suggesting a biological source for religious belief or spirituality bringing about a reduction of the impact of chronic pain (Borg, Andree, Soderstrom, & Farde, 2003). Much more research is required to substantiate this finding, but it is interesting because of the possible implications it has for assisting people to manage their own pain.

In a qualitative study of 15 adults living with chronic pain, Sorajjakool et al. (2006) found that the journey through chronic pain stripped away meaning from the person's life and as they adjusted to the continuous pain, a spiritual insight was often developed. The understanding that emerged incorporated the distress of living with pain and the person was able to reconcile the pain within their lives and they were able to reintegrate meaning

Many people live quite happily without religious belief and this does not usually change when chronic pain descends into their lives. Religion and spirituality were certainly not mentioned by most of the participants and even when mentioned did not seem to be a prominent part of the person's repertoire of coping mechanisms for pain.

Outside the intimate circles of significant other, family and friends and God, the longstanding rural community connections buoy up the person as they face adversity (Sartore, Kelly, Stain, Albrecht, & Higginbotham, 2008). In the country, people are recognized as individuals, whether they belong to the community or not. From personal observation across dozens of country towns, making eye contact in the street, exchanging smiles and nods even with strangers is normal. On country roads, drivers acknowledge the existence of another person in the oncoming car by a lift of a hand or finger or a quick upward lift of the chin. These gestures indicate a connection that is generally not found in the city streets. Brigid says in her town, you *know everybody by name* (p. 12, L354) while June says that in the city, *you are just another cattle going through the stalls* (Field notes, June). Knowing most of the people in the district for extended periods of time strengthens the feelings of community, of safety and of comfort. Having observed these fellow community member's behaviour, and been imbued with local stories since childhood gives the individual a sense of trust in most community members (and the knowledge of who to avoid, or to take with a grain of salt) that is mostly lacking in the more populous areas because of a lack of common history, knowledge and background. Brigid would not live anywhere else because her town is *just a lovely little community. People are helpful and friendly* (p. 9, L279). The feeling of community in some areas is starting to change as more community members move away for schooling, jobs, health care needs, and others come to live in the small towns (service industry personnel, tree-changers). Often, people are regarded as outsiders until they have lived in a rural town for a generation.

The connections are there. *My cleaning lady that comes from home help to do my cleaning is the mother of one of my daughter's friends at school* (Diane, p. 7, L245-247). But sometimes the support is not. Diane says that *sometimes when I'm just having a bad patch. So people become then sort of become almost aggressive, especially when I have to say 'Look, I'm sorry, no, I can't come to this or be part of that or do the other things'* (p. 5, L163-166). More often, in a small town, or country area, there is good support – neighbours rally around. Again, Diane demonstrates this. *A couple of months ago I got sick and had some trouble breathing and they rushed me off to hospital in an Ambulance and my next-door neighbour collected my daughter from school and then the next day she had a stroke and she was carted off to a different hospital in an Ambulance, so one of my neighbours looked after my daughter because my parents were in New Zealand on holidays as these things always happen, so one of their neighbours then was contacted by one of my neighbours to say that I was in hospital so then my parents had organised for them to feed their animals and look after their house and they came round and sorted out my house and brought casseroles for my daughter and came up and did my washing and all of those sorts of things and all of this sort of happened sort of via the community grapevine really. And I mean you would never get that in a city environment* (p. 7/8, L256-270). This vignette demonstrates the care and responsibilities that neighbours assume when someone is unable to look after their own needs. From focus group interviews about the reaction to adversity from the drought, Sartore et al. (2008) discovered the importance of connection to community in coping. This connection would be just as important to the support of the person living with chronic pain.

This type of community support is necessary, as well as heart warming, because the services that are available in the cities are often minimal, fragmented or entirely lacking in the country towns. Personal empowerment of the person living with chronic pain is bolstered by supportive political and social institutions, adequate medical and mental health care (Sherman, 2005). Brett says *there's a lot of services that are in the city that don't make it out here. If you get to the city, they've probably got 60 different people you can talk to and out here, you've got on person you can talk to ad half the time, they're away doing training* (p. 10, L287-290). When a service provider or health care professional leaves the town for training, holidays or any other reason, there is often no back-fill – no one takes over their job, and the people who use the service just go without. This extends from the doctor to the pharmacist to the nurse. If a locum can be arranged, that person is adrift in the rural culture and often does not 'find his feet' until it is time to go back to the city.

Brigid agrees with Brett. *There's no place out here where you can go and sit and have a good yarn about it* (the pain experience) *except to my GP, Dr P and he's back today* (p.2, L59-60). The range of services is very limited, and often the health care professional who is available in the country town works outside of their scope of practice of necessity. The lack of local services is a big problem. Not only is there a lack of services, but those that are available are restricted by the numbers of needy users and the lack of human and financial resources. There is a need to ration their use, which in the following case, Diane construed as indifference if not hostility. *When it first became really bad I contacted - my GP said contact Community Health and get some home help, but when I rang the local Community Health Nurse she, after our initial conversation, she asked me how old I was and I said at this time I was sort of 36 I think, 36 or 37 and she said "You know these services are for old people that really need our help". I had an eight year old who was being treated for anxiety and I was a single parent. I really needed their help and I was sort of very firmly told that I was sort of - I should be ashamed of myself for wanting to take valued services away from elderly people in the community that really needed it. And that's not the only time I've come across an attitude like that* (p. 3, L81-94). The Community Health Nurse in this scenario could have been more diplomatic, and avoided antagonizing her client.

On the other hand, Brigid, although she concedes that the services are limited, is reasonably satisfied with what she is able to receive. *We have allied health. They've given me um come with me* (we went to the bathroom to see the modifications to the toilet, tub and shower). *Allied Health and Lifeline are marvelous people. They're so helpful and now HACC between them are also helpful. HACC are on call. Whatever you need, they'll hike up the street to do your shopping for you. They'll have them come and clean the house* (p. 12, L372-376). The hospital is a bit different though. *Well, it's had the surgery shut down. They don't operate here. There's only the one doctor and, oh dear, I don't think it would have any more than 20 beds – if it would have 20 beds. No, it's very small. He* (doctor) *puts you there and if you look like he can't handle it, he flies you out* (p. 13, L390-393). Services are a difficulty for small towns – the small population base does not warrant the expense of the full suite of health care professionals and services, nor are there the professionals available to staff such services if the resources could be found for the infrastructure. This along with factors such as global economic forces, the diminishing role of government and growing role of the private sector in allocating resources and policy changes to reduce support for very small or remote communities (Wakerman & Humphreys, 2008) is changing the landscape of rural towns. Without a hospital or with fewer and fewer effective services, the health care needs of the people of the community will not be met to the same level as those in the larger centres. People will need to travel further afield for health care or indeed will be forced to relocate to the larger centres. Health care access is currently and will continue to be for the foreseeable future one of the most important of the health issues in rural Australia (Bourke & Sheridan, 2008).

Again, Diane has analysed her position and comes up with: The main problem is accessing services and services being available to access. I got a letter from Disability Services while I was in a wheelchair full-time saying I was eligible for their Home Support Program which has some name that I can't remember now where they sort of offered you all sorts of wonderful things like you know social visitors and transport and re-training opportunities blah blah blah blah but that program is in Brisbane, you know. And five years down the track I'm still getting letters saying I'm on the waiting list for the program which I don't actually need now because I'm not in a wheelchair at the moment, you know. When I was first became really bad I applied to the Housing Commission for a wheelchair - and disabled accommodation. Because at that point I was living in a Housing Commission house on top of a very steep hill with a bathtub and a driveway I couldn't walk up and down, and that was the same. They said "Well you're on the waiting list and there's an eight year wait" you know and I think that sort of things like that just make a bad situation that much more desperate (p. 27, L1067- 1087). *It is not just people living in country areas that come up against a disintegrating health care system, but offering someone in a country town services that are available only in the biggest city is insensitive and insulting.*

Diane tells another story about the lack of community support – although this is the broader community of Queensland Health. *My parents bought a second-hand wheelchair for me and it works okay but it's really too heavy for my mother to lift in and out of the car so I said to the Occupational Therapist you know "Is there a program available to help fund a lighter weight wheelchair?" because they're very very expensive and the more technologically advanced you get, the more expensive they become and she said "Oh yes, you know, here are the forms" and we looked through the forms and she said "Oh you don't qualify because you're not disabled enough". I thought "I'm in a wheelchair. How much more disabled do I have to get?" "Oh you have to be paralysed" and I found that was - that was another thing I found very difficult though I can deal with it much better now than I did back then, but it's very difficult to deal with the way that the cut-offs are so sharply defined. If you're not a paraplegic than a lot of things you don't qualify for and that's the end of the matter. There's no....there's really nowhere else to appeal, there's no way of getting around that, there's virtually nothing you can do*. (p. 27, L1098-1116). Social structural constraints such as that experienced by Diane and other people who are living with a chronic condition like pain add an extra burden to an already stressful situation and become a psychosocial process that can lead to loss of self-esteem, feelings of worthlessness and other negative emotional states (Martikainin, Bartley, & Lahelma, 2002).

He just doesn't understand – dealing with the health care professionals

Sharing confidences with another generally increases intimacy, and paradoxically produces a tension as we are giving another person access to our innermost thoughts, which may alter the intimate relationship negatively. That it does not is the beginning of trust because the role relationship is not altered and can continue into the future. Health care professionals hold a privileged position in our society in that they are trusted with private information without reciprocating. Disclosing private information to others who are not in an ascribed confidential role relationship is often humiliating to the discloser. It is also threatening to personal integrity because in small towns, there is a very active and efficient ‘grapevine’, permitting everyone in town to soon know an individual’s business if the person confided in is not discreet. Brigid says the reason she could talk to a psychologist was *because she wasn’t living in this town and she was helping me through a very bad time and of course being a professional someone that – you know small towns? How word of mouth gets around so quick. So I know it wasn’t going any further than her* (p. 7, L214-217). Privacy is crucial to both our autonomy (Cowan, 1969, p. 10; Ingham, 1978, p. 44) and to our human dignity.

The biomedical paradigm of mind-body dualism is frequently shared by Health Care Professionals and most of their patients but often causes stress and anxiety (Bates, Rankin-Hill, & Sanchez-Ayendez, 1997; Parsons et al., 2007). If the chronic pain patient and the GP have different world-views, ‘miscommunication, diminished quantity and quality of treatment and reduced quality of life for the patient’ is the outcome (p.1440). There is an ambiguous relation between specific pathophysiological findings and the experience of pain and the concomitant experience of depression. This combination often causes stress in the relationships between the person living with chronic pain and their health care providers. The chronic pain patient finds the health care provider off hand and unhelpful, perhaps chasing after a symptom that is troubling, but not the root of the difficulties. Carl says that his GP seemed to *miss the point and fixate on one symptom and miss the significance of another one* (Field notes, Carl) leaving the person to get on with it as best they can. Leah has an even less effective relationship with her GP. She *says he’s good as in he is my only, I guess, way that I can get the drugs that I need. He is not compassionate about it. He doesn’t understand it. But – and like he doesn’t prescribe and never prescribed any drugs for me…well, they referred me to an orthopaedic surgeon to start with and I’ve seen her a million times but she’s just as useless* (p. 2/3, L47-54). Leah was left for months without pain relief before a friend who was an RN advised her to ask for specific analgesics. This type of disregard by the health care provider destroys any productive relationship there might have been, and sends the person living with chronic pain to someone else to seek relief.

Although it is important to relate to people as individuals (Bates et al., 1997), often health care professionals have great difficulty in relating to people who live with chronic pain for myriad reasons. Getting to know the person living with chronic pain is the first step in establishing a relationship (Kautz, 2008) and permits tailoring their management to their individual situation. This is difficult to do in the intermittent and short consultations usually available at the surgery. The communication style of the health care practitioner (e.g. use of complex words or those with negative connotations, or an arrogant approach to the patient) and power struggles can compromise the patient-practitioner interaction as the patient attempts to gain benefits and the practitioner attempts to control the patient (Frantsve & Kerns, 2007). Diane's (who was an RN prior to the onset of the chronic pain) experiences demonstrate this. *Doctors tend to treat you in one of two ways. Either they become quite belligerent and say 'Don't tell me how to do my job, missy' or 'Tell me what you want me to prescribe and I'll write it out for you, dear'* (p. 15, L564-567). Neither of these approaches is helpful and leaves the person living with chronic pain to again, heal themselves. A balanced approach by the GP, somewhere between autocratic arrogance and a laisse faire attitude is necessary for the nurturing of a working relationship in what will prove to be a very long-term association.

Parsons, et al. (2007) found, in a meta-analysis of research on physician - chronic pain patient interaction, that respect, equality within the relationship and straightforward communication were desired by both. Other factors were equivocal, but being believed by the GP, being taken seriously and legitimating the pain were important in most of the studies. An explanation of the pain problem is as important to the person living with chronic pain as is a cure according to an interview study of 77 people referred to a pain clinic, and this expectation does not seem to be understood by many physicians (Petrie et al., 2005). This expectation can only be met within a reasonably functional relationship.

Pseudo addiction has been a recognized difficulty for decades (Weissman & Haddox, 1989) and Diane ably demonstrates that it still is. *There's a presumption that if you're complaining of severe back pain then it must be just because you want narcotics or the other end it's if you don't want narcotics then the pain can't be to bad* (p. 23, L926-930) Pseudo addiction occurs when pain is under treated and the patient tries to obtain relief from medication. However, these requests are seen as drug seeking by the health care professional (Lusher, Elander, Bevan, Telfer, & Burton, 2006). The distrust engendered by the misunderstanding becomes an interpersonal problem between the health care professional and the person living with chronic pain.

The health care provider often finds interaction with the chronic pain patient difficult because there is little or nothing that medical intervention has found to help many of the people who live with chronic pain. The impotence of not being able to cure or even ameliorate the pain is frustrating and the frustration is sometimes turned into anger against the person, rather than the cause of the frustration. Frantsve and Kerns (2007) suggest that women have a more complex relationship with health care providers than do men and need to balance disclosure of their pain condition without evoking negative gender stereotypes to ensure that the judgment of their pain is accurate. Some find the chronic pain patient to be a complainer and noncompliant with treatments and dislike treating the patient for these reasons. The entrenched myths about chronic, non-malignant pain such as psychological genesis of the pain, hypochondriac behaviour and malingering intent of patients continue to impede the development of productive patient practitioner relationships (Brennan et al., 2007; Dohrenwend et al., 1999; Smith & Friedemann, 1999)

These difficult relationships are uncomfortable and health care professionals succumb to the line of least resistance, returning to the biomedical model of pain management and giving out prescriptions for symptoms. Often, these are ineffective, or cause terrible side-effects leading to cessation of the treatment. Trust is eroded causing a crumbling of the relationship. Brigid demonstrates this deterioration in the relationship she had with the previous GP in her town: *Well, the one before Dr P. didn't understand, just didn't know anything about this and wouldn't- wasn't interested. He just said straight out that wasn't his line,-. he wasn't going that way. And um he couldn't um understand, I suppose the amount of pain. He was forever telling me that um don't do this don't do that. In his opinion I should have been just be sitting in my chair you know, knitting the rest of my life away* (p. 10 ,L286-290).

Health care professionals, as well as those living with chronic pain need to accept the idea that complete relief of the pain is most often not achievable with current treatment options (Nicholas, 2008). To assist the person to resume and maintain as normal a lifestyle as possible, a multifocal approach to assessing and assisting the person with chronic pain is mandatory. This type of treatment requires time, patience, interest in the subject and a broad knowledge of what is available and how it works – all of these can be difficult to find in one health care professional. Patience and interest do go a long way toward assisting the person with chronic pain to adjust their lives to live with the pain, and more and more information and helpful guidelines are available on the Internet. Brigid contrasts the former GP with this intrapersonal aspect of her present GP, whom she trusts and discloses to: *No he just wasn't interested put it that way. Dr P is different. He's caring and he's interested. He's a heart surgeon but he wanted a break away from it. But he's… he's the one who got me to the pain clinic* (p. 10, L291-293).

The GP is often the most important point of contact with the health care system that people who are living with chronic pain have. There are other professionals involved, but because small towns in rural areas do not have the numbers of people to support any more than the basics in health care, there is a limited range of health care professionals available. Very often a GP and a very few Enrolled and Registered Nurses are practicing in the town, and few, if any, of these people have robust pain management skills. Pain management has become a specialty over the past couple of decades, and even now, pain management is reasonably neglected in the curricula of nurses and of physicians. Although there are excellent pain management curricula available for use from various professional bodies, their inclusion within established curricula is problematic because of the time constraints within the university system. As well, student nurses have little involvement in specialized pain management units during their education because of the need to gain competence in the general nursing skills during very attenuated clinical exposure.

Many small town hospitals and clinics are serviced by locum doctors, or 'fly-in-fly-out' arrangements and often agency nurses staff the hospital and surgery. These health care professionals are strangers to the town and do not know the rural areas or culture (Nelson, Pomerantz, Howard, & Bushy, 2007), and do not know the person either as an individual or as a patient with chronic pain. Investing in the type of knowledge and relationship required to assist someone with chronic pain takes a great deal of time and commitment, often not available to the short term health care professional. No trust is able to be developed. Brigid says *They do a good job, but they are mostly agency nurses – come for 6 weeks. We've only got – at present we've* *only got 2 local people 2 sisters.* (p. 13, L401-404). She continues with *Oh, I find a lot of the young ones don't understand…they don't know what they're dealing with. They know nothing about my implant for a start* (p. 13, L406-407). These short stay health care professionals do not have a stake in building a rapport with the people they care for, increasing the chance that care will be professional, but not personal. This again reduces the confidence of the person living with chronic pain in health care professionals.

Since there is often only one GP in town, there is no choice as to the medical practitioner to be consulted. There is no problem with this if the relationship with the GP is satisfactory. However, if trust has been eroded, or if a productive relationship has never been established, consulting this professional is not done. For example, June found the GP unsympathetic and he did not examine her, even superficially (he did not take her blood pressure or pulse) when she attended his surgery. Not meeting the basic expectations of the patient will prevent the establishment of an effective working relationship, as the patient cannot be confident that the doctor knows what he is doing. There was a long waiting list to see him, and sometimes she had to *wait at least 3-4 weeks to get in and get anything done* (p. 2, L42-43). Hoffman et al. (2002, p. 221) suggest that the infrequency of treatment may intensify the pain experience for rural people.

As well, June says her current GP spoke English as a second language and she had difficulty in making herself understood, and in understanding him (June, p. 2. L43 – 46). Disclosing information as private and personal as pain is is awkward enough when the person you are talking to was reared in your language and culture. Trying to explain the psychosocial ramifications of the pain experience to someone whose grasp of English is only 'adequate' reduces the discussion to a list of symptoms. And, even this may not have much intellectual or psychological meaning for the health care professional who has no long-term immersion in either the Australian culture or the culture and dialect of the bush (Nelson et al., 2007). The culture of the rural countryside emphasises the perception of illness as an inability to work, strong feelings of self-reliance, self-care, use of informal support networks, and the importance of a strong work ethic that may be little known to those outside the culture (Nelson et al., 2007). It may seem very strange and inscrutable to a city practitioner if their patient reported the ineffectiveness of using horse liniment on areas of chronic pain, as Gary did (p. 3, L79).

Another facet of living in a small town is often the necessity to rely on an overworked health care professional. Carl says *there is a doctor in town but – and he was a very good doctor I started going to - but he, to me, was overworked and I used to talk to him about a few things and he would do his best* (p.3, L62-65). The rushed appointment schedules that this suggests are not conducive to dealing with chronic pain from a multifactoral viewpoint, leading back to reliance on the biomedical model. Even a holistic assessment including psychological as well as physical health is not frequently undertaken because of the focus of the GPs (Pols & Battersby, 2008) and the time constraints of being a lone GP in a busy surgery. Hoffman, et al.(2002, p. 221) report that rural folk living with chronic pain do not receive treatment as often as their urban counterparts citing the relative lack of availability of health care providers and suggesting that the health care provider must become more assertive in detecting and offering treatment options for this population.

People in small towns travel long distances to see the GP of their choice. For people living with chronic pain, this alternative is really difficult. As well as the actual travel, there are financial costs involved in getting to the next town or city, in staying overnight or longer, in leaving paid employment or farm work for hours to days. There are also the intangible costs of finding someone to mind the pet or the beasts, of the social isolation in a strange town when coping is difficult and being a stranger in a new environment. As a result, many of the participants in this study managed their pain on their own, with occasional trips to a distant town to consult a GP they trusted. Carl for instance traveled a couple of hours *to my Doctor on the coast who was the initial Doctor that stuck with me* (p. 3, L66-67).

Although Kulig et al. (2008, p. 31) state that nurses see themselves ‘as first-line providers of health care’ in the rural area, amongst the participants in this study, interactions with nurses were conspicuously absent. Nurses must have been in the doctor’s surgery, in Pain Clinics, or in hospitals when the participant were being seen there, but only Brigid and Diane had anything at all to say about nurses, despite questions/prompts being asked about nursing care to most of the participants. Nurses are meant to be part of the support afforded to patients in any capacity, but this aspect of their caring was not present with these people living with chronic pain.

Conclusion

This chapter has given a flavour of the relationships established and maintained by the participants in the study. Relationships with significant others, and with less intimate family and friends, included discussions of silence and stoicism as well as the need for individual privacy and the independence that stem from stoicism. Relationships with pets were important to some of the participants, as were their relationship with God. Support from friends as well as from the broader community support network were addressed. A long look was taken at the special relationship that develops between the health care professional and the person living with chronic pain.

The following chapter will address the findings in this study that were common to other qualitative and especially phenomenological studies found in the literature. Specific aspects of findings that have few if any parallels in the literature will be further explored.

Chapter 10 - Closing the circle

Introduction

Four existential essences emerged from the interviews with participants in this study and are represented in Figure 1 (below). The four essences and the named themes were discussed in previous chapters. Several sub-themes grew out of and merged into each of the others to evolve into the named themes. This chapter will briefly re-present the essential sub-themes, supporting qualitative literature and the distinct findings of the current study.

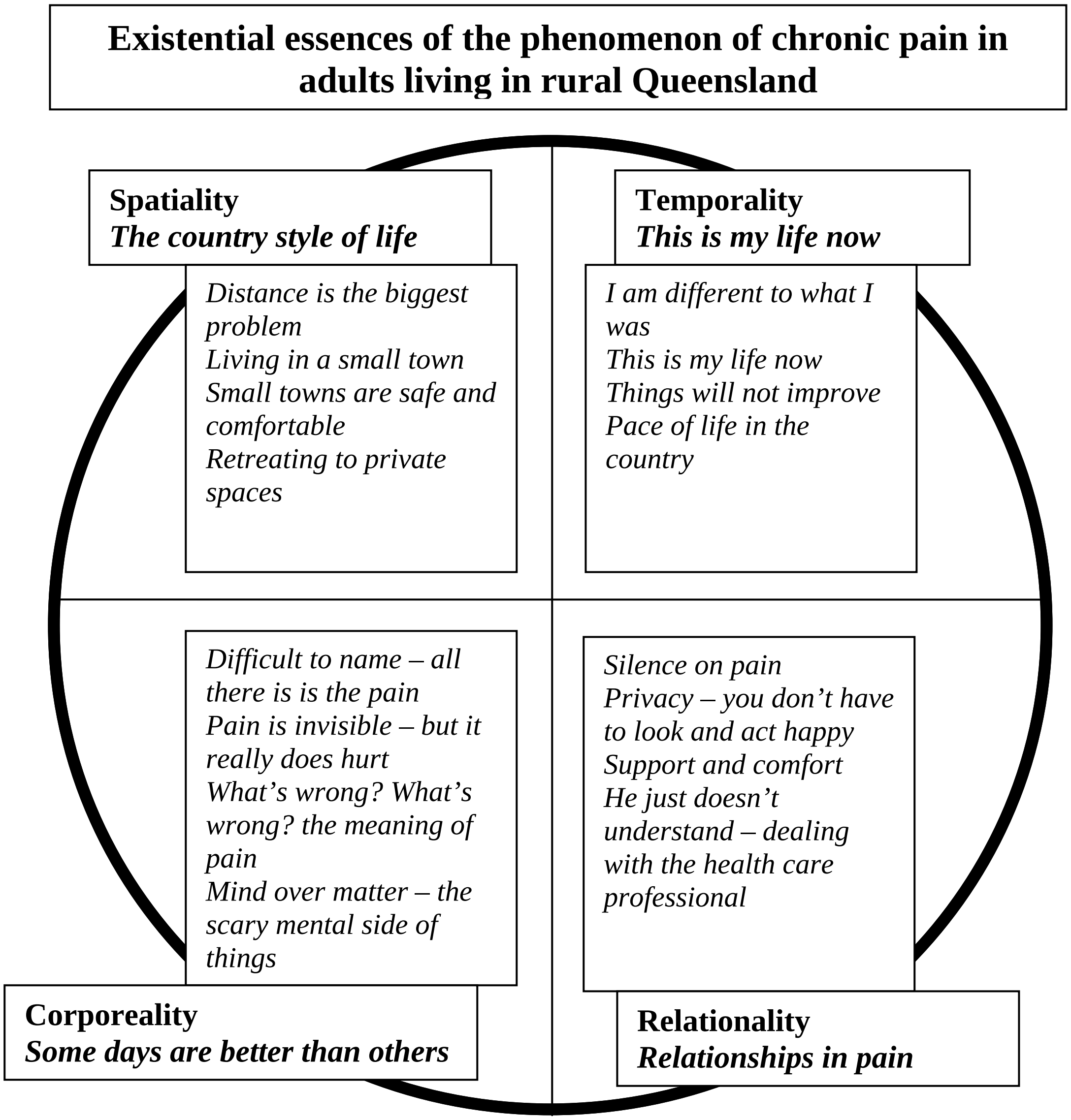

Figure 1 The hermeneutic circle

Understanding of a phenomenon occurs at the juncture of the experiences of self and those of the other. Although understanding of another can never be perfect or complete because experiences are unique, a deeper understanding of another person's experiences is enabled by a deeper knowledge of related experiences of others. Reading phenomenological accounts of various lived experiences of people in situations of interest to the nurse provides a more visceral knowledge of these experiences and an emotional engagement with them than does the usual textbook and other received methods of transmission of knowledge. The resultant resonances can promote more genuine caring practices. The ultimate aim of phenomenological research in nursing is to acknowledge and illuminate the various ways people experience their diverse states of ill health and of well being (Sjostrom & Dahlgren, 2002).

This study has presented the phenomenological accounts of experiences of living with chronic pain in a rural setting. Neither of these (living in a rural area; chronic pain) is particularly uncommon, but there is an impact on the individual's experience when they occur together. This nexus is the point of this study. People living with chronic pain in a rural area can tell of their experiences, and it is up to the phenomenological researcher to interpret their words, and to make coherent sense of the material in the total texts. "To interpret a text is to come to understand the possibilities of being revealed by the text"(van Manen, 1990, p. 180). Thus it is a means of approaching the hermeneutic circle – relating the parts derived from interpretation of the interview text to the whole of the participant's context.
This study has presented a discussion of the phenomenological accounts of experiences of rural people who are living with chronic pain. Neither of these (living in a rural area; chronic pain) is particularly uncommon, but there is an impact on the individual's experience when they occur together. This nexus is the point of this study. People living with chronic pain in a rural area can tell of their experiences, and it is up to the phenomenological researcher to interpret their words, and to make coherent sense of the material in the total texts. "To interpret a text is to come to understand the possibilities of being revealed by the text" (van Manen, 1990, p. 180). Thus it is a means of approaching the hermeneutic circle – relating the parts derived from interpretation of the interview text to the whole of the participant's context.

Parallel findings about the experience of chronic pain

The chronic pain experience has been previously explored both quantitatively and qualitatively and many facets of this experience are available in the literature. Much of the material about chronic pain found in the participants' transcripts and presented in this thesis has been described in previous studies. Sometimes the way participants in this study articulated material was different to the findings in other researchers' work, but many of the findings are parallel. A brief summary of these common experiences is presented here.

Spatiality

'Retreating to private spaces' was one of the sub-themes that constituted the spatiality theme. This was one of the major coping measures used by the participants in the current study. Closs, Staples, Reid, Briggs and Bennett (2007) undertook focus groups with 30 people living with chronic neuropathic pain, and similarly found that mental and physical disengagement and retreat helped them to relax and cope with the pain more effectively. Their participants also stated that bed was not the optimum place of comfort it used to be. In addition, the participants in the current study discussed further aspects of spatiality that have not been reported in qualitative literature and are highlighted below.

Temporality

'I am different to what I was' emerged as a sub-theme of the existential Temporality in this study. Other qualitative studies did not specifically identify this phenomenon, but there were quotes and suggestions that this theme was subsumed into other areas explored by the various authors (Dewar, White, Posade, & Dillon, 2003; Fisher et al., 2007; Osborne & Smith, 2006; Richardson et al., 2006). In particular, Dewar and Lee (2000) discussed their participants coming to the realisation of their situation and giving up unrealistic expectations, learning to live within their new circumstances. Dewar and Lee (2000) undertook a grounded theory based qualitative study to describe how people bear continuous suffering

Self-identity and self-image were important to the participants in this study and were mainly positive. Strandmark (2004) describes a very dark or bleak phenomenological study that emphasized the feelings of worthlessness of the individual, the limitations imposed by the pain and the suffering endured by the participants. In contrast, the people living with chronic pain in the current study worked very hard to maintain a positive self-image by maintaining their mobility, independence and relationships. They did not particularly see themselves as 'suffering' but rather bore their pain stoically, and found other ways of buoying themselves.

‘This is my life now’, another sub-theme of Temporality, represented learning to accept the situation. Although the pain was pervasive, the participants learned new ways of doing things to enable them to maintain independence and get on with their life, although in a different way from their former experience. Acceptance was a major theme/sub-theme in most of the qualitative studies found (Dewar et al., 2003; Fisher et al., 2007; Osborne & Smith, 2006; Richardson et al., 2006). Dewar and Lee (2000) called this ‘Facing the reality’. This supports the findings of the current study.

‘Things will not improve’, a Temporality sub-theme in this study, denoted the realisation that the pain would be with the individual for the remainder of their days. Dewar et al (2003) found their cohort of participants was emotionally distressed, frustrated and at times enraged by this conclusion. Dewar and Lee (2000) also found anger to be one way that their participants dealt with the bleak future of constant pain; however, they used strategies to limit the amount of emotional suffering such as making a conscious effort not to ruminate about their condition. This mirrored the coping mechanisms of participants in the current study. Anxiety about the future was explored by Werner et al (2003) who followed up their participants after a support group treatment program and found that the women learned about their sickness in a different way, and tried to understand the existential questions intrinsic to living with chronic illness in both the past and into the future. The women found the information within the group more effective than that supplied by their health care professional and developed competence in living a satisfying, hopeful and contributing life within the limitations imposed by the pain (p. 506).

Corporeality

‘Describing the pain’, a sub-theme of Corporeality, was difficult if not impossible for most of the participants in this study. They described what they could no longer do with their bodies, but their ability to actually put the pain experience into words failed them. Thomas and Johnson (2000, p. 690) report one of their participants being “stunned with the pain” and the inarticulate nature of the pain was evident in this phenomenological exploration of the experiences of 13 people living with chronic pain. Scarry (1985) concurs that the pain experience is difficult if not impossible to express, although her discussion was about acute as well as chronic pain.

Giving it a name and finding an explanation was an important component of the sub-theme of ‘Describing the pain’ that was found with all the participants in the current study. Other researchers have found this to be relevant to chronic pain as well. Richardson et al. (2006) used patient biographies to help people find explanations for the pain, linking the pain experience to the person’s life narrative to assist them to understand their pain. Using a nominal group technique, participants with chronic pain perceived that their needs were not being met and sought further or more extensive validation of their chronic pain experience (Dewar et al., 2003).

‘Pain is invisible’ was expressed by participants in this study and is a sub-theme of Corporeality. This is a common finding in qualitative research into chronic pain. Werner et al (2003) interviewed middle aged women who were living with chronic pain and used a phenomenological approach to analyse the transcripts. These authors found that their participants reported that others had difficulty in recognizing their limitations because the pain was invisible (p. 499). Osborne and Smith (2006) and Fisher et al. (2007) found the same. The participants in Dewar et al.’s (2003) study felt that since their chronic pain was not visible they were not credible and felt stigmatized.

‘Keeping the balance’ between maintaining a relatively normally active life and minimizing the pain and fatigue was a strong sub-theme of Corporeality arising from the participants. Maintaining their independence was paramount to most of the participants in the current study. Thomas and Johnson (2000) concur, reporting that their participants felt their bodies had become a barrier to activity and were seen as damaged obstacles rather than as enablers of a normal lifestyle. Osborne and Smith (2006) found that chronic pain significantly alters the person’s usual experience of the body, changing the relationship between the self and the body, and ensuring the ongoing awareness of the body, compromising their ability to undertake the most mundane tasks. Sofaer et al. (2005) used a grounded theory approach and found that their participants desired independence and control as well as adapting to the chronic pain. Their adaptation strategies paralleled those used by the participants in the current study – acceptance and non-acceptance, pacing activities, helping other people, the use of prayer and ‘looking good and feeling good’ (p. 464) which was not letting others know how much pain is being endured. These are similar findings to those in the current study.

Taking analgesic is part of 'Keeping the balance' (a sub-theme of corporeality in this study) of pain and function. Dickson and Kim (2002) interviewed seven Korean American women and used a grounded theory approach to reconstruct the meaning of pain in their lives. These women all used analgesic and other pain relief methods (e.g. moxa cautery – a type of acupuncture involving heat) even if the methods seemed to be ineffective, to protect their bodies from pain and allow them to restore their self esteem. Blomqvist and Edberg's (2002) participants used analgesia and other medication to attempt to control the pain and reported side effects to be common occurrences. These people were elderly and living partially independently – at home but with daily professional assistance. Many of the participants in the current study used analgesia as a background treatment, although the pain was never removed. Often the side-effects had to be balanced against the benefits of pain reduction. Other forms of pain control, including heat and cold application, use of various rubs and rest, were also used. Cost was a definite factor in the types of alternate therapies used, with most of the participants stating that they had never tried complementary or alternate therapies or had tried them, but found them ineffective, not available in their town or too expensive for continual use.

Keeping busy was a key strategy for the participants of the current study, as part of 'Keeping the balance', to reduce the impact of the pain. Fisher et al. (2007) conducted a study of people living with chronic pain who were employed within an occupation and found that pain levels were decreased when the person was engaged in activities, and was further decreased when the activity was enjoyable. These people balanced their work with short rest breaks to manage the pain better.

The scary mental side of things, a sub-theme of 'Keeping the balance' included several aspects. Fear of losing our mind, the brain fog – which described the loss of memory and lack of ability to concentrate due to the pain were common to most of the participants in the current study. The research article by Dewar et al. (2003) confirmed these findings. These authors reported cognitive symptoms including confusion, memory loss, decreased ability to concentrate and the inability to focus on anything but the pain in their cohort.

Depression is a constant companion for some who live with chronic pain, including several of the participants in the current study. Depression, irritability, memory and concentration lapses were found by Dewar et al. (2003). Fisher et al. (2007) also found depression was associated with the inability to undertake activities related to the pain in a phenomenological exploration of chronic pain and occupation. These authors found the depression was due to overwhelming negative emotion, helplessness and hopelessness.

Relationality

Participants of the current study described ‘Silence on pain’ with their significant others to protect themselves and their loved ones from the fallout of the pain experience. Dickson and Kim (2003) found this reticence in their cohort of Korean-American women living with chronic osteoarthritic pain. Blomqvist and Edburg (2002) interviewed 90 elderly folk who lived with chronic pain, and found that pain threatened these people’s self-image as independent individuals. A large percentage of them tried to hide the pain with silence and a reluctance to complain. They were unwilling to put the strain of their pain onto their significant others. These qualitative studies support the findings of the current study. Dewar and Lee (2000) found that although the significant other was a valuable source of support, bearing the condition was essentially up to the individual, and this realisation was instrumental in adjusting to their circumstances. Participants in the current study also indicated this was an effective strategy to assist them to live with the pain.

‘Support and comfort’, another sub-theme of Relationships, emerged as a very significant finding in the current study, as in other qualitative research articles. About half of Blomqvist and Edberg’s (2002) participants reported strong and warm relations with friends and family, the other half found that family, friends and especially acquaintances were indifferent to their pain and misunderstood their experiences. The participants in Fisher et al.’s (2007) phenomenological study reported that their friends and coworkers did not understand their pain or wish to hear of it, so the pain was not discussed in their presence.

Pets are part of many families, and provide companionship, unconditional love and a snuggle-factor of touch and warmth. The majority of the participants in the current study found pets provided both support and comfort to them. Strandmark (2004) substantiates the importance of pets to some of her participants, as does the review by Halm (2008). Johnson et al (2008), although not a qualitative study, reported an increased perception of wellbeing and improved health by those who had had a series of pet therapy visits. Other studies reported positive results of research into pet therapy, but no other qualitative studies on pets or companion animals were located.

God and spirituality, part of the sub-theme of ‘Support and comfort’, were mentioned by only a few of the participants in this study. The qualitative literature emphasizes the importance of spirituality and religion (Dunn & Horgas, 2004; Sorajjakool et al., 2006; Wachholtz et al., 2007). However, this importance was not borne out within the current work.

‘He just doesn’t understand’ – the issue of relating to health care professionals was a significant proportion of the discussions with the participants in this study. They demonstrated difficulty in establishing an effective interaction with their health care professional. Particularly, being believed by the health care professional and not being seen as a malingerer was important. The establishment of a trusting and equal relationship was difficult if not impossible for most of the participants. Reliance on the biomedical paradigm by both participants and health care practitioners did not allow for a multifactoral approach to pain management. Education or even discussion about the pain condition was limited by both lack of knowledge or interest and the lack of available time on the part of the health care professional, and the participants were left to get on with their lives without either direction or support in many cases. These findings were mirrored in a community based qualitative study on relationships between health care professionals and their clients with chronic pain (Dewar et al., 2003). The authors found that their participants were unable to access effective and acceptable care and the participants specifically stated that the family physician was unable to meet their pain related needs. The beliefs and expectations of both physician and patient about chronic pain influenced the trust that was established (Parsons et al., 2007). Fisher et al (2007) also found the health care professional and patient interaction fraught with misunderstanding, and lack of respect and belief in the pain.

Distinctive findings about the experience of chronic pain while residing in a rural setting

Some qualitative nursing research work has been undertaken about chronic pain, less about rural health. It is not surprising then that there are similar findings to those of the current study in the available research on chronic pain. When people who are living with chronic pain are also living in a rural area, the composition changes and there are both superficial and fundamental changes in the experience. As a researcher, it meant that I needed to use van Manen's (1997) approach of relating the 'particular' to the 'universal' and returning to the particular to fully understand the experience. Considering the experiences in a holistic manner or reentering the hermeneutic circle helps the researcher to put the pieces of the jigsaw together in a manner that echoes with the veracity of the account. The following findings that are unique to this study are discussed and suggestions are offered as to how these might e used to improve the quality of life for the person living with chronic pain in a rural setting.

Spatiality

Although Australia is the most urbanized country in the world (Clancy, 2004), a significant proportion of the population remains rural. The participants in this study all lived in or near small country towns and found that there were negative and positive aspects to their hometowns.

'Distance is the biggest problem' represented the specific difficulties associated with living with chronic pain in the country. Travel was necessary to access anything other than basic services and travel when dealing with chronic pain can range from being a nuisance to being excruciating. Movement or protracted time periods of sitting still can both exacerbate pain, and trigger breakthrough pain (i.e. additional pain on top of the usual background pain). Driving a truck or car can also trigger the pain as the stillness and enforced muscle tension in arms, legs, shoulders, back, hips and neck can produce muscle spasm and cramp. Not only the actual act of traveling can be problematical, there is also the time and financial costs associated with going to a distant regional town or city for medical care. Worry about home, family and the beasts is also inherent in traveling. Fitzgerald et al. (2001) found that their participants with various chronic illnesses had similar distance-related difficulties. These authors suggested better organization and consideration from the consulting room staff. The current study also found that scheduling of appointments was a problem, with different examinations being scheduled on different days, necessitating a longer stay in the city. These findings suggest that better coordination between GPs, specialists and diagnostic facilities could improve rural peoples' experiences when undertaking the arduous travel needed to diagnose and manage their chronic pain.

As well, distance was a barrier to engaging in desired activities, both leisure and social, for some of the participants. Accessing materials for leisure activities was difficult if not impossible in the smaller country towns, necessitating participants to either impose on others to obtain the materials, get them during infrequent trips to larger centres, or foregoing the activity altogether. Fortunately, most commodities are available via the Internet. However, Internet use is not as frequent in country areas as in urban areas for a number of reasons including expense and its often not being available in homes, or sometimes, even public areas. A strategy to tap into the use of the Internet, such as teaching via outreach courses, and using the Internet facilities available in most town libraries or schools may make access less difficult.

For these participants, social activities were often arranged around some active engagement such as dancing, races, and so on, making it difficult to enjoy the social interaction because of the difficulty in mobilizing, although most of the participants would not engage in such activities because of the effect of the pain on their comfort in socializing, rather than because of the needed mobility. Small, infrequent social outings, and especially of people with chronic pain, as in a support group could assist the person living with chronic pain to both socialize more comfortably and also gain the support and strategies offered in a group of people who are living with a similar condition.

Living in a small town is private and quiet, permitting the person living with chronic pain to deal with their pain more comfortably. Small towns are safe and comfortable was a major theme that emerged. Participants felt physically and mentally secure in the midst of people they knew and trusted, in the conservativeness of the small town, with the solicitousness that evolves in a close knit community. People treated each other as individuals and small kindnesses assured the participants that they remained important members of their community. However, this finding cannot be extrapolated into a larger centre, since the small town, and closeness of the community is inherent in the security felt by the people who live in it.

Temporality

‘The slower pace of life’ was an aspect of living in the rural context that was discussed by the participants. Nothing relating to this aspect of country living was found in the literature accessed. The slower pace of life in the country is more relaxing than the frenetic pace often found in our urban centres. This contributes to a less stressful lifestyle, with time to listen to the butcherbirds or watch the sunset, both of which are distracting and relaxing, making muscles less tense, and providing comfort.

This finding of ‘the slower pace of life’ might be unique to the country lifestyle, but aspects of it, such as limiting interactions with strangers, reducing stimulation from crowded areas, and traffic, removing the necessity for clock watching may be the basis for strategies to reduce the perception of chronic pain in some people. For instance, someone who is not working may be encouraged to shop at a local shopping centre consistently, rather than venture into the bigger malls. They could be encouraged to shop or run errands when the road traffic is minimal, and the business of the shopping centre is limited.

Corporeality

Rural people see themselves as able–bodied, and find it extremely difficult to give in to the pain. Cuts, bruises, aches and pains are scoffed at and ignored as the work goes on (Bushy, 2008). Only as work is impeded or prevented is illness conceded. Something that cannot be seen or proved (i.e. with a medical diagnosis) cannot therefore be enough to prevent the person from working. The work ethic in the rural setting is usually firmly engrained and those who do not work hard are marginalized. Further, there is a broad conservative streak within a rural community that views anyone who is seen as unwilling to pull their own weight as ‘hangers-on’. When someone cannot engage fully in supporting themselves or their family because of an invisible affliction, they are seen and often labeled as malingerers or, more commonly, the colloquial ‘bludgers’. Again, the penchant for hard work is inherent in the rural character, as is an impassivity or stoicism to the difficulties encountered. Knowledge of this may assist health care professionals to provide more timely and effective assistance to someone with these characteristics living with chronic pain in rural settings.

Relationality

The relationships that were revealed in the participants' interviews varied from firmly supportive to apathetic to destructive. However, whether positive or negative, each interaction described was the result of the person living with chronic pain inserting themselves into the human world (Arendt, 1998) and enlisting the help of another to accomplish something. The community involvement and concern was particularly important and not found in other studies of people living with chronic pain. Friends and neighbours pitching in to help when the person living with chronic pain could not accomplish their chores, or offering a cheery word on the street, were integral to the participants' experiences of small town living.

Stoicism and the resultant reticence to discuss the pain were expressed by all of the participants. This was also found by other researchers (Douglas et al., 2008), however combining this with other 'country traits' such as viewing pain as the inability to work (Nelson et al., 2007), and the reluctance to report pain, the busi-ness of the physician (Hoffman et al., 2002) and the often biomedical focus of the physician (Pols & Battersby, 2008) increases the need to assess pain effectively. Effective assessment is especially important for rural folk since other sources of professional support are often not readily available in rural areas. This point is crucial to effectively assisting the person living with chronic pain to do so well.

Health care professionals and their relationships with the participants was a large sub-theme. One significant finding was that often, people living in a rural context had no choice of their doctor, but were forced by distance and by availability to see the only doctor in town. Greenwood and Cheers (2002) substantiated this finding in their interview-based study of health care professionals in the bush. Fitzgerald et al (2001) found the choice of specialist physicians very limited in country towns, rather than the availability of GPs in their phenomenologically based study. Often, in the current study, the participants reported that the doctor was uninterested in their pain problem, or did not understand them (language, bush dialect and bush culture), making the relationship unproductive and damaging. Some of the participants undertook long and arduous trips to another town to consult a sympathetic physician. Perhaps awareness of these shortcomings, and an education syllabus for health care professionals that addresses the contextual issues of people living with chronic pain in small, isolated communities could ameliorate the problems over time. There is also a need for better education and in-service training on chronic pain, its assessment and management.

Another effective strategy might be specialist Nurse Practitioners (NP) who are experienced in managing chronic pain to make regular visits to country towns in their district. Perhaps an NP with specialist knowledge and experience in pain assessment (Daly & Bryant, 2007) and management could mentor nurses who are working in rural areas to improve their knowledge and confidence in assisting people living with chronic pain in country areas.

One of the participants in this study, Leah, encountered laugher from the receptionist when she phoned to check on an appointment she had made, but could not remember the time or date for. She felt particularly belittled and vulnerable when this occurred. This example demonstrates that the relationship with the doctor involves a whole team of people and there is a need to better prepare all those who interact with clients. Possibly, health care professional’s receptionists need some education about communication and dealing appropriately and respectfully with the vulnerable populations they serve.

Nurses are conspicuous by their absence from the interviews in this study. Although nurses are the largest group of health care professionals, the people in this study mostly denied meaningful contact with nursing staff. Many of the strategies for adequately managing and adapting to pain are educational – self-management, pacing, knowledge of the condition, effective use of analgesia- and nurses should have a significant role in this education. These are all roles at which nurses excel. Why is the presence of the nurse so minimal in the rural areas? The rural nurse should be complementing and supporting the work of the GP (Daly & Bryant, 2007) by undertaking these roles. The inclusion of more theory and practical application of that theory about pain, pain assessment and management strategies with a focus on both particular contexts and patient groups needs to be addressed in nurse education curricula. Possibly, with the advent of the National Registry for nurses, this will be considered.

Nurse Practitioners with pain management backgrounds could add a significant depth to the care of people in pain who live in the rural context. Gardner, Hase, Gardner, Dunn and Carryer (2008) report that only 20% of Nurse Practitioners live and practice in rural and regional Australia. Efforts to recruit more rural based RNs to undertake further studies, and especially in pain management could offer people in rural Australia another avenue of assistance with living with chronic pain. Some strategies might include endowing scholarships, establishment of a service-for-education scheme, or perhaps even just providing time and backfill for interested RNs to pursue higher education.

Greenwood and Cheers (2002) conducted interviews with both female physicians and RNs working in rural and remote areas. From these, they suggest that nurses, who have extensive knowledge of the context, are not included in the planning of medical programs at the macro level. This dooms the projects to failure because of the lack of bush cultural fit to non-rural evidence-based plans. Overall, we know that nurses are often excluded from planning and goal setting and are not 'invited to the table' to present their ideas and utilise their knowledge and experiences to assist with decision making when planning for care delivery. This is not a good example of utilization of human resources, since nurses are the most numerous of the health care workforce in country areas, and could be taking a much greater lead in current and future planning.

Conclusion

'Closing the circle' has presented a drawing together of the disparate findings and discussion from this study. Initially, the experiences of the participants that were common to those involved in earlier studies were presented, and the discussion substantiated with reference to the earlier works. Material distinctive to this study was then described and discussed in greater depth. Some ideas for improving the care of people living with chronic pain in rural areas were suggested. These ideas are discussed in the final chapter, Implications, Limitations and Recommendations.

Chapter 11 - Implications, Limitations and Recommendations

Introduction

The previous chapter discussed the major findings of the study. This final chapter examines the implications of the study and also outlines and discusses the limitations. Recommendations for changes in practice, proposals for educational improvement and suggestions for further research are then provided.

Implications

Sjostrom and Dahlgren propose that phenomenological research, while not suggesting clinical solutions to patient problems, does “influence a thoughtful reflective practice by its revealing of conceptions of human experience”(Sjostrom & Dahlgren, 2002, p. 343). This reflection is especially important when the healthcare professional is situated in a relatively isolated practice, and is a limited resource in a small town.

This study has uncovered several implications to caring for people who live with chronic pain in a rural area. Their experiences and the material from the readings indicate that there are difficulties with interpersonal relationships with the primary health care provider. Trust is easily eroded by any indication that the health care provider does not believe the person’s report of pain, or any suggestion that the pain is not ‘real’, or if the health care provider is not interested or is not reasonably well versed in dealing with chronic pain. There must be a reciprocal relationship in which both honesty and respect are apparent.

However, the primary care provider is the GP and is often a lone practitioner in the town, is often overworked and tired from being on-call. As well, participants found that their health care provider sometimes had English as a second language and had difficulties in understanding both their language and the rural culture. Often patients had to rely on serial health care providers as the only professional available were Locums, who stayed for a few weeks or a few months, never long enough to establish a firm therapeutic relationship.

Implications for nursing practice

Chronic pain is a ubiquitous ‘disease entity’ (Brennan, Carr & Cousins 2004, p. 207) that health care professionals confront on a daily basis within any health care practice. Chronic pain afflicts a large percentage of the adult population in any country and the incidence increases with age. Since Australia and the rest of the western world is currently facing the beginning of the bulge of the aging ‘Baby Boomer’ generation, with an increasingly aging population for at least the next generation (Auret & Schug, 2005), excellence in pain assessment and management is imperative for all health care professionals.

Assisting our patients to overcome or to live with their chronic pain in a positive and productive way is inherent in our duty of care [Australian Code of Ethics, Value Statements 3 and 5 ("Australian Code of Ethics", 2002)]. To do this we are required to understand the chronic pain phenomenon, not only from the medical professional’s perspective, but from the person living with chronic pain’s perspective as well. We need to be cognizant of the person’s perception of their chronic pain experience and be aware of the coping strategies they use. In addition, it is important for nurses and other health care professionals to value their experience, expertise and the skills they have developed to manage the condition as this will assist with the provision of effective, holistic care. Further, by developing a partnership of mutual understanding and respect, we will be able to create and implement effective clinical interventions for each individual we encounter who is living with chronic pain.

Nurses are becoming more and more frequently the health care professional who is responsible for the assessment and management of chronic pain in the community and especially in the rural community. It is incumbent on each ‘rural’ nurse, then to understand the impact of the context on his/her patients. Chronic pain management for adults in the rural areas is complicated by the rural context in both positive and negative ways. Nurses who practice in this geographical location must appreciate these contextual factors.

Nurses were not viewed as an important support for the people living with chronic pain in this study. Nurses and perhaps the more experienced advanced nurses (i.e. those with Rural and Isolated Practice Endorsed Registration or NP qualifications) who are emerging as significant health care providers in country areas, need to establish themselves within their communities as helpful resources for people living with chronic pain. Chang, et al. (1999) in a randomised control trial, demonstrated that NPs working in a rural emergency setting provided satisfactory care at an acceptable standard for wound management. Extrapolating from this study, NPs with appropriate education and support from their medical colleagues could be just as effective in assisting people living with chronic pain in rural situations.

Limitations

This study was a descriptive phenomenological and exploratory study to examine the lived experience of chronic pain in a small number of rural adults. As such, it is not generalisable in any way but simply gives some indication of some of the ways rural people live with chronic pain. It is meant to raise to consciousness the variety of experiences that people encounter during their disease process and the attend to the infinite explanations of those experiences (van Manen, 2002).

Although the cohort was small, the interviews yielded an immense amount of rich and varied data. The small sample size is appropriate for a phenomenological study, but with only 7 participants, the data set may be limited. The researcher is a novice at qualitative interviewing, and this may have limited the scope of data that was gathered. Since the study used a phenomenological hermeneutic approach to analyse the material, other researchers may have interpreted the data in a different way. There is no claim to special status for the insights in this study. Van Manen (2002) warns that ‘no interpretation is complete, no explication of meaning is final and no insight is beyond challenge’ (p. 7). Although the researcher made every effort to remain cognizant of her own experiences with chronic pain and with living and working in rural towns, and to eliminate bias, this may have crept into the analysis and discussion of the material.

Only a very small number of different locations were accessed. Although each person lived in or near a rural town, only 5 different locations were used. This in itself may have influenced the findings as asking the same questions of people living with chronic pain in different locations may elicit very different responses. Small towns develop a culture that is unique to each one and would influence the way an individual experienced their pain. Davidhizar and Giger (2004) discuss culture as a force that moulds beliefs and values that influence the way pain is expressed. This applies to the culture that develops in a small town as easily as it does to a culture of people who are immigrants.

All of the participants were English speaking, white Australians. A homogenous cultural sample was unintended, but may have been influential in the processes of both data collection and of analysis. People of other cultures undoubtedly do experience chronic pain in a different way (Davidhizar & Giger, 2004), and the findings of a research study on another culture would result in very different findings and discussion.

The sub-themes that emerged from the data were arranged in a logical progression and their placement in the discussion may not be indicative of their importance. Some themes are discussed initially, prior to more significant themes, to set the scene for later themes. As well, some aspects of sub-themes may take on more or less significance in different cultures or environments. Support from partners/spouses in for example, a clan or village culture such as Fiji would not have the central role in dealing with chronic pain that it does for the participants in this study, because there is more support from an extended family, which lives around the person. Distance proved to be a difficulty for participants in this study and earlier ones. Distance from health care services, imposes huge obstacles for those a rural area of a developing country such as Fiji. Although the journey is less in kilometres in rural parts of Fiji than in the vastness of Australia, it is fraught with more difficult terrain (e.g. river crossings without bridges, paths in the hills, not roads, isolated islands, non-existent public transport, severely limited private and Ministry of Health transport) making walking the most common method of getting to health care services and thus preventing anyone with chronic pain from accessing these services (personal experience).

Recommendations

Education:

Recommendation 1

Education of undergraduate health care professionals specific to chronic pain and its management from a rural perspective should be encouraged. National pain management curricula for each discipline (nursing, midwifery, medicine, pharmacy, physiotherapy and occupational therapy) could be developed in conjunction with all the other disciplines for use across all accredited courses. Ideally, this curriculum would address both chronic pain and assisting people in various situations (including a rural environment) to live with their pain. The International Association for the Study of Pain has developed such a curriculum for health care professionals to insert into their various accredited curricula. Students should be offered the opportunity to attend a clinical experience in a rural area during their educational years to allow them to gain an appreciation of the differences between living in a small rural town and an urban centre where the various Schools of Nursing are (generally) located.

Recommendation 2

Education at the postgraduate level that is specific to chronic pain should be addressed. Post-graduate certificates and diplomas could be recognised by health service districts and acknowledged monetarily, to encourage RNs to undertake further study in pain management. Scholarships, release from service as well as increased remuneration are suggested as rewards for undertaking such study.

Recommendation 3

Master's level education courses with pain management as a recognised practice specialty is suggested for Registered Nurses and as part of the Nurse Practitioner (NP) courses. These NP courses in pain management would prepare NPs to work in Specialist Pain Clinics and to work in the rural sector to assist people to live more peacefully with their chronic pain. Nurse Practitioners will need to be actively recruited for rural areas as only about one fifth of NPs practice outside of urban centres and the majority of these choose remote nursing.

Recommendation 4

Education at the professional development level for qualified professionals to enable them to become more familiar with the current concepts of both acute and chronic pain and to employ contemporary strategies to both prevent the development of chronic pain and to teach those who are living with chronic pain to manage it and their lives more effectively. These education sessions could be interdisciplinary and delivered via teleconference.

Recommendation 5

Assessment of chronic pain emerged as a significant shortfall in the participants' experiences and in the literature. Addressing the multifactoral assessment required for assisting the patient with a chronic pain condition needs special consideration in any educational endeavour.

Practice:

Recommendation 6

Because stoicism and reticence about the pain were found in this small sample, and from reluctance in reporting of pain to the health care professional by rural people (Yong, 2006), I strongly suggest that health care professionals take the lead in asking about and assessing pain levels in their patients. A proactive approach to pain assessment is required to appropriately manage chronic pain.

Recommendation 7

Nurse Practitioners who are expert in pain management (i.e. those with further theoretical qualifications and relevant experience) could increase access to more comprehensive treatment for chronic pain for people who live in rural areas. This might be accomplished by, for example, a specialist NP who travels to each town in her district at regular intervals for a clinic. People could self-refer, or alternately be referred by the GP. This strategy would have funding implications and would currently be very controversial because NPs as yet do not have provider numbers and have only limited prescribing privileges. They may need to work with a GP to provide complete management including analgesic and other medications. Societal attitudes, government policies and professional trends all impact on the expansion of the nurses' role. This macro-level of political work is in great need of resolution.

Recommendation 8

Nurse Practitioners who are expert in pain management (i.e. those who have gained further qualifications and experience in pain management) could undertake mentoring of rural-based hospital and community nurses to assist them to increase their knowledge, skills and confidence in helping people living with chronic pain to live more comfortably. For example, a specialist Pain Clinic NP could be available via teleconference or videoconference to the nurses she is mentoring on either an *ad hoc* or on a regular, scheduled basis.

Recommendation 9

The recognition that chronic pain is a different problem to acute pain and requires a different understanding and approach to its management is crucial to effective practice. Blythe, Macfarlane and Nichols (2007) discuss the bio-psycho-social aspects of chronic pain. These authors suggest that this multidimensional, multi-factorial view of chronic pain is poorly understood by most health care professionals and requires therapies that are based on multidisciplinary team effort and have many more facets than simply symptom control. This understanding has implications for assessment of chronic pain and for its management. Practicing nurses need to remain current in their knowledge about chronic pain. Specialty organisations provide current information, best practice guidelines and helpful hints for assisting people living with chronic pain at such websites as:

www.icsi.org

This site provides assessment and management guidelines (2008) for chronic pain for professionals, and a more reader-friendly guideline suitable for patients and families. There is also an executive summary of the guideline

www.ampainsoc.org

This site has dozens of papers and guidelines for specific painful chronic conditions. The American Pain Society hosts it and the papers are peer reviewed and their dates range from the mid 1990s to the present.

www.iasp-pain.org

The prestigious International Association hosts this site for the Study of Pain. This association, founded in 1973 is the world’s largest multidisciplinary association with a focus on pain research and treatment (IASP, 2008), however, there is a fee for becoming a member. Membership includes a subscription to ‘Pain’, a leading peer reviewed journal. Perhaps health districts could subscribe and enable the health care professionals in that area to access this valuable resource.

Study days or paid leave for study would increase the individual nurse’s ability to undertake further education. Provision of hospital or health centre Internet use for off-duty nurses could also assist.

Recommendation 10

Adoption of standardised pain management strategies by professional organisations, and especially dissemination of these through their rural networks would assist health care professionals to practice in a consistent and contemporary way. This could be supported by professional development education seminars, online workshops, video-conferenced sessions, all held several times to enable interested nurses to attend without disrupting the work in the hospital or health care centre, or necessitating ‘backfill’ positions. Some strategies suggested by the participants of this study and the literature accessed are:

- Encouraging pets as companions for those who are interested
- Encouraging establishment and maintenance of chronic pain support groups (these could be actual or virtual, depending on access to the Internet and the individual’s preferences)
- Limiting the amount of incidental and peripheral social interactions to a comfortable level (e.g. shopping locally and at a quiet time)
- Encouraging the use of the Internet as a social support, to obtain information and to reduce the amount of travel (i.e. purchasing goods on the Internet rather than traveling to the city for specialised materials)

Recommendation 11

The various health care departments of the Australian states need to examine their attitude to health care provision, especially in rural areas. Health care is in a transition currently, with the level of acute care provision not being sustainable over the long term. More interest and effort will be needed to provide primary care for the population, and nurses are numerically in an excellent position to do this. However, there will need to be visionary leadership and a determined effort to achieve such a monumental change. Nurses have a wealth of experience and many understand the complexities of providing care in rural settings. These nurses need to be included in the planning and implementing phases of health care initiatives for rural areas.

Research:

Recommendation 12

Further exploration of the phenomenon of living with chronic pain in a rural area is required. Culturally diverse participants would also be required. This research should be initially based within the qualitative paradigm to enable a basic understanding of the strengths and problems inherent in this contextual situation.

Recommendation 13

Pain assessment and pain management are currently taught in the health care disciplines and have been for at least a couple of decades (personal experience). Understanding of why this knowledge has not translated into practice is essential in order to address the indifference, lack of knowledge and the stigma that people living with chronic pain face from the professionals who are supposed to assist them. Assiduous research into this conundrum is required because the education that is currently being provided is not effective in assisting people living with chronic pain.

Conclusion

In conclusion, this final chapter has discussed the implications of the study. A brief discussion of the limitations was provided. Thirteen recommendations were made. Clearly, the findings of this study reveal the complexity of living with chronic pain within any setting. Importantly, the findings have also revealed the special impact that living with chronic pain while residing in a rural area meant to these participants. Their stories will be used to help others in similar situations in the future. The knowledge gained from the participants about living with chronic pain in a rural area is new and as such, will have important implications for practice, education and research. Recommendations for education, practice and research have been presented that should be used to guide future developments.

References

AIHW. (2001). *Profile of depression in Australia*. Canberra: Australian Institute of Health and Welfare.

Altman, I. (1975). *The environment and social behaviour: Privacy, personal space, territory, crowding*. Monterey, Ca: Brooks Cole Publishing.

Anderson, L. (2001). Reality research: Project time management and recruitment. *Journal of Vascular Nursing, 19*(4), 137-138.

Aoun, S., & Howe, K. (1998a, August 27-28, 1998). *Rural Health Initiative in General Practice: Chronic Pain Management.* Paper presented at the 4th Biennial Australian Rural and Remote Health Scientific Conference, Toowoomba, Queensland.

Aoun, S., & Howe, K. (1998b). *Rural health initiative in general practice:chronic pain management.* Paper presented at the 4th Biennial Australian Rural and Remote Health Scientific Conference, Toowoomba, Queensland.

Arendt, H. (1998). *The Human Condition*. Chicago: University of Chicago Press.

Arnstein, P., Caudill, M., Mandle, C., Norris, A., & Beasley, R. (1999). Self efficacy as a mediator of the relationship between pain intensity, disability and depression in chronic pain patients. *Pain, 80*, 483-491.

Aroian, K., & Norris, A. (2000). Resilience, stress, and depression among Russian immigrants to Israel. *Western Journal of Nursing Research, 22*(1), 54-67.

Asch, S., Connor, S., Hamilton, M., & Fox, S. (2000). Problems in recruiting community based physicians for Health Services research. *Journal of General Internal Medicine, 15*(8), 590 - 596.

Ashgari, A., & Nicholas, M. K. (2006). Personality and pain-related beliefs/coping strategies: A prospective study. *Clinical Journal of Pain.*, *22*(1), 10 – 18.

Atli, A., & Loeser, J. D. (2004). Chronic nonmalignant pain: rational management. *Consultant*, *44*(13), 1693-1701.

Auret, K., & Schug, S. A. (2005). Under utilisation of opioids in elderly patients with chronic pain: Approaches to correcting the problem. *Drugs Aging, 22*(8), 641-654.

Australian Code of Ethics, Australian Nursing and Midwifery Council; Royal College of Nursing; Australian Nursing Federation (2002).

Bamford, E., & Dunne, L. (2001). *Quantifying Access to Health Facilities.* Paper presented at the 6th National Rural Health Conference, Canberra, ACT, March 4-7, 2001.

Bates, M. S., Rankin-Hill, L., & Sanchez-Ayendez, M. (1997). The effects of the cultural context of health care on treatment of and response to chronic pain and illness. *Social Science & Medicine, 45*(9), 1433-1447.

Becker, L. (1998). *A new stoicism*. Princeton: Princeton University Press.

Benard, B. (2007). The foundations of the resiliency paradigm. In N. Henderson (Ed.), *Resiliency in Action: Practical ideas for overcoming risks and building strengths in youth, families and communities*. Ojai, CA: Resiliency in Action Inc.

Benner, P., Janson-Bjerklie, S., Ferketich, S., & Becker, G. (1994). *Moral dimensions of living with a chronic illness*. Thousand Oaks, Ca, USA: Sage Publications.

Beyond the Blame Game. (2008). Retrieved 05.01.09, 2008, from www.nhhrc/publishing.nsf/Content/504AD1E61C23F15ECA2574430000E2B4/$File/BeyondtheBlameGame.pdf

Bigbee, J., & Lind, B. (2007). Methodological challenges in rural and frontier nursing research. *Applied Nursing Research, 20*(2), 104-106.

Birkholtz, M., Aylwin, L., & Harman, R. M. (2004). Activity pacing in chronic pain management: One aim, but which method? Part one: Introduction and literature review. *British Journal of Occupational Therapy, 67*(10), 447-452.

Black, J., Hawks, J., & Keene, A. (2001). *Medical-Surgical Nursing Clinical Management for Positive Outcomes* (6 ed. Vol. 1). Philadelphia: W.B.Saunders Co.

Blomqvist, K., & Edberg, A. K. (2002). Living with persistent pain: Experiences of older people receiving home care. *Journal of Advanced Nursing, 40*(3), 297-306.

Blyth, F., Macfarlane, G. J., & Nicholas, M. K. (2007). The contribution of psychosocial factors to the development of chronic pain: The key to better outcomes for patients? *Pain, 129*, 8-11.

Blyth, F., March, L., Brnabic, A., Jorm, L., Williamson, M., & Cousings, M. (2001). Chronic pain in Australia: a prevalence study. *Pain, 89*, 127 - 134.

Blyth, F., March, L., & Cousins, M. J. (2003). Chronic pain-related disability and use of analgesia and health services in a Sydney community. *The Medical Journal of Australia [online], 179*(2).

Boersma, K., & Linton, S. (2006). Psychological processes underlying the development of a chronic pain problem. *Clinical Journal of Pain, 22*(2), 160-166.

Boles, M., Getchell, W. S., Feldman, G., McBride, R., & Hart, R. G. (2000). Primary prevention studies and the healthy elderly: Evaluating barriers to recruitment. *Journal of Community Health., 235*(279-292).

Bondas, T., & Eriksson, K. (2001). Women's lived experiences of pregnancy: A tapestry of joy and suffering. *Qualitative Health Research, 11*, 824-840.

Bonica, J. J., & Loeser, J. D. (2001). History of Pain Concepts and Therapies. In J. D. Loeser, S. H. Butler, C. R. Chapman & D. C. Turk (Eds.), *Bonica's Management of Pain, 3rd Edition* (pp. 3-16). Philadelphia: Lippincott, Williams & Wilkins.

Boogaerts, M., & Merritt, A. (2008). Psychosocial care. In E. Chang & A. Johnson's *Chronic illness and disability: Principles for nursing practice.* Sydney: Elsevier.

Borg, J., Andree, B., Soderstrom, H., & Farde, L. (2003). The serotonin system and spiritual experiences. *American Journal of Psychiatry, 160*, 165-169.

Bourke, L., & Sheridan, C. (2008). Understanding rural health - key concepts. In L. Siaw-Tang & S. Kilpatrick (Eds.), *A textbook of Australian rural health*. Canberra: Australian Rural Health Education Network.

Branston, P., Rogers-Clarke, C., Hegney, D., & Bishop, J. (2000). Gender roles and geographic location as predictors of emotional distress in Australian women. *Australian Journal of Rural Health, 8*, 154-160.

Breen, J. (2002). Transitions in the concept of chronic pain. *Advances in Nursing Science, 24*(4), 48-60.

Breivik, H., Borchgrevink, P. C., Allen, S. M., Rosseland, L. A., Romundstad, L., Breivik Halls, E. K., et al. (2008). Assessment of pain. *British Journal of Anaesthesiology, 101*(1), 17-24.

Brennan, F., Carr, D. B., & Cousins, M. J. (2007). Pain management: A fundamental human right. *Pain Medicine, 105*(1), 205-221.

Brooke, C. (2006). How the Stoics became Atheists. *The Historical Journal, 49*, 387-402.

Buckelew, S. P., Shutty, M. S., Hewett, J., Landon, T., Morrow, K., & Frank, R. G. (1990). Health locus of control, gender differences and adjustment in persistent pain. *Pain, 42*, 287 - 294.

Bushy, A. (2000). *Orientation to Nursing in the rural community*. Thousand Oaks, CA, USA: Sage.

Bushy, A. (2008). Conducting culturally competent rural nursing research. *Annual Review of Nursing Research, 26*, 221-238.

Buys, L., Roberto, K. A., Miller, E., & Blieszner, R. (2008). Prevalence and predictors of depressive symptoms among rural older Australians and Americans. *Australian Journal of Rural Health, 16*, 33-39.

Byers, M., & Bonica, J. (2001). Chapter 3: Peripheral pain mechanisms and nociceptor plasticity. In S. H. B. J. D. Loeser, C.R Chapman & D.C. Turks (Ed.), *Bonica's Management of pain. (2001)* (3rd ed.). Philadelphia: Lippincott Williams & Wilkins.

Caldwell, T. M., Jorm, A. F., & Dear, K. B. G. (2004). Suicide and mental health in rural, remote and metropolitan areas in Australia. *electronic Medical Journal of Australia, 181*(7 Supplement), S10-S14.

Carson, M. G., & Mitchell, G. (1998). The experience of living with persistent pain. *Journal of Advanced Nursing, 28*(6), 1242-1248.

Chapman, C. R., & Gavrin, J. (1993). Suffering and its relationship to pain. *Journal of Palliative Care, 9*(2), 5 - 13.

Chapman, C. R., & Gavrin, J. (1999). Suffering: the contributions of persistent pain. *Lancet, 353*(June), 2233-2237.

Chudler, E. H., & Bonica, J. (2001). Chapter 5: Supra-spinal mechanisms of pain and nociception. In S. H. B. J. D. Loeser, C.R Chapman & D.C. Turk (Ed.), *Bonica's Management of pain. (2001)* (3rd ed.): Philadelphia: Lippincott Williams & Wilkins.

Clancy, L. (2004). *Culture and Customs of Australia*. Westport, Connecticut: Greenwood Press.

Closs, S. J., Staples, V., Reid, I., I., B. M., & Briggs, M. (2007). Managing the symptoms of neuropathic pain: An exploration of patients' experiences. *Source: Journal of pain and symptom management, 34*(4), 422-433.

Corbin, J. (2001). *Introduction and Overview: Chronic Illness and Nursing.* New York: Springer Publishing Company.

Cordes, S. M. (1985). Biopsychosocial imperatives from the rural perspective. *Social Science & Medicine, 21*(12), 1373-1379.

Cosgrove, N., Borhani, N. O., Bailey, G., Borhanib, P., Levin, J., Hoffmeier, M., et al. (1999). Mass mailing and staff experience in a total recruitment program for a clinical trial. *Controlled Clinical Trials, 20*(2), 133-148.

Cowan, Z. (Writer) (1969). The Private Man. In A. B. Commission (Producer), *The Boyer Lectures*. Australia.

Crombez, G., Vlaeyen, J., Heuts, P., & Lysens, R. (1999). Pain-related fear is more disabling than pain itself: evidence on the role of pain-related fear in chronic back pain disability. *Pain, 80*, 329-339.

Crotty, M. (1996). *Phenomenology and Nursing Research*. Melbourne: Livingston.

Daly, J., & Bryant, R. (2007). Professional organisations and regulatory bodies: Forging and advancing the role of nurses in Australian primary care. *Contemporary Nurse, 26*, 27-29.

Davidhizar, R., & Giger, J. N. (2004). A review of the literature on care of clients in pain who are culturally diverse. *International Nursing Review, 51*, 47-55.

Davis, P. T. G., Glynn, C. J., & Kadry, M. A. (2003). Expectations of patients attending a combined headache clinic. *Journal of Headache and Pain, 4*(2), 79-82.

de la Rue, M., & Coulson, I. (2003). The meaning of health and well-being: voices from older rural women. *Australian Journal of Rural Health, 3 (online)*(192).

Deary, V. (2005). Explaining the unexplained? Overcoming the distortions of a dualist understanding of medically unexplained illness. *Journal of Mental Health, 14*(3), 213-222.

DeGood, D. E., & Kiernan, B. (1996). Perception of fault in patients with chronic pain. *Pain, 64*, 153 - 159.

DeLeon, P. H., Wakefield, M., & Hagglund, K. J. (2002a). The behavioral health care needs of rural communities in the 21st century. In B. Hudnall Stamm (Ed.), *Rural Behavioral Health Care*. Washington, D.C.: American Psychological Association Books.

DeLeon, P. H., Wakefield, M., & Hagglund, K. J. (2002b). The behavioral health care needs of rural communities in the 21st century. In B. H. Stamm (Ed.), *Rural Behavioral Health Care.* Washington: American Psychological Association.

Denzin, N., & Lincoln, Y. (2000). Chapter 1: Introduction: The discipline and practice of qualitative research. In N. Denzin & Y. Lincoln (Eds.), *The handbook of Qualitative Research.* Thousand Oaks, Ca.: Sage.

Dewar, A., & Lee, E. A. (2000). Bearing illness and injury. *Western Journal of Nursing Research, 22*(8), 912-926.

Dewar, A., White, M., Posade, S. T., & Dillon, W. (2003). Using nominal group technique to assess chronic pain, patient's perceived challenges and needs in a community health region. *Health Expectations, 6,* 44-52.

Dick, B. D., & Rashiq, S. (2007). Disruption of attention and working memory traces in individuals with chronic pain. *Anaesthesia & Analgesia, 104*, 1223-1229.

Dickson, G. L., & Kim, J. I. (2003). Reconstructing a meaning of pain: Older Koean American women's experiences with the pain of osteoarthritis. *Qualitative Health Research, 13*(5), 675-688.

Dohrenwend, B., Raphael, K., Marbach, J., & Gallagher, R. (1999). Why is depression comorbid with chronic myofascial pain? A family study test of alternative hypotheses. *Pain, 83,* 183-192.

Douglas, C., Windsor, C., & Wollin, J. (2008). Understanding chronic pain complicating disability: Finding meaning through focus group methodology. *Journal of Neuroscience Nursing, 40*(3), 158-168.

DuBois, D. L., Tevendale, H. D., Burk-Braxton, C., Swenson, L. P., & Hardesty, J. (2000). Self-system influences during early adolescence: Investigation of an integrative model. *The Journal of Early Adolescence, 20*, 12-43.

Dunlop, M. (1994). Chapter 2: Is a science of caring possible? In P. Benner (Ed.), *Interpretive Phenomenology: Embodiment, Caring an Ethics in Health and Illness*. Thousand Oaks: Sage.

Dunn, K. S., & Horgas, A. L. (2004). Religious and nonreligious coping in older adults experiencing chronic pain. *Pain Management Nursing, 5*(1), 19-28.

Eagleman, D. M. (2008). Human time perception and its illusions. *Current Opinion in Neurobiology,*(doi:10.1016/j.comb.2008.06.002 (online).).

Edwards, R. R. (2005). Individual differences in endogenous pain modulation as a risk factor for chronic pain. *Neurology, 65,* 437-443.

Eyles, R., & Smith, B. (1995). Rural Health in Queensland: A Changing Focus. *Australian Journal of Rural Health, 3,* 186 - 191.

Fanker, S., & O'Brien, L. (2008). Depression: Its scope, impacts , treatment and nursing management. In E. Chang & A. Johnson (Eds.), *Chronic Illness and Disability: Principles for Nursing Practice*. Chatswood, NSW: Churchill Livingston.

Fenwick, C., & Stevens, J. (2004). Post-operative pain experiences of central Australian Aboriginal women. What do we understand? *Australian Journal of Rural Health, 12*(1), 22-27.

Ferrer, R. L., Palmer, R., & Burge, S. (2005). The family contribution to health status: A population-level estimate. *Annals of Family Medicine, 3*(2), 102-108.

Fields, H. (1999). Pain: an unpleasant topic. *Pain, Pain Supplement 6*, S61-S69.

Fike, F. (2007). Cold grace: Christian faith and stoicism in the poetry of J.V. Cunningham. *Renaissance, 59*(3), 141-159.

Fisher, B., Haythornthwaite, J., Heinberg, L., Clark, M., & Reed, J. (2001). Suicidal intent in patients with chronic pain. *Pain, 89*, 199-206.

Fisher, G. S., Emerson, L., Firpo, C., Ptack, J., Wonn, J., & Bartolacci, G. (2007). Chronic pain and occupation: An exploration of the lived experience. *The American Journal of Occupational Therapy, 61*(3), 290-204.

Flaherty, M. (1999). *The watched pot: How we experience time*. New York: New York University Press.

Frantsve, L. M. E., & Kerns, R. D. (2007). Patient-provider interactions in the management of chronic pain: Current findings within the context of shared medical decision making. *Pain Medicine, 8*(1), 25-35.

Fredheim, O. M., Kaasa, S., Fayers, P., Saltnes, T., Jordhoy, M., & Borchgrevink, P. C. (2008). Chronic non-malignant pain patients report as poor health related quality of life as palliative cancer patients. *Acta Anaesthesiology Scandinavia, 52*, 143-148.

Freshwater, D. (2005). The poetics of space: researching the concept of spatiality through relationality. *Psychodynamic Practice, 11*(2), 177-187.

Friedman, W. (1990). *About time*. Cambridge, Mass, USA: MIT Press.

Gadamer, H. G. (1976). *Philosophical Hermeneutics*. Berkley, Ca,: University of California Press.

Gagliese, L., & Melzack, R. (1997). Chronic pain in elderly people. *Pain, 70*, 3 - 14.

Gallagher, R. M. (2002, 02.10.02). The pain-depression conundrum: bridging the body and mind. Retrieved 10.10.02, 2002, from http://medscape.com/viewprogram/2030_pnt

Galvin, R. (2002). Disturbing notions of chronic illness and individual responsibility: Towards a genealogy of morals. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 6*(2), 107-137.

Gardner, A., Hase, S., Gardner, G., Dunn, S., & Carryer, J. (2008). From competence to capability: a study of nurse practitioners in clinical practice. *Journal of Clinical Nursing, 17*, 250-258.

Gatchell, R. J., Peng, Y. B., Peters, M. L., Fuchs, P. N., & Turk, D. C. (2007). The biopsychosocial approach to chronic pain: Scientific advances and future directions. *Psychological Bulletin, 133*(4), 581-624.

Gauthier, M. A., & Clarke, W. P. (1999). Gaining and sustaining minority participation in longitudial research projects. *Alzheimer Disease Association Disorder, 13*(Suppl 1).

Gillespie, B. M., Charboyer, W., & Wallis, M. (2007). Development of a theoretically derived model of resilience through concept analysis. *Contemporary Nurse, 25*(1-2), 124-135.

Girdhari, S., & Smith, S. (2006). Assisting older adults with orthopaedic outpatient cute pain management. *Orthopaedic Nursing, 25*(3), 188-195.

Gray, E. (2001). Linking chronic pain and depression. *Nursing Standard, 15*(25), 33-36.

Greenwood, G., & Cheers, B. (2002). Doctors and nurses in outback Australia: Living with bush initiatives. *Rural and Remote Health 2, (online)*, http://rrh.deakin.edu.au.

Hadjistavropoulos, T., Herr, K., Turk, D. C., Fine, P. G., Dworkin, R. H., Helme, G., et al. (2007). An interdisciplinary expert consensus statement on assessment of pain in older persons. *Clinical Journal of Pain., 23*(1), S1-S43.

Halm, M. A. (2008). The healing power of the human-animal connection. *American Journal of Critical Care, 17*(4), 373-377.

Hampton, T. (2004). Stress and memory loss link. *Journal of the American Medical Association, 292*(34), 2963.

Hampton, T. (2005). Pain and the brain: Researchers focus on tackling the pain memories. *Journal of the American Medical Association, 293*(23), 2845-2846.

Harvey, D., Sandhu, G., & Strasser, R. (1995). Unresolved health care issues in rural and remote Australia: Preliminary findings from a National Rural Health survey. *Australian Journal of Rural Health, 3*, 34-36.

Hays, R. (2002). *Practicing Rural Medicine in Australia*. Melbourne: Eruditions Publishing.

Health, Q. (2008). Home and community care program (HACC). from http://www.health.qld.gov.au/hacc/

Heenan, D. (2006). The factors influencing access to health and social care in the farming communities of County Down, Northern Ireland. *Ageing and Society, 26*, 373-382.

Hegney, D., Pearson, A., & McCarthy, A. (1997). *The Role and Function of the Rural Nurse in Australia*. Canberra: Royal College of Nursing, Australia.

Heidegger, M. (1927/1962). *Being and Time.* (J. Macquarrie & E. Robinson, Trans.). Oxford: Blackwell.

Heidegger, M. (1972). *On Time and Being* (J. Stambaugh, Trans.). New York: Harper Torchbooks.

Hoffman, P. K., Meier, B. P., & Council, J. R. (2002). A comparison of chronic pain between an urban and rural population. *Journal of Community Health Nursing, 19*(4), 213-224.

Hudnall Stamm, B., Metrick, S. L., Kenkel, M. B., Davenport, J. A., Davenport, J., Hudnall, A. C., et al. (2003). *Introduction*.Washington: American Psychological Association.

Husserl, E. (1981). Husserl's Inaugural Lecture at Frieburg im Breisgau (1917) (R. W. Jordan, Trans.). In P. McCormick & F. A. Elliston (Eds.), *Husserl's Shorter Works*. Notre Dame, Indiana: University of Notre Dame Press.

IASP. (2008). Vision statement. Retrieved 26.11.08, 2008, from www.iasp-pain.org

ICSI. (2008). Clinical Guidelines for the Assessment and Management of Chronic Pain.

Ingham, R. (1978). Privacy and psychology. In J. B. Young (Ed.), *Privacy*. New York: John Wiley & Sons.

Jacelon, C. S. (1997). The trait and process of resilience. *Journal of Advanced Nursing, 28*, 123-129.

Jackson, D., Daly, J., & Chang, E. (2004). Chapter 9: Approaches in qualitative research. In Z. Schneider, D. Elliott, G. LoBiondo-Wood & J. Haber (Eds.), *Nursing Research: Methods, Critical Appraisal and Utilisation*. Sydney: Mosby.

Jahn, R. G., & Dunne, B. J. (2001). A modular model of mind/matter manifestations (M^5). *Explore, 3*(3), 311-324.

James, F. R., & Large, R. G. (1992). Chronic pain, relationships and illness self-construct. *Pain*, 263-271.

James, F. R., Large, R. G., Bushnell, J. A., & Wells, J. E. (1991). Epidemiology of pain in New Zealand. *Pain, 44*, 279 - 283.

Jamison, R. N., & Virts, K. L. (1990). The influence of family support on chronic pain. *Behavioural Research Therapy, 28*(4), 283-287.

Janesick, V. J. (2000). Chapter 13: The choreography of qualitative research design. In N. Denzin & Y. Lincoln (Eds.), *The Handbook of Qualitative Research.* Thousand Oaks, Ca: Sage.

Jensen, M. (2006). Using pain quality assessment measures for selecting analgesic agents. *Clinical Journal of Pain, 22*(1), S9-S13.

Jensen, M., Romano, J., Turner, J., Good, A., & Wald, L. (1999). Patient beliefs predict patient functioning: further support for cognitive-behavioural model of chronic pain. *Pain, 81*, 95 - 104.

Jensen, M., Turner, J., Romano, J., & Fisher, L. (1999). Comparative reliability and validity of chronic pain intensity measures. *Pain, 82*, 157-162.

Johnson, R. A., Meadows, R. L., Haubner, J. S., & Sevedge, K. (2008). Animal-assisted activity among patients with cancer: Effects on mood, fatigue, self-perceived health, and sense of coherence. *Oncology Nursing Forum, 35*(2), 225-232.

Johnson, S., Mebane-Sims, I., Hogan, M. S., & Stoy, D. (1995). Recruitment of postmenopausal women in the PEPI trial. *Controlled Clinical Trials, 16*(4 (Supp 1)), 20-35.

Kautz, D. (2008). Inspiring hope in our rehabilitation patients, their families and ourselves. *Rehabilitation Nursing, 33*(4), 148-177.

Keefe, F., Lefebvre, J., Ebert, J., Affleck, G., Sullivan, M., & Caldwell, D. (2000). The relationship of gender to pain, pain behavior and disability in osteoarthritis patients, the role of catastrophizing. *Pain, 87*, 325-334.

Keleher, H., & Ellis, J. (1996). Rural people utilising city hospitals: issues for service provision. *Australian Journal of Rural Health, 4*, 144-150.

Klein, D. N., Shankman, S. A., & Rose, S. (2006). Ten-year prospective follow-up study of the natural course of dysthymic disorder and double depression. *American Journal of Psychiatry, 163*, 872-880.

Kleinman, A. (1992). Pain and Resistance: the Deligitimation and Relegitimation of Local Worlds. Chapter 7. In M.D.Good, P.E.Brodwin, B.J.Good & A. Kleinman (Eds.), *Pain as Human Experience: An Anthropological Perspective*. Berkley: University of California Press.

Kloss, L. L. (2001). Seeking confidentiality in medical records. In E. Hein (Ed.), *Nursing issues in the 21st century: Perspectives from the literature*. Philadelphia: Lippincott, Williams & Wilkins.

Kugelmann, R. (1999). Complaining about chronic pain. *Social Science & Medicine, 49*, 1663-1676.

Kulig, J. C., Andrews, M. E., Stewart, N. L., Pitblado, R., MacLeod, M. L. P., Bentham, D., et al. (2008). How do Registered Nurses define rurality? *Australian Journal of Rural Health, 16*, 28-32.

Lane, J. (2004). 'Rurality' and 'Community'. *Australian Journal of Rural Health, 12*, 176.

Larsen, P. (2000). Effective pain management in older patients. *AORN, 71*(1), 205-208.

Leddy, S., & Pepper, M. (1998). *Conceptual Basis of Professional Nursing* (4 ed.). Philadelphia: Lippincott.

LeFort, S. (2000). A test of Braden's Self-Help Model in adults with chronic pain. *Journal of Nursing Scholarship, 32*(2), 153-160.

Leonard, V. (1994). A Heideggerian Phenomenological Perspective on the Concept of Person. In P. Benner (Ed.), *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness*. Thousand Oaks, Ca: Sage.

Liebeskind, J. C. (1991). Pain can kill. *Pain, 44*, 3 - 4.

Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences, 18*, 145 - 153.

Lipsius, J. (1584). *Second Book of Constancy* (J. Stadling, Trans.) New Brunswick: Rutgers University Press.

Livneh, H. (1999). Psychosocial adaptation to heart diseases: The role of coping strategies. *Journal of Rehabilitation, 65*(3), 24-33.

Llewellyn, G., Sullivan, G., & Minichello, V. (2004). Chapter 9: Sampling in qualitative research. In V. Minichello, G. Sullivan, K. Greenwood & R. Axford (Eds.), *Handbook of Research Methods for Nursing and Health Science*. Frenchs Forrest, NSW: Pearson Educational, Australia.

Loeser, J. D., & Turk, D. (2001). Multidisciplinary pain management. In J. D. Loeser, S. H. Butler, C. R. Chapman & D. Turk (Eds.), *Bonica's Management of Pain* (3 ed.). Philadelphia: Lippincott Williams and Wilkins.

Lopez, K., & Willis, D. (2004). Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qualitative Health Research, 14*(5), 726 - 735.

Lovering, S. (2006). Cultural attitudes and beliefs about pain. *Journal of Transcultural Nursing 17*(4), 389-395.

Lusher, J., Elander, J., Bevan, D., Telfer, P., & Burton, B. (2006). Analgesic addiction and pseudo addiction in painful chronic illness. *Clinical Journal of Pain, 22*(3), 316-324.

MacKellar, D. (1908). My Country. In *The Spectator*. Paddington, NSW: Curtis Brown.

MacPherson, R. (2000). The pharmacological basis of contemporary pain management. *Pharmacology and Therapeutics, 88*, 163-185.

Martikainin, P., Bartley, M., & Lahelma, E. (2002). Psychosocial determinants of health in social epidemiology. *International Journal of Epidemiology, 31*, 1091-1093.

Mayer, D., Torma, L., Byock, I., & Norris, K. (2001). Speaking the language of pain. *American Journal of Nursing, 101*(2), 44-50.

McCaffery, M., & Ferrell, B. (1996). Correcting misconceptions about pain assessment and the use of opioid analgesics: educational strategies aimed at public concerns. *Nursing Outlook, 44*(4), 184-190.

McCance, K. L., & Huether, S. E. (2006). *Pathophysiology: The biologic basis for disease in adults and children.* (5 ed.). St Louis: Elsevier.

McCracken, L., Spertus, I., Janeck, A., Sinclair, D., & Wetzel, F. (1999). Behavioral dimensions of adjustment in persons with chronic pain: pain-related anxiety and acceptance. *Pain, 80*, 282-289.

McGrath, P. J. (2006). 'The biggest worry..': research findings on pain management for Aboriginal peoples in Northern Territory, Australia. *The International Electronic Journal of Rural and Remote Health, Research, Education, Practice and Policy.(Online)*(July 9, 2006 @ http://rrh.deakin.edu.au).

McLachlan, H. & Waldenstrom, U. (2005). Childbirth experiences in Australia of women born in Turkey, Vietnam and Australia. *Birth 32*(4), 272-282.

Melzack, R. (1999). From the gate to the neuromatrix. *Pain, Pain Supplement 6*, S121-S126.

Melzack, R., & Casey, K. L. (1968). Sensory, motivational, and central control determinants of pain. In D. R. Kenshalo (Ed.), *The Skin Senses*. Springfield, IL, USA: C.C. Thomas.

Melzack, R., & Wall, P. D. (1965). Pain mechanisms: a new theory. *Science, 150,* 971 - 979.

Melzack, R., & Wall, P. D. (1975). *The Puzzle of Pain*. Hammondsworth, England: Penguin.

Mendelson, G., & Mendelson, D. (2004). Malingering pain in the medicolegal context. *Clinical Journal of Pain*, *20*(6), 423-432.

Merleau-Ponty, M. (1962a). *Phenomenology of Perception* (C. Smith, Trans.). London: Routledge.

Merleau-Ponty, M. (1962b). *Phenomenology of Perception.* London: Routledge.

Miaskowski, C., Zimmer, E. F., Barrett, K. M., Dibble, S. L., & Wallhagen, M. (1997). Differences in patients' and family cargivers' perceptions of the pain experience influence patient and caregiver outcomes. *Pain, 72*, 217-226.

Millen, N., & Walker, C. (2001). Overcoming the stigma of chronic illness: Strategies for normalisation of a 'spoiled identity'. *Health Sociology Review, 10*(2), 89-97.

Minichello, V., Sullivan, G., Greenwood, K., & Axford, R. (2004). Introduction. In V. Minichello, G. Sullivan, K. Greenwood & R. Axford (Eds.), *Handbook of Research Methods for Nursing and Health Science* (2nd ed.). Frenchs Forrest, NSW: Pearson Education, Australia.

Mol, M., Carpay, M., Ramakers, I., Rozendaal, F. V., & Jolles, J. (2007). The effect of perceived forgetfulness on quality of life in older adults: a qualitative review. *International Journal of Geriatric Psychiatry, 22*, 393-400.

Moore, B. (1984). *Privacy: Studies in social and cultural history*. New York: Sharpe Inc.

Moran, D. (2000). *Introduction to Phenomenology*. London: Routledge.

Morse, J. M., Beres, M.A., Spiers, J.A., Mayan, M., & Olson, K. (2003). Identifying signals of suffering by linking verbal and facial cues. *Qualitative Health Research, 13,* 1063-1077.

Morse, J., & Penrod, J. (1999). Linking concepts of enduring, uncertainty, suffering and hope. *Image: Journal of Nursing Scholarship, 31*(2), 145-150.

Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks: Sage.

Munoz, M., & Estevez, R. (2005). Reports of memory functioning by patients with chronic pain. *Clinical Journal of Pain, 21*(4), 287-291.

Murphy, R. F. (1984). Social distance and the veil. In F.Schoeman (Ed.), *Philosophical dimensions of privacy: An anthology*. Cambridge: Cambridge University Press.

Musshauser, D., Bader, A., Wildt, B., & Hochlietner, M. (2006). The impact of sociodemographic factors vs gender roles on female hospital workers' health: Do we need to shift emphasis? *Journal of Occupational Health, 48,* 383-391.

Nelson, W., Pomerantz, A., Howard, K., & Bushy, A. (2007). A proposed rural health care ethics agenda. *Journal of Medical Ethics (online), 33,* 136-139.

Newton-John, T. R., & Williams, A. C. (2006). Chronic pain couples: Perceived marital interactions and pain behaviours. *Pain, 123*, 53-63.

Nicholas, M. K. (2007). The pain self-efficacy questionnaire: Taking pain into account. *European Journal of Pain (Online), 11*, 153-163.

Nicholas, M. K. (2008). Pain management in musculoskeletal conditions. *Best Practice & Research Clinical Rheumatology, 22*(3), 451-470.

Nnoaham, K. E., & Kumbang, J. (2008). Transcutaneous electrical nerve stimulation (TENS) for chronic pain (Review). *The Cochrane Collaboration.*(3), 1-11.

O'Brien, L. (2003). Chapter 13: Phenomenology. In D. E. Z. Schneider, G. LoBiondo-Wood & J. Haber (Ed.), *Nursing Research: Methods, Critical Appraisal and Utilisation* (2nd ed.). Sydney: Mosby.

O'Loughlin, A. (1999). On living with chronic pain. In I. Madjar & J. Walton (Eds.), *Nursing and the experience of illness*. St Leonards, NSW: Allen & Unwin.

Osborne, M., & Smith, J. A. (2006). Living with a body separate from the self. The experience of the body in chronic benign low back pain: an interpretive phenomenological analysis. *Scandanavian Journal of Caring Sciences*, *20*, 216-220.

Pao-Feng, T. (2004). Predictors of distress and depression in elders with arthritic pain. *Journal of Advanced Nursing, 51*(2), 158-165.

Parsons, S., Harding, G., Breen, A., Foster, N., Pincus, T., Vogel, S., et al. (2007). The influence of patients' and primary care practitioners' beliefs and expectations about chronic musculoskeletal pain on the process of care. A systematic review of qualitative studies. *Clinical Journal of Pain, 23*(1), 91-98.

Pashen, D., Grant, M., Veitch, C., Sheehan, M., & Chalmers, E. (2002). Life stages, health and Disease in Rural Australia, Chapter 6. In D. Wilkinson & I. Blue (Eds.), *The New Rural Health*. Melbourne: Oxford University Press.

Paterson, B. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship, 33*(1), 21-26.

Peach, H., & Bath, N. (1999). Cardiovascular risk in a rural area. *Australian Journal of Rural Health, 7,* 23-27.

Peat, G., Thomas, L. H., J., & Croft, P. (2004). Social networks and pain interference with daily activities in middle and old age. *Pain, 112*(3), 397-405.

Petrie, K. J., Frampton, T., Large, R. G., Moss-Morris, R., Johnson, M., & Meechan, G. (2005). What do patients expect from their first visit to a pain clinic? *Clinical Journal of Pain, 21*(4), 297-301.

Phillips, C., & McLeroy, K. (2004). Health in rural America: Remembering the importance of place. *American Journal of Public Health, 94*(10), 1661-1663.

Plager, K. A. (1994). Hermeneutic Phenomenology: a methodology for family health and health promotion in nursing. In P. Benner (Ed.), *Interpretive phenomenology: embodiment, caring and ethics in health and illness* (pp. 65-83). Thousand Oaks, CA: Sage.

Pols, R. G., & Battersby, M. W. (2008). Coordinated care in the management of patients with unexplained physical symptoms: depression is the key issue. *Medical Journal of Australia, 188*(12), S133-S137.

Polt, R. (1999). *Heidegger: an Introduction*. Ithaca, NY: Cornell University Press.

Porth, C. M. (2005). *Pathophysiology. Concepts of altered health states.* (7 ed.). Philadelphia: Lippincott Williams & Wilkins.

Preston, G. (2001). *Mapping the Differences: An Examination of Hospitalisation of Remote, Rural and Metropolitan Australians.* Paper presented at the 5th National Rural Health Conference.

Price, C. I. M., Curless, R. H., & Rodgers, H. (1999). Can stroke patients use Visual Analogue Scales? *Stroke, 30,* 1357-1361.

Proulx, E. A. (2006). Brokeback Mountain. In E. A. Proulx (Ed.), *Close Range*. London: Harper Perennial.

Raheim, M., & Haland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life. *Qualitative Health Research, 16*, 741-761.

Rey, R. (1995). *The history of pain* (J. A. C. Louise Wallace, S.W. Cadden, Trans.). Cambridge, Massachusetts: Harvard University Press.

Rhodes, A. M. (2006). Protecting the right to privacy and confidentiality in information. In M. Craft-Rosenberg & M. J. Krajicek (Eds.), *Nursing excellence for children and families*. New York: Springer.

Richardson, C., Adams, N., & Poole, H. (2001). Chronic pain and coping: a proposed role for nurses and nursing models. *Journal of Advanced Nursing, 34*(5), 659-667.

Richardson, J. C., Ong, B. N., & Sim, J. (2006). Is chronic widespread pain biographically disruptive? *Social Science & Medicine, 63*, 1573-1585.

Rippentrop, A. E. (2005). A review of the role of religion and spirituality in chronic pain populations. *Rehabilitation Psychology, 50*(3), 278-284.

Risdon, A., Eccleston, C., Crombez, G., & McCracken, L. (2003a). How can we learn to live with pain? A Q-methodological analysis of the diverse understanding of acceptance of chronic pain. *Social Science & Medicine, 59*, 375-386.

Rodgers, B.L. & Cowles, K.V. (2008). A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing 25*(5), 1048-1053.

Rolley, J., Chang, E., & Johnson, A. (2008). Spirituality and the nurse: Engaging in human suffering, hope and meaning. In E. Chang & A. Johnson (Eds.), *Chronic illness and disability: Principles for nursing practice*. Sydney: Churchill Livingstone.

Romano, J., Turner, J., Jensen, M., Friedman, L. S., Bulcroft, R. A., Hops, H., et al. (1995). Chronic pain patient-spouse behavioural interactions predict patient disability. *Pain, 63*, 353 - 360.

Ross, M., & Crook, J. (1998). Elderly recipients of home nursing services: pain, disability and functional competence. *Journal of Advanced Nursing, 27*(6), 1117 -1126.

Samwel, H. J. A., Evers, A. W. M., Crul, B. J. P., & Kraaimaat, F. W. (2006). The role of helplessness, fear of pain, and passive pain coping in chronic pain patients. *Clinical Journal of Pain, 22*(3), 245-251.

Sartore, G.-M., Kelly, B., Stain, H., Albrecht, G., & Higginbotham, N. (2008). Control, uncertainty, and expectations for the future: A qualitative study of the impact of drought on a rural Australian Community. *Rural and Remote Health, 8*, 950-964.

Scarry, E. (1985). *The body in pain: The making and unmaking of the world*. New York: Oxford University Press.

Schaffer, S. D., & Yucha, C. B. (2004). Relaxation and pain management. *American Journal of Nursing, 104*(8), 75-82.

Schoeman, F. D. (1984). *Philosophical dimensions of privacy: An anthology*. Cambridge: Cambridge University Press.

Seligman, M. (2002). *Authentic happiness: Using the new positive psychology to realize your potential for lasting fulfillment.* Sydney: Random House, Australia.

Sherman, N. (2005). *Stoic warriors. The ancient philosophy behind the military mind*. Oxford: Oxford University Press.

Siddall, P. J., & Cousins, M. J. (2004). Persistent pain as a disease entity: Implications for clinical management. *Anaesthesia & Analgesia, 99*, 510-520.

Silverman, H. J. (1987). *Inscriptions: Between Phenomenology and Structuralism*. New York: Routledge & Kegan Paul.

Sjostrom, B., & Dahlgren, L. O. (2002). Applying phenomenology in nursing research. *Journal of Advanced Nursing, 40*(3), 339-345.

Smith, A. A., & Friedemann, M. L. (1999). Perceived family dynamics of persons with chronic pain. *Journal of Advanced Nursing, 30*(3), 543-551.

Smith, J. D. (2004). *Australia's Rural and Remote Health - A Social Justice Perspective*. Croydon, Vic.: Tertiary Press.

Sofaer, B., Moore, A., Holloway, I., Lamberty, J., Thorp, T., & O'Dwyer, J. (2005). Chronic pain as perceived by older people: a qualitative study. *Age and Ageing, 34*, 462-466.

Sofaer-Bennett, B., Holloway, I., Moore, A., Lamberty, J., Thorp, T., & O'Dwyer, J. (2007). Perseverance by older people in their management of chronic pain: A qualitative study. *Pain Medicine, 8*(3), 271-280.

Sorajjakool, S., Thompson, K. M., Aveling, L., & Earl, A. (2006). Chronic pain, meaning, and spirituality: A qualitative study of the healing process in relation to the role of meaning and spirituality. *The Journal of Pastoral Care & Counseling, 60*(4), 369-378.

Spierenburg, P. C. (1991). *The broken spell: A cultural and anthropological history of preindustrial Europe*. New Brunswick, NY: Rutgers University Press.

Spillers, R. L., Wellisch, D. K., Kim, Y., Matthews, A., & Baker, F. (2008). Family caregivers and guilt in the context of cancer care. *Psychosomatics, 49*(6), 511-520.

Stake, R. (2000). Case Studies. In N. D. Y. Lincoln (Ed.), *Handbook of Qualitative Research* (2nd ed.). Thousand Oaks, Ca.: Sage.

Stamm, B. H., Metrick, S. L., Kenkel, M. B., Davenport, J. A., Davenport, J., Hudnall, A. C., et al. (2003). A tough row to hoe: Policy and practice implications of caregiving in rural America. In B. H. Stamm (Ed.), *Rural behavioural healthcare: an interdisciplinary guide*. Washington, D.C.: American Psychological Association Books.

Stevenson, M. (1936/1984). Footprints in the Sand. Retrieved December 29, 2008, from http://www.footprints-inthe-sand.com/index.php?page=Poem/Poem.php

Stokowski, L. A. (2008). The inhospitable hospital: No peace, no quiet. *Medscape CME* Retrieved 12.06.08, 2008, from http://www.medscape.com/viewprogram14587_pnt

Strand, E. B., Zautra, A. J., Thoreson, M., Odegard, S., Uhlig, T., & Finset, A. (2006). Positive affect as a factor of resilience in the pain - negative affect relationship in patients with rheumatoid arthritis. *Journal of Psychosomatic Research, 60*(5), 477-484.

Strandmark, M. (2004). Ill health is powerlessness: a phenomenological study about worthlessness, limitations and suffering. *Scandanavian Journal of Caring Sciences, 18*, 135-144.

Strasser, R. (2000). Rural Health Research: Have We Turned the Corner? *Australian Journal of Rural Health, 8*, 249-253.

Streubert, H. J., & Carpenter, D. R. (1999). *Qualitative Research in Nursing - Advancing the Humanistic Imperative*. Philadelphia: Lippincott.

Sullivan, M. (2004). Exaggerated pain behaviour: By what standard? *Clinical Journal of Pain, 20*(6), 433-439.

Taylor, D. R., Webster, L. R., Chun, S. Y., Reinking, J., Stegnam, M., Shoemaker, S., et al. (2007). Impact of breakthrough pain on Quality of Life in patients with chronic, non-cancer pain: patient perceptions and effect of treatment with oral transmucosal Fentanyl Citrate. *Pain Medicine, 8*(3), 281-288.

Terman, G. W., & Bonica, J. (2001). Chapter 4: Spinal mechanisms and their modulation. In S. H. B. J. D. Loeser, C.R Chapman & D.C. Turk (Ed.), *Bonica's Management of pain. (2001)* (3rd ed.): Philadelphia: Lippincott Williams & Wilkins.

Thomas, S. P. (2000). A phenomenological study of chronic pain. *Western Journal of Nursing Research, 22*(6), 683 - 705.

Thomas, S. P., & Johnson, M. (2000). A phenomenological study of chronic pain. *Western Journal of Nursing Research, 22*, 683-705.

Tipples, J. (2008). Negative emotionality influences the effects of emotion on time perception. *Emotion, 8*(1), 127-131.

Todres, L., & Galvin, K. (2008). Embodied interpretation: a novel way of evocatively re-presenting meanings in phenomenological research. *Qualitative Research, 8*, 568-583.

Tollefson, J., Piggott, K., & Fitzgerald, M. (2008). Chapter 8. Chronic pain. In E. C. A. Johnson (Ed.), *Chronic illness and disability: Principles for nursing practice.* Sydney: Elsevier.

Tortora, G. J., & Grabowski, S. R. (2003). *Principles of anatomy and physiology.* (10 ed.). New York: John Wiley & Sons.

Tsai, P. F. (2005). Predictors of distress and depression in elders with arthritic pain. *Journal of Advanced Nursing, 51*(2), 158-165.

van Manen, M. (1990). *Researching Lived Experience: Human science for an action sensitive pedagogy*. London, Canada: The Althouse Press.

van Manen, M. (1997). *Human Science: Researching the Lived Experience*. London, Ontario: Althouse Press.

van Manen, M. (1999). The pathic nature of inquiry and nursing. In I. Madjar & J. Walton (Eds.), *Nursing and the experience of illness: Phenomenology in practice*. Sydney, Australia: Allen & Unwin.

van Manen, M. (2002). Writing phenomenology. In M. van Manen (Ed.), *Writing in the Dark: phenomenological studies in interpretive inquiry*. London, Ontario: Althouse Press.

van Manen, M., & Levering, B. (1996). *Childhood's secrets - intimacy, privacy and the self reconsidered*. New York: Teacher's College Press.

Vasalou, S. (2008). Personal identity as a task. *Inquiry, 51*(3), 288-311.

Vlaeyen, J. W. S., & Morley, S. (2005). Cognitive-behavioural treatments for chronic pain. What works for whom? *Clinical Journal of Pain, 21*(1), 1-8.

Von Korff, M., Dworkin, S. F., Le Resche, L., & Kruger, A. (1988). An epidemiological comparison of pain complaints. *Pain, 32*, 179 - 183.

Wachholtz, M. J., Pearce, M. J., & Koenig, H. (2007). Exploring the relationship between spirituality, coping and pain. *Journal of Behavioural Medicine, 30*, 311-318.

Wade, J. B., & Hart, R. P. (2002). Attention and the stages of pain processing. *Pain Medicine., 3*(1), 30-38.

Wagonfeld, M. O. (2002). *Portrait of Rural and Frontier America.* Washington: American Psychological Association.

Wagstaff, G. F., & Rowledge, A. M. (1995). Stoicism: Its relation to gender, attitudes toward poverty and reactions to emotive material. *The Journal of Social Psychology (ejournal), 135*(2), 181-184.

Wakerman, J., & Humphreys, J. (2008). Rural and remote health - definitions, policy and priorities. In S.-T. Liaw & S. Kilpatrick (Eds.), *A textbook of Australian rural health*. Canberra, ACT: Australian Rural Health Education Network.

Watkins, K., Shifren, K., Park, D., & Morrell, R. (1999). Age, pain and coping with rheumatoid arthritis. *Pain, 82*, 217-228.

Weiner, C., & Dodd, M. (2001). Coping amid uncertainty: An illness trajectory perspective. *Scholarly Inquiry for Nursing Practice, 7*, 17-31.

Weissman, D. E., & Haddox, J. D. (1989). Opioid pseudoaddiction: an iatrogenic syndrome. *Pain, 36*, 363-366.

Werner, A., Steihaug, S., & Malterud, K. (2003). Encountering the continuing challenges for women with chronic pain: Recovery through recognition. *Qualitative Health Research, 13*(4), 491-509.

Williams, L. J., Jacka, F. N., Pasco, J. A., Dodd, S., & Berk, M. (2006). Depression and pain: An overview. *Acta Neuropsychiatrica*, *18*, 79-87.

Yong, H. H. (2006). Can attitudes of stoicism and cautiousness explain observed age-related variation of levels of self-rated pain, mood disturbance and funtional interference in chronic pain patients? *European Journal of Pain (Online), 10,* 399-207.

Yong, H. H., Gibson, S. J., de L.Horne, D. J., & Helme, R. D. (2001). Development of a pain attitudes questionnaire to assess stoicism and cautiousness for possible age differences. *The Journals of Gerontology*, *56B*(5), 279-284.

Young, J. B. (1978). Introduction: A look at privacy. In J. B. Young (Ed.), *Privacy*. New York: John Wiley & Sons.

Zautra, A. J., Johnson, L. M., & Davis, M. C. (2005). Positive affect as a source of resilience for women in chronic pain. *Journal of Consulting and Clinical Psychology*, *73*(2), 212-220.

Appendices

ADMINISTRATIVE APPENDICES HAVE BEEN REMOVED