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DOCTOR OF PHILOSOPHY

ON..... 9 December 2003

Sec. Research Graduate School Committee

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AUTHENTICATING & REPAIRING PERSONHOOD
The experiences of opioid dependent back pain sufferers

Submitted by

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ADDENDUM

1. The candidate noted and acknowledged concerns expressed regarding the use of the word 'recommendation'. After deliberating over these concerns with my Supervisor, the author concurs and therefore readers are asked to substitute 'recommendations' with the words **'insights and implications'**.

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KEY TO EDITED TRANSCRIPTS

- [] researchers' comments, additions, to make the context and/or meaning clear
- (...) words, phrases or sections of the interview deleted
- Incomplete sentence without editing.
- I means the researcher (interviewer)
- P means the participant (interviewee)
- Ffg Female focus group participant
- Mfg Male focus group participant
- Ffg Family focus group participant
- Nfg Nurses focus group participant
- S Survey respondent
- Int. Interview
- M. Memo
- FN Field Note

Italics are used throughout the thesis when presenting exemplars from focus group discussion, participant interviews, survey responses, field notes and memoing.

ABSTRACT

This thesis explores the processes that people with chronic non-malignant back pain (CNMBP) which is being managed with long term opioid therapy (LTOT) use to regain an authentic personhood and meaningful life. Symbolic interactionism (Blumer 1969) and grounded theory (Strauss & Corbin 1998) provided the methodological framework for this study. Whilst LTOT is now generally considered to be a legitimate and effective treatment for some CNMBP in clinical practice it remains controversial, especially among nurses. This opioiphobia can lead to stigmatising and negative stereotyping of CNMBP sufferers treated with LTOT as malingerers and drug addicts, which profoundly damages their personhood. Furthermore, whilst addiction remains an issue for many nurses and some family members, it was not an issue for sufferers.

Findings from this study indicate that the core problem for CNMBP sufferers treated with LTOT to be fragility. Fragility was caused by being discredited, 'not being believed' (in vivo code), 'losing me' (in vivo code), undergoing losses/changes and experiencing compromised health. Fragility is characterised by vulnerability. Those individuals who find hope move from feeling fragile through the authenticating and repairing personhood cycle (core process). This process was developed from 'loss of self', 'legitimising pain, LTOT and self' and 'struggling for a valued life'. This cycle comprises of three phases: reconciling losses, self-determining normalcy and striving for normalcy. Reconciling losses is a personal journey of acknowledging, re-evaluating, grieving and receptivity towards CNMBP treated with LTOT in order to move on. The losses which sufferers found the most difficult to reconcile were 'losing me', loss of work and loss of sexual desire and function. Self-determining normalcy is a self-initiated

exploration of what constitutes their normalcy. It is a process of taking responsibility, setting goals and seeking resources to support their choices and decisions with respect to achieving goals and constructing an honoured personhood and meaningful life. Striving for normalcy sees the sufferer attempting to construct and maintain a new meaningful life as close to their pre-morbid life as possible in order to reduce the stigma and negative stereotyping and thus their fragility. This process may include passively resigning.

Whilst the authenticating and repairing personhood process is presented in linear phases, in reality it is cyclical, dynamic and convoluted. Given the chronicity of their condition, it represents a life long journey with no final destination. The degree of engagement in the authenticating and repairing process is determined by sustained hope, the level of pain control, sense of fragility and by the individual's will and capacity to do so. Those individuals, who cannot find hope, passively resign themselves to a life controlled by pain. Authenticating and repairing actions permit activity toward reconstructing a robust personhood and a meaningful life where the individual, not their pain, is in control. The findings of this study support the need for a coordinated multidisciplinary approach to CNMBP management with the sufferer and general practitioner being equal members of the team. A number of recommendations relating to nursing practice and education, the general practitioners role in LTOT, health care policy and workers' compensation and traffic accident insurers are made.

Monash University

GENERAL DECLARATION

Statement of Authorship

Except where reference is made to the text of the thesis, this thesis
Contains no material published elsewhere or extracted in whole or in
part from a thesis by which I have qualified for or been awarded
another degree or diploma.

No other person's work has been used without due acknowledgment
in the main text of the thesis.

This thesis has not been submitted for the award of any degree or
diploma in any other tertiary institution.

Signature

Date

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INTRODUCTION

This thesis details a study that took place predominantly in the metropolitan areas of Melbourne, with additional participants from various States and Territories throughout Australia during 1996/2001. A framework is presented for use by consumers who wish to successfully manage the consequences of their chronic non-malignant back pain (CNMBP) and treatment with long term opioid therapy (LTOT). This framework may also be helpful for health care practitioners who recognize the value of working in partnership with CNMBP clients receiving LTOT to manage their pain. Symbolic interactionism (Blumer 1969) provided the theoretical underpinnings and grounded theory (Strauss & Corbin 1998) methodological procedures for the study.

The study focuses on clients who have experienced severe intractable back pain and have been prescribed opioids to manage their situation for longer than six months. People with malignant intractable back pain are not a feature of this study.

RESEARCH QUESTION

How do CNMBP sufferers treated with LTOT manage the consequences of their pain and treatment?

AIMS AND SCOPE OF THE STUDY

This study aims to explicate the process clients' use when coping with CNMBP treated with LTOT. Specifically this study aims to:

- ascertain the impact on personhood of CNMBP treated with LTO therapy as perceived by clients;
- determine the structural and interactional factors (specific context and conditions) that contribute to positive and negative consequences for clients in respect of managing their situation;

- develop a substantive theory/framework about the way clients manage the consequences of suffering CNMBP treated with LTOT.

This study does not address the issues relating to whether opioids should be made available to clients with severe intractable CNMBP; neither does it attempt to evaluate the legitimacy of the participants' pain and treatment. Thus the study is not exploring why CNMBP clients take opioids to manage their pain but focuses on how consumers manage the long-term consequences related to CNMBP treated with LTOT.

RESEARCH APPROACH

There were a number of criteria used to substantiate the selected methodological approach used in this study. Given the purpose of this enquiry was to elicit knowledge of clients' perceptions, understanding and behavior it demanded a method of enquiry with the ability to explore and conceptually explain personal experiences of a particularly vulnerable group of clients within their individual social context. Such an enquiry is corroborated philosophically and epistemologically by symbolic interactionism (Mead 1934; Blumer 1969) and methodologically by grounded theory (Glasser & Strauss 1969, Fiveash 2000). In addition, because the researcher, a nurse, herself suffers CNMBP that is treated with LTO therapy this issue needed to be acknowledged and dealt with 'up front' in the study. Grounded theory requires the researcher to "*intentionally become immersed in the world of the research subjects*" (Bowers 1988:43) for the purpose of discovering what that world is like, how it is constructed and experienced (Blumer 1969; Schatzman & Strauss 1973; Chenitz & Swanson 1986). Thus electing to use grounded theory the study permitted me to wear two 'hats', one of nurse researcher and another as a member of society who also suffers severe CNMBP that is treated with LTOT. This was a constant challenge and struggle throughout the study.

Grounded theory's philosophic and theoretical underpinnings emanate from symbolic interactionism. George Herbert Mead (1934) and Herbert Blumer (1969) primarily laid down the intellectual foundations of symbolic interactionism. It offered an alternative view of social life put forward by the grand functionalist theories associated with Talcot Parsons and Robert Merton that dominated sociological thought and enquiry during the late 19th and mid 20th century. Herbert Mead and Blumer offered an alternative view of social life where society is a fluid and dynamic process of action and reciprocating interactions (Kendall 1999). It is a theory of social interaction underpinned by three basic premises (Blumer 1969). The first being that individuals act towards things (physical and non-physical) on the basis of the meaning they assign to them. The second premise is that the meaning of such things emerges from the social interactions engaged in between individuals. The final premise is that the meanings assigned to these shared symbols are continually modified through an interpretive process used by the individual dealing with the things encountered in his/her world. This process includes not only giving meaning to self, to ones social world, and how others perceive another but also encompasses a prediction and determination of how self and others will act (Bowers 1988). Understanding the actions and behaviors of individuals or groups can only be achieved from the stance of the social context from which they developed (Bowers 1988). Thus, symbolic interactionism endorses enquiry of the natural setting and individuals in regard to their own understanding of their social and historical context. Thus, the processes encompassed in symbolic interactionism permit the researcher to discover CNMBP clients' knowledge of their personhood and life care within their social context and social interactions. Grounded theory as a transactional system corroborates well with symbolic interactionism being based on the assumption the way phenomena are expressed is through

resolute and related action/interactions that are embedded in sets of conditions which are socially constructed, historically placed and valued based (Strauss & Corbin 1998). Grounded theory aims to discover what the participants' world is like and how it is constructed and experienced (Strauss & Corbin 1998; Schatzman & Strauss 1973; Chenitz & Swanson 1986).

This study aims to generate a theory from the data collected through interviews, focus groups, participant observation, emails, and a postal survey undertaken during the study in accordance with the ethical policies and procedures of the university's Standing Committee on Ethics in Research on Humans. Grounded theory is applicable to enquiry into client related phenomena and the underlying processes involved including causal conditions, context, intervening conditions, action/interactions and consequences (Strauss & Corbin 1998). Thus the type of knowledge that will be explored includes the nature of clients' experiences of suffering CNMBP that are treated with LTOT. In addition, the processes used by clients to address the positive and negative consequences of such a condition and treatment. These include the conditions under which they commenced LTOT; the impact of CMMBP treated with LTOT on their personhood and life, and the processes used by clients to maintain a valued self and life. However, the research process of Grounded theory differs from some other research methods of enquiry in that specific research question(s) and hypotheses emanate from the data (Bowers 1998). In order to give the study a starting point a preliminary problem statement follows:

PROBLEM STATEMENT

There have been considerable advances (Caraceni & Portenoy 1999, Sessle 2000) in the management of pain, especially in relation to the treatment of acute, cancer and arthritic pain. However, severe CNMBP in the most part remained neglected and maligned by society,

health care practitioners and policy makers. Sufferers can not only be ignored by health care practitioners but can suffer at their hands (Fagerhaugh & Strauss 1977). The suffering can be experienced on both a physical level, as a consequence of treatment and/or on an emotional level when the practitioners fail to validate their pain, LTOT and personhood. Furthermore, some patients with severe CNMBP suffer not because their pain is untreatable but because many health care practitioners are opioiphobic (Turk 1996). Many research studies (Cole 1995, Turk et al 1994, Coniam 1989, Turk & Brody 1991) addressing the under-treatment of pain with opioids identify peer pressure, lack of knowledge about opioids, actual and perceived regulatory pressures as contributing to the problem. Current chronic pain services tend to focus on cancer, arthritic and non-specific chronic back pain. For the latter the focus is on reducing the number of CNMBP patients becoming permanently disabled and dependent on long-term opioids using cognitive behavioural methods for which they should be commended (Turk & Okifuji 2001). However, such programs tend to primarily focus on cognitive-behavioural approaches to pain management and often request patients come off all medication before they are accepted into the program. Unfortunately, such programs tend not to address the plight of those CNMBP sufferers for whom the current health care system including numerous 'back programs'¹ has already failed. For those selective groups of severe CNMBP clients which LTOT, combined with other alternative and medical pain management techniques, offer the only hope of a tolerable and valued life. Furthermore, CNBMP clients receiving LTOT are likely to suffer further discrimination in the health care system because they are often considered weak and less deserving (Cole 1995). This is often complicated by CNMBP clients seeking compensation for their injuries, pain and suffering which results in further stigmatization

¹ 'Back programs' refer to a formally, accredited multi-disciplinary rehabilitation programs designed to help people overcome acute back injuries. They are usually intense, in-patient programs with long term outpatient follow-up.

related to accusations of malingering for monetary gain (Fagerhaugh & Strauss 1977).

Whilst LTOT is well accepted for the management of cancer pain, its use in the management of non-malignant pain remains controversial (Savage 1996, Krames 1993, Portenoy & Foley 1986). Opioids were believed to actually contribute to the severity of pain felt by the CNMBP client and bring about behavioral dysfunction e.g. drug seeking, drug abuse, psychological addiction (Fishbain et al 1991, Halpern & Robinson 1985, Taylor et al 1980). However, it is now recognized that LTOT can be beneficial in the treatment of some patients with severe, refractory CNMBP caused by a primary lesion or dysfunction in the nervous system (Moulin et al 1996; Schofferman 1993; Jaddad et al 1992; Turk & Brody 1992). In response to the increasing use of LTO for chronic non-malignant pain in Australia (Bell 1997), the Australian Pain Society in 1996 began to develop guidelines for the management of opioid maintenance therapy for non-malignant pain (Graziotti & Goucke 1997/2003). The guidelines are an attempt to minimize addiction and drug abuse in those patients on LTOT (Graziotti & Goucke 1997/2003). Regardless, of the increasing acceptance that, for certain conditions and individuals, opioids do have a role in CNMBP management many practitioners, including nurses, remain opioiphobic denying some patients this option as part of their pain management regime.

There is general agreement amongst health care professionals and clients that CNMBP management is a multidisciplinary endeavor. However, at present the Australian Council of Health Standards (ACHS) has only five identifiable pain clinics on their data base, with only two of them being fully accredited multidisciplinary pain clinics. However, if a hospital is accredited and they have a designated pain unit, it automatically gets accredited along with the hospital. Thus, there may be other accredited pain units hidden in the ACHS data

base. Today most CNMBP clients are treated by individual pain specialists (primarily trained in areas such as anesthesiology, psychiatry and rehabilitation medicine), tending to be located in the private sector with many instances of only having ad hoc access to other health care practitioners. The current situation, with regards to pain management services, poses access problems for clients living in rural areas and significant financial problems for those CNMBP clients whose care is not covered by a third party i.e. Workcover, Traffic Accident Commission.

Nursing's role in chronic pain management is generally ill defined, posing a challenge for those working in isolated 'pain units' without a coherent multidisciplinary team. Nursing is a high-risk profession in relation to back injuries and thus one might expect nurses to be more empathetic and understanding towards CNMBP sufferers than other practitioners. However, their attitudes towards CNMBP clients, many of whom are injured nurses, can at times be indifferent, patronizing and/or judgmental (Fagerhaugh & Strauss 1977, Gardner 2001 [Appendix 1]).

DEFINITIONS

For the purpose of this study the following terms are used:

CNMBP. includes spinal (skull→coccyx) and radicular pain that persists for longer than three months and which is not related to the presence of malignant disease (Merskey & Bogduk 1994). Although CNMBP may be due to the persistence of the original injury/disease, In many cases new pathology, including iatrogenic, develops resulting in chronicity (Waddell 1996). Such pathology may involve discs, nerve roots, facets joints, arachnoid mata, neuromuscular and vascular changes (Schofferman 1993; Turk & Brody 1992). Furthermore, the absence of detectable spinal pathology does not

necessarily mean the pain is psychosomatic, as current research suggests some chronic pain may be related to morphological cerebral changes (Derbyshire 1994).

CNMBP client: is a person who has suffered severe, intractable non-malignant spinal and referred pain from the spine for more than three months. The term client is used in preference to 'patient' because the term infers passivity rather a paying consumer (either directly or indirectly) for health care services.

Opioids: a term used to refer to a number of synthetic or natural analogues of opium alkaloids derived from *Papaveretum somniferum* (the opium poppy) that have in common the capacity to bind specifically and to produce actions at specific receptors (e.g. mu, delta and kappa) (Robinson 2000; Dickenson 1996). They are separate in terms of structure and location and function to produce analgesia (Robinson 2000; Dickenson 1996). Opioids have actions at a number of sites in the central and peripheral nervous systems, which contribute to both analgesia and unwanted side effects (Dickenson 1996). Initially the WHO arbitrarily categorized opioid analgesics as either 'weak' or 'strong' (Hanks 1996). Today the nomenclature relates to its pharmacological basis and categorized into Level I opioids for mild-to-moderate pain (e.g. codeine), Level II opioids for moderate-to-severe (e.g. morphine) and Level III opioids which includes Hydromorphone (Laval 2002). These preparations are administered through a variety of routes i.e. oral, rectal, injectable, epidural, intrathecal, intravenous via Hickman's catheter and via trans-dermal patches. Until recently it was believed that there was no end-organ pathology from opioid analgesia (versus liver and renal effects Non-steroid anti-inflammatory drugs (NSIADS). Opioids do produce adverse effects as respiratory depression, constipation, insomnia, dysphoria and potential for neuropsychological impairment

(Cole 1995). While these side effects of opioids are generally well known among medical practitioners and nurses, the adverse effects of LTOT are not so well documented. Pituitary dysfunction's such as hypogonadism and metabolic disorders including diabetes and thyroid dysfunction have been reported in clients receiving LTOT (Hockings et al 2001). It has been known for two decades that intrathecal morphine can produce a syndrome characterized by amenorrhoea, polyarthralgia and spontaneous lactation (Lamb & Hosobuchi, 1990). Other problems include development of tolerance, psychological addiction (Bell 1997; Bramley-Moore & Wodak 1998; Portenoy 1996; Molloy 1997; Gourlay & Cherry 1991), although the real risk of psychological addiction when clients take opioids for legitimate pain is thought to be approximately 1:1000 (Cole 1995; Fishbain et al 1992).

Addiction: refers to a psychological and behavioral syndrome characterized by a) a strong desire for the drug and obsession regarding accessing further supplies; b) compulsive drug use e.g. unauthorized self medication including escalating dose; and/or c) evidence of one or more aberrant behaviors, including manipulating physicians and prescriptions to obtain extra drugs, drug hoarding and selling (Portenoy 1990).

Pain management: refers to the tasks and strategies undertaken by the client and health care practitioners to alter the experience of pain in order for the client to live a valued life.

LTOT: refers to a legally prescribed opioid treatment regime for the purpose of relieving chronic pain, administered for a period of more than six months.

Personhood: encompasses ones physical, psychological, functional, social and spiritual identities, culture, interests, values, beliefs that

have developed, changed and shaped through years of living (Buzzell et al 1993). It represents the uniqueness of each individual's past, present and future and the mutual impact on context (Buzzell et al 1993:14).

Life Care: refers to the long-term health care required to give CNMBP treated with LTOT a valued life. The term is used in preference to long term care, which denotes dependence and institutional care.

Concepts: "conceptual labels placed on discrete happenings, events and other instances of phenomena" (Strauss & Corbin 1990:61). In grounded theory they are linked together to form categories and sub-categories and as such underpin any grounded theory.

Core category: emerges for the conceptual analysis of the data as the central phenomenon around which all other categories are integrated to form theory (Strauss & Corbin 1990).

Constant comparative method: another term often used to denote grounded theory. It refers to the continual process of the constant interplay between proposing, checking and comparing data of similar and opposing concepts. Making comparisons is an essential technique for both discovering and developing categories and identifying links between them. This process does not proceed independently but concurrently with other analytic processes (Chamberlain, 1999). According to Glaser & Strauss 1967:105) the constant comparative method has four phases: 1) comparing incidents applicable to each category; 2) integrating categories and their properties; 3) delimiting the theory; and 4) writing the theory.

In vivo codes: participants own words that hallmark important data that is transformed analytically into concepts (Strauss & Corbin 1998).

Theory: is schematically identifying abstract phenomena, proposing the nature of propositions and plausible relationships between concepts. A grounded theory is one that is inductively derived from the phenomenon it describes. It is discovered, developed and provisionally verified through systematic data collection and analysis relevant to that phenomenon (Miller & Fredericks 1999, Strauss & Corbin 1998).

Memos: a written record of data analysis related to the discovery of theory.

Normalcy: is concerned with a sense of control, accommodating the illness experience into everyday living, and where possible contributing to the welfare of others.

Theoretical notes: summarizing memos which include "the products of inductive or deductive thinking about relevant and potentially relevant categories, their properties, dimensions, relationships, variations and processes" (Strauss & Corbin 1990:197).

Theoretical sampling: refers to a style of data collection whereby data are collected according to the developing theory and the concurrent comparison between samples. It aims to identify categories and their properties, and to propose the interrelationships into a theory (Glaser & Strauss 1967).

Theoretical saturation: the point in time when further analysis fails to identify anything new or important regarding categories; all the paradigm elements are accounted for and the relationships between categories are strongly established and validated (Strauss 1967, Strauss & Corbin 1990/1998).

Theoretical sensitivity: refers to an individual personal trait of the researcher, who demonstrates a heightened awareness of the subtleties of meaning of data (Strauss & Corbin 1990/98).

STIMULUS FOR THE STUDY

The idea for this study arose from my own personal experience as a sufferer of intractable neuropathic pain treated with LTOT. Like many of the research subjects my CNMBP resulted from a workplace injury and after exploring every treatment modality, including both conservative and alternative pain management routes, chose LTOT administered through an implanted intrathecal Synchromed computerized drug pump as one of my main pain management strategies. The use of opioids in the management of chronic non-malignant pain still remains controversial and I was ill prepared for dealing with the situations when this controversy was played out in clinical practice and in the community. Thus, one had to develop strategies not only to manage pain but also to cope with the affront on ones' personhood resulting from these situations. After observing for eight years how other CNMBP people treated with LTOT coped with their pain, use of opioids and interactions with health care practitioners which, like my own, were often negative, I was interested in discovering the processes that underpin the successful and unsuccessful management of these situations.

Another important issue that has influenced my thinking regarding CNMBP treated with LTOT is that these clients are often cared for in acute care facilities even though their condition is no longer amenable to acute medical/surgical treatment. Many practitioners and administrators have not thought through the profound differences in philosophies and goals between acute, restorative care and that of long term maintenance treatment (life care)(Buzzell 1989). Acute care is often characterized by dominant/submissive

relationships which can lead to learned helplessness, distinguished by motivational, cognitive and emotional deficits (Slimmer 1987). In such environments I have observed some CNMBP clients treated with opioids display such behaviors whilst others did not, and I was curious to learn the underlying processes and interactions that produced the different responses to the environment within which they were cared for.

PURPOSE, SIGNIFICANCE AND JUSTIFICATION OF THE STUDY

The purpose of this investigation is to find out how CNMBP clients treated with LTOT manage the consequences of their pain and treatment. The need for such a study is based on the assumptions that the extent to which CNMBP clients treated with LTOT perceive that their personhood, pain and treatment are respected, and that they have some control over their pain and treatment, could affect their appraisal of pain severity, stress, disability, their ability to cope and perceived quality of life (Gardner & Sandhu 1997[Appendix 2]; Buzzell 1989). With the increased use of opioids in the treatment of non-malignant pain in Australia (Bell 1997; Bramley-Moore 1998; Graziotti & Goucke 1997) and the need to live with a long-term treatment regime it is in the clients, practitioners and communities interest that CNMBP clients maintain self-respect and control over their pain and lives (Fiveash 2000). If CNMBP clients treated with LTOT are to live a valued and meaningful life it is useful for family members, health care practitioners and policy makers to have a greater understanding of the inherent interactions and processes of managing their pain and treatment. Such knowledge and understanding could assist them in determining their role in supporting the positive interactions and processes.

Severe intractable CNMBP is invisible to most health care practitioners and community members. Thus a study which allows

sufferers to articulate their individual subtle signs and symptoms of CNMBP, and how they manage them, could prove helpful in developing appropriate assessment tools and management protocols which nurses, in particular, are calling for (Gardner 2001; Twycross 2002).

Much of the research related to CNMBP treated with LTOT has been quantitative and focused on issues of efficacy and addiction (Penn & Paice 1987; Onofrio & Yaksh 1990; Fishbain et al 1992; Portenoy 1996; Jamison 1996; Savage 1997; Haythornbwaite et al 1998; Dellemmijn 1999). Efficacy is one of the major controversies surrounding the use of LTOT for CNMBP. Many practitioners uphold the view that for an opioid to be considered effective it must result in both a reduction in pain and an improvement in the client's function and abilities (Portenoy 1990; Schofferman 1993). Thus, even though opioids may result in the patient with CNMBP feeling better as a result of pain reduction, they may be withheld if there is not a corresponding, significant improvement in functioning determined by the medical practitioner and not the client. The practice of requiring that both criteria be met, notes Turk (1996), raises a number of difficult ethical and practical issues, including the ethics of withholding treatment that has the potential to decrease pain severity and the failure to prescribe opioids to relieve pain as grounds for malpractice. To date no one has sought to determine through qualitative research the processes that CNMBP clients use to manage the consequences of their pain and treatment.

When CNMBP treated with LTOT are cared for in an acute care facility, their care tends to be generalized, prescriptive and directive, and a low priority (Fagerhaugh & Strauss 1977; Gardner 2001[Appendix 3]). In such facilities health care practitioners are more likely to fail to help CNMBP clients treated with LTOT become involved in their care and to maximize their health potential (McLeod

Clark 1993). Thus, a study in which CNMBP clients treated with LTOT are given the opportunity to articulate their perceived specific life care needs and the resources, needed to meet them, may be helpful to other CNMBP clients treated with LTOT. In addition, it may assist nurses, doctors, allied health professionals, administrators and policy makers in all areas of health care but in particular in relation to the growing number of 'pain units' being developed throughout Australia (A.P.S. 2000). Through discovering individual's perceptions, views and actions, future clients may be empowered by this knowledge thereby giving them the opportunity to assume a greater sense of control over their pain, treatment and life.

ASSUMPTIONS UNDERLYING STUDY

Several assumptions are central to this study, these are:

- LTOT is a legitimate treatment for the management of some cases of CNMBP (Zenz 1991; Portenoy 1996; Graziotti & Goucke 1997).
- clients are responsible for the 24 hr management of their CNMBP which may include self pacing, physiotherapy, psychological counseling, diversional therapy, hydrotherapy regimes, meditation and relaxation techniques and managing their LTOT, including consequences of taking opioids i.e. physical and social consequences (A.P.S.2000)
- consciousness raising involves self knowledge and self advocacy;
- dialogue produces new and liberating knowledge that is part of the healing process which facilitates action, including changes that occur both within the individual and groups (e.g. nurses) (Parse, 1981);
- all clients, regardless of diagnosis and treatment, are entitled to be treated with equal respect and dignity.

Given that CNMBP treated with LTOT impacts on families and all health care practitioners it was not possible to focus solely on clients. However, in the main, the findings refer to clients.

STRUCTURE OF THESIS

The remainder of this thesis is presented in chapters. Chapter one explores predominantly medical and psychological literature on CNMBP and its treatment with LTOT. This chapter sets the scene so the findings can be understood within the current pain management trends. The discussion outlines the issues facing CNMBP clients who chose opioids as part of their pain management regime, including how family members and health care practitioners (e.g. nurses) view these clients.

Chapter two incorporates a discussion of the research approach utilized in this study relating to the interpretative paradigm, symbolic interactionism and grounded theory. Chapter two also gives a general presentation and discussion of the methods needed for data collection and analysis.

Chapter three describes the procedures used for data collection and analysis. It includes description of study population, participant profiles, ethical considerations, participant recruitment and data collection timetable.

Chapters four and five describe the core problem, fragility. In these chapters fragility and related concepts of vulnerability, discrediting, 'not being believed' (in vivo code), 'losing me' (in vivo code), undergoing losses/changes and experiencing comprised health are also described and discussed in relation to the relevant literature. Chapters six and seven describe the core process, authenticating and repairing self, that participants use to overcome feelings of fragility. Authenticating and repairing self is initiated by finding hope. In

chapter six authenticating and repairing self and finding hope is described and discussed in relation to other categories and relevant literature. Chapter seven describes and discusses the categories that form the cycle of authenticating and repairing self. This cycle consists of three phases, (1) reconciling losses, (2) self-determining normalcy and (3) striving for normalcy. These concepts are also discussed in relation to the relevant literature. Chapter eight summarizes and concludes the thesis, discusses the critical findings and conclusions, identifies the limitations of the study, and recommendations of the findings for CNMBP sufferers treated with LTOT, health care practitioners, education, research and health care policy making.

Within each of the chapters data are presented and explored and related literature discussed to contextualize the findings, in so doing in some instances seminal works have been used because of both their role in understanding the biography of current thinking and their acknowledged current relevance.

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CHAPTER 1: CNMBP & LTOT: CURRENT TRENDS

INTRODUCTION

This chapter sets the scene so that the findings can be understood within the current Australian CNMBP management context. It focuses on CNMBP, its management including the increase use of opioids and related technology and the consequences for clients. This chapter also briefly examines the literature on suffering given the close correlation between chronic pain and suffering and the paucity of research addressing the issue of suffering related to CNMBP treated with LTOT.

THE PREVALENCE OF CNMBP

Back pain is among the major health issues confronting western societies, with estimates that 60-80% of adults in western societies have had or will have an episode of low back pain at some time (Schofferman 1999). Low back pain is the second most common reason that people attend a general practitioner (Waddell 1996). The majority of people improve with or without medical intervention, but there is a high level of relapse (Schofferman 1996). However, some people go on to have chronic pain that is refractory to treatment (Van den Hoogen et al 1997; Von Korff & Saunders 1996). According to the 1995 Australian National Health Survey¹ 25.8% of the Australian population experience long term back related musculoskeletal problems with, 21.5% intervertebral disc disorders and 3.5% sciatica (A.B.S. 1995). The number of persons suffering from intervertebral disc disorders has increased from 2.8% of the population in 1991 to 21.5% in 1995 (A.B.S. 1995). Musculoskeletal back disorders tend to affect people in the prime of their life, with 19.1% of persons aged

¹ 2001 National Health Survey corresponding data has not yet been released.

between 45-54 years experiencing back problems (A.B.S. 1995). Forty-two percent of those suffering back pain seek help from health care practitioners i.e. medical practitioners, chiropractors and physiotherapists (A.B.S. 1995). Fifty-seven percent of people reporting back pain use medications to alleviate their pain (A.B.S. 1995). The only data to date that has been released from the 2001 National Health Survey relating to CNMBP is that back and disc problems is one of the most commonly reported (21%) long term medical conditions experienced by Australians (ABS 2002). Its incidence increases with age with 16% of persons aged between 15-24 years and 32% of persons aged between 55-64 years (ABS 2002). There has been a substantial increase in opioid prescribing for non-malignant pain. Between 1986-1995 the amount of oral morphine used in Australia rose from 177 to 578 kg (Bell 1997). In NSW the number of health department authorities to prescribe opioids for non-cancer pain rose from 3326 in June 1990 to 5743 in June 1997 (73% increase) (Bell 1997). In NSW back pain accounted for 37% of cases for which opioids had been prescribed for non-malignant pain (Bramley-Moore et al 1998). This increase in prescribing opioids for non-cancer pain led the Australian Pain Society in 1997 to undertake developing practitioner guidelines for their use in non-malignant chronic pain (Graziotti & Goucke 1997). In 2002 the Australian Pain Society released a position paper on management strategies relating to the use of oral opioids in clients with non-malignant pain (Graziotti & Goucke 2002). Thus, the management of chronic pain, especially CNMBP, consumes an enormous amount of Australia's scarce health resources. However, despite its prevalence, debilitating effects and demand on health, social and financial resources, CNMBP remains an enigma to a majority of health care practitioners, especially nurses.

CHRONIC NON-MALIGNANT BACK PAIN

CNMBP is a complex, multifactorial disorder having physical, psychological, social and economic consequences. Chronic pain is generally defined as persistent pain that is not amenable, as a rule, to treatments based upon specific remedies, or to the routine methods of pain control such as non-narcotic analgesics' (Merskey & Bogduk 1994). CNMBP includes spinal, radicular and referred pain that persists longer than three months and which is not related to the presence of malignant disease (Merskey & Bogduk 1994). The types of pain experienced by CNMBP clients include neuropathic pain, nociceptive, somatic pain, bone, muscular and combinations of these. Living with CNMBP means engaging in a constant struggle to remain in control of one's pain and life, and thus sufferers tend to define and evaluate their CNMBP in terms of their whole life situation (Pellino & Oberst 1992).

The causes of CNMBP, like its' consequences, are varied and complex. In the past chronic pain has tended to be viewed as a syndrome, masking psychological problems emanating from unresolved life crisis such as childhood abuse (Gamsa 1994). However, modern advances in neurophysiology are giving more credence to the pathophysiological bases of CNMBP (Jayson 1994). Although CNMBP may be due to the persistence of the original injury/disease, in many cases new pathology develops, some iatrogenic in nature, resulting in chronicity (Waddell 1996). Intervertebral disc lesions can give rise to chronic pain given that it is now known that the annulus fibrosus is innervated (Colhoun et al 1988; Jayson 1994). Facet joints are another potential source of CNMBP as each facet joint is innervated by more than one nerve root (Jayson 1994). "Abnormalities of muscle tone can occur secondary to neurological damage and may in turn contribute to chronicity" (Jayson 1994:681). Degenerative change in the spine can be associated with obstruction of the epidural veins, fibrosis of the nerve

roots and atrophy of the neurons inside the nerve root (Hoyland et al 1989). Venous obstruction can result in perineural anoxia and the development of perineural fibrosis and neuronal atrophy (Jayson 1994). "Distended veins in the epidural plexus, and damage to pain receptors in the nerve root sheaths, and loss of neurons could lead to chronic pain" (Jayson 1994:681). Furthermore, the absence of detectable spinal pathology does not necessarily mean the pain is psychosomatic as research into CNMBP is now focusing more on the brain stem and the brain itself (Jayson 1994; Derbyshire et al 1994). Recent research is suggesting that some chronic pain may be related to morphological cerebral changes (Derbyshire et al 1994).

CNMBP has many manifestations, ranging from a localized, low-grade discomfort to a moderate and severe diffuse pain experiences; pain can be described, for example, as burning, aching, throbbing, and stabbing. Neuropathic pain is characterized by three cardinal symptoms. They include burning dysesthetic pain, paroxysmal pain which is usually "fleeting, intense and lancing" (Moulin 1996:485). Thirdly, aberrant perception of pain in response to a normally innocuous stimulus (Moulin 1996). Nerve injury can result in pain in a number of ways. Aberration of peripheral nerves may produce nerve-sheath pain by irritating the small afferent (Nervi vervorum) that innovate nerve trunks (Asbury & Fields 1984). Axon injury produces nerve sprouts and neuroma, which are the source of ectopic impulses. Dorsal root ganglion cells and areas of demyleantion along the axon also become sources of ectopic pain impulses. The sites are extremely sensitive to any mechanical stimulation (Moulin 1996). Peripheral nerve injury can also result in denervation hypersensitivity of the dorsal horn, thalamus and primary somatosensory cortex resulting in central pain (Jayson 1994). Severe, refractory CNMBP can devastate a person's life and even lead to suicide (Liebeskind 1991). Furthermore, it has long been recognized that unrelieved pain can be associated with immunosuppression effecting morbidity and

mortality, thus no back pain can be considered benign (Liebeskind 1991).

Unlike acute pain, chronic pain rarely produces detectable physiological changes to prove its' presence, although with positron emission tomography cerebral physiological changes have been imaged in response to painful stimuli (Jones & Derbyshire 1996). Furthermore, many CNMBP sufferers have developed strategies for covering up their pain and often fail to demonstrate 'pain' behaviors (e.g. grimacing, crying) which nurses believe they need to observe in order to validate the client's pain and its severity. However, the skilled clinician who has developed a long-standing therapeutic relationship can often detect the subtle tell tale signs unique to each client that they are in extreme pain, as do family members (Gardner & Sandhu 1997). For whilst the CNMBP experience may be shared, each individual sufferer interprets the experience and gives meaning to it based on their unique 'personhood' (Buzzell et al 1993). Thus, in order to recognize, know and understand a client's CNMBP it is important to first know and understand the 'person' that is the client. Getting to know the CNMBP client as a person is somewhat difficult when in clinical practice our encounters are so brief as a result of today's health care system being diagnosis and dollar driven. Client histories, with their emphasis on medical data, rarely provide a comprehensive picture of the whole person (Fagerhaugh & Strauss 1977). Furthermore, both CNMBP clients and staff can be rendered suspicious, angry, confused and cynical from previous 'failed' encounters with health care practitioners and CNMBP clients respectively, imposing further difficulties in establishing a trusting therapeutic relationship (Fagerhaugh & Strauss 1977; Gardner 2001).

Thus severe CNMBP is a unique experience for each sufferer and how they manage their pain can depend on a number of factors, including personhood and where they reside.

CURRENT CNMBP MANAGEMENT

It is generally accepted that CNMBP requires a multidisciplinary team approach to its management although there is still a need for more studies relating to their cost-effectiveness (Coughlin et al 2000; Turk 2001). To date there has also been some ambiguity as to what constitutes a multidisciplinary team and 'pain units'. The Australian Pain Society (APS) has developed a nomenclature for the different levels of pain management being offered throughout Australia. Currently pain management ranges from formalized pain management programs delivered by formalized multidisciplinary teams to 'pain management' administered by lone medical practitioners, for example: general practitioners, anaethetists, psychiatrists, and rehabilitation practitioners who have specialized in pain management. 'Pain management' in this context may be a combination of medication, counseling and invasive therapies i.e. nerve blocks. Some lone practitioners may provide routine, ad hoc, or no referrals to other allied health care practitioners e.g. psychologists, physiotherapists, occupational therapists. Whilst nurses role in acute and cancer pain are well defined and respected, their role in chronic non-malignant pain management remains ambiguous for many nurses (Gardner 2001).

Organizational pain management programs

The current ideal interdisciplinary model of pain management as put forward by the Australian Pain Society consists of four integrated components: (1) cognitive behavior program, (2) graduated activity program, (3) education program and (4) lifestyle modification teaching (Speldewinde 2003).

1. Cognitive Behavior Program

Identifies beliefs and expectations. Addresses specific maladaptive attitudes, beliefs and thoughts of clients. Modifies

inappropriate behavior. Emphasizes the importance of predictability, reliability and regularity of activities for developing confidence, "using time contingency activity enhancement or time-contingent activity- enhancement" (Speldewinde 2003:2). It teaches participants to manage doubt, guilt, anger, and loss etc., as well as relationships (Guzman et al 2002; Speldewinde 2003).

2. Graduated Exercise Program

The major aim is to increase the client's level of physical functioning despite their pain and to address fear avoidance behavior.

3. Education program

The education program teaches clients about the different types of pain. Concepts of the sick and disability role and the patients role and responsibilities. Gate theory of pain. The "side effects" pain. Medications and their risks. Aspects of dependency and substance abuse. Goal setting and pacing techniques.

4. Lifestyle modification

Incorporates goal setting, pacing, communication skills and return to work skills.

To date there are 88 'pain units' registered with the Australian Pain Society (APS) and of these only two are fully accredited multidisciplinary pain units. 'Pain Units' range from sole practitioners who specialize in pain management in the private sector, to In and Out patient pain management services at public hospitals. Needless to say, the fully accredited units have waiting lists for their well-advertised programs, and being in major cities, people in other states and rural areas are disadvantaged in terms of access. Furthermore, in some cases there is a pre-requisite to entering such programs and that is you must cease all pain medications. The APS

is formulating a classification of pain units in order that sole practitioners and private hospitals that they attend cannot call themselves a pain unit unless they meet certain criteria for a particular level of pain management. Other pain management programs that are specifically designed for people with back injuries are generally directed at the person with an acute injury and thus their focus is preventing chronicity and not managing chronic back pain. In addition, such programs are often seen as a 'once off' program, especially when they are being paid for by a third party i.e. Workcover, Traffic Accident Corporation. When in reality severe CNMBP, including that being treated with LTOT, it becomes a life long need to have regular maintenance rehabilitation for ongoing assessment and reinforcement of positive pain management strategies. Thus, although CNMBP management is touted as a multidisciplinary endeavor, in the main, it remains grounded in the medical model. This results in many CNMBP clients being treated by sole medical practitioners such as Anesthetists, Psychiatrists and General Practitioners who may or may not offer routine access to other health care practitioners with particular expertise in CNMBP.

Another issue inherent in pain management programs relates to their purpose and goals as perceived by CNMBP clients. Whilst optimal 'pain control' and improved 'quality of life' may be the client's goal for undertaking a formalized pain management course, there can be an underlying fear that the ulterior program goal is to return them to the workforce regardless of the level of pain control achieved (Fagerhaugh & Strauss 1977). This situation is more likely to arise when the program is being paid for by a third party (i.e. insurance companies) (Fagerhaugh & Strauss 1977). The draft goals of the APS pain management programs are:

- Assess and obtain a comprehensive understanding of the patient's predicament.

- Improve the patient's understanding of their predicament.
- Reduce the patient's level of pain and suffering
- Improve the patient's level of physical functioning, accepting that there will be some ongoing pain.
- Provide coping skills and strategies for dealing with chronic pain, disability, distress and life changes,
- Reduce the patient's future reliance on others, such as for medications and other therapies.
- Minimize the patient's future use of health care services (Speldewinde 2003)

Few of the existing programs cater for the growing number of severe CNMBP who, with their medical practitioner, have decided to add opioids to their pain management strategies (Bramley-Moore et al 1998). Many of these clients have already undertaken rehabilitation and pain management programs and even with all these skills on board, their degree of pain remains unacceptable and adding opioid use to their pain management strategies remains their only choice even though they risk further stigmatization.

Personal pain management strategies

Ultimately most pain management is self-care. Regardless of what medical and alternative therapies one has sought and adopted it is up to the individual to follow through with recommended strategies (except in the case of surgical procedures). Thus, for most people with severe refractory CNMBP pain management is a 24-hour personal business. It calls for using a variety of conservative and/or alternative therapy strategies in order to remain in control of their pain(s) and thus their lives. Each individual develops and uses

different strategies for various pain scenarios. For example, 'pacing' which is scheduling activities with rest and relaxation periods. Adopting different postures to relieve or reduce certain types of pain, as does the application of heat and cold depending on the type and level of pain experienced. The use of aids to facilitate independence e.g. walking aids, raised toilet seats, pick up sticks. Many find help in managing their pain in the alternative therapy domain e.g. acupuncture, reiki, meditation). Diversional therapy including exploring different art, crafts and further education. Medications can be a central pain management strategy for severe CNMBP and they may include a combination of the classes of medications (refer Table 1). However, not all CNMBP clients have ready access to some of the more recent pain management medication (e.g. Ketamine) due to cost and accessibility problems from living in rural areas. Those who take 'moderate to severe' opioids (morphine, pethidine, fentanyl) risk further stigmatization, (already at risk due to suffering a 'bad back' resulting in being labeled a malingerer), by being additionally labeled as addicts (Cole 1995; Fagerhaugh & Strauss 1977). This can result in discrimination within the health care setting (Cole 1995; Fagerhaugh & Strauss 1977) which adds to their personal struggle of managing their CNMBP. The incidence of malingering and low back pain has been reported to be as low as <5% of low back patients meeting the criteria for malingering (Leavitt & Sweet 1986). Regular periods of 'time out' in hospital can also be part of a severe CNMBP personal client's planned pain management regime. These admissions can be lengthy (> 7-10 days) for respite and drug reviews and are another potential financial burden on the individual and an already under resourced health care system (Gardner 2001).

Pharmaceutical management of pain

As stated previously, pharmaceutical management is often an adjunct to most long-term personal CNMBP management programs. There are eight classes of pharmaceuticals that are regularly used in CNMBP management (Moulin et al 1996). They are listed in Table 1.

CLASS	EXAMPLES
ANTI-DEPRESSANTS	Amitriptyline, Desipramine, Paroxetine, Venlafaxine, Nefazodone
ANTI-CONVULSANTS	Carbamazepine, Phenyton, Gabapentin, Lamotrigine
MUSCLE RELAXANTS	Baclofen
LOCAL ANAESTHETICS	Lidocaine, Mexiletine, Flecainide
SYMPATHETIC BLOCKERS	Clonidine, Phenoxybenzamine, Prazosin
TOPICAL AGENTS	Capsaicin, Lidocaine cream
NMDA ANTAGONISTS	Ketamine
OPIOID ANALGESICS	Codeine, Morphine, Pethidine, Methadone,

Table 1. Classes of pain management medications.

The goal of pharmacological management of chronic pain is to bring the pain into a tolerable range with minimum side effects, given that it is unlikely that any drug or combinations of them will provide complete pain relief (Moulin et al 1996). However, access to some of these medications can be problematic for people in rural communities and those not covered by a third party insurer, as some medications are extremely expensive and not regularly stocked by local pharmacies. In addition, access to opioids can be difficult due to medical practitioners being opioidphobic related knowledge deficit,

peer pressure, concerns regarding addiction and concerns about actual or perceived regulatory pressure (Turk et al 1994; Cole 1995).

LONG TERM OPIOID THERAPY (LTOT)

The term opioid is used to refer to a number of synthetic and natural analogues of opium alkaloids derived from *Papaveretum somniferum* (the opium poppy) that have in common the capacity to bind specifically and to produce actions as specific receptors (e.g. mu (μ), delta (δ) and kappa (κ_1) receptors) that are separate in terms of structure and location and function to produce analgesia (Robinson 2000; Dickenson 1996). Opioid ligands' act at a number of sites in the central and peripheral nervous systems which contribute to both analgesia and unwanted side effects (Dickenson 1996). Seventeen different opioid receptor sub-types have been identified (Smith 2001). Recent research has shown that the difference in some of the variants of δ receptors occur at the intracellular domain and not at the extracellular level where opioid ligands interact (Smith 2001). Recent research has shed light on the possible significance of multiple splice variants of opioid receptors (Jordon 1999; George et al 2000; Gomes 2001). These findings indicate that these sub-types or splice variants have different pharmacological characteristics to the δ , μ , κ_1 and have the "potential to act as targets for the development of a new generation of opioid analgesic drugs" (Smith 2001: 57).

Initially the World Health Organization (WHO) arbitrarily categorized opioid analgesics and either 'weak' or 'strong' (Hanks 1996). The nomenclature relates to its pharmacological basis and until 2002 categorized into opioids for mild-to moderate pain, Level I (e.g. codeine), and opioids for moderate-to-severe, Level II (e.g. morphine) (Hanks 1996). In 2002 WHO introduced another category of opioids,

Level III which includes Hydromorphone (Laval 2002). These preparations are administered through a variety of routes i.e. oral, rectal, injectable, epidural, intrathecal, intravenous via a Hickman's catheter and via trans-dermal patches. LTOT is usually administered either as a sustained release oral preparation or intrathecally via implantable pumps (Graziotti & Goucke 1997). Whilst initially there were no known end organ pathology from opioid analgesia (versus liver and renal effects of non-steroid anti-inflammatory drugs (NSIADS), opioids are known to produce adverse effects such as respiratory depression, constipation, insomnia, dysphoria and potential for neuropsychological impairment (Cole 1995). In addition, recent research (Hockings et al 2001) has described pituitary dysfunction (e.g. hypogonadism) and significant metabolic disorders (e.g. diabetes, thyroid dysfunction) appearing in clients receiving LTOT. Intrathecal morphine has also been known to be associated with a syndrome characterized by amenorrhoea, polyarthralgia and spontaneous lactation (Lamb & Hosobuchi 1990). Other problems include development of tolerance, psychological addiction (Bell 1997; Bramley-Moore & Wodak 1998; Portenoy 1996; Molloy 1997; Gourlay & Cherry 1991), although the real risk of psychological addiction when clients take opioids for legitimate pain is thought to be approximately 1:1000 (Cole 1995; Fishbain et al 1992).

LTOT whilst well accepted for the management of cancer pain, it remains controversial for those with chronic, non-malignant pain including CNMBP (Savage 1997; Portenoy & Foley 1986). Until recently the prevailing view held by medical practitioners was that there was no role for LTOT in the management of CNMBP (Fishbain et al 1991; Halpern & Robinson 1985; Dellemmijn P 1999; Savage 1997). Opioids were believed to actually contribute to the severity of pain felt by the patient and bring about behavioral dysfunction e.g. drug abuse (Fishbain et al 1992, Dellemmijn 1999; Halpern & Robinson 1985). However, it is now recognized that LTOT can be beneficial in

the treatment of some patients with severe, refractory CNMBP caused by a primary lesion or dysfunction in the nervous system (Moulin et al 1996; Schofferman 1993, 1999, Jaddad et al 1992, Turk & Brody 1991). Opioid medications, particularly sustained release formulations, are recommended for CNMBP patients by a number of authors in Australia and overseas (Graziotti & Goucke 1997; Jamison 1996; Portenoy 1996; Jensen et al 1991). Some practitioners recommend patient contracts for those receiving LTOT whereby they commit to only using one medical practitioner and pharmacy for scripts, and agree to certain conditions e.g. that they will not sell their medications on the 'open market' (Graziotti & Goucke 1997). Such contracts uphold the paternalistic model of health care and gives greater emphasis to issues such as drug abuse, addiction that research has already shown to be no more significant than in the general population (Cole 1995; Fishbain et al 1992), Taub 1982).

Efficacy is one of the major controversies surrounding the use of LTOT non non-malignant pain. Many practitioners uphold the view that for an opioid to be considered effective it must result in both a reduction in pain and an improvement in client's function and abilities i.e. return to work (Portenoy 1990; Schofferman 1993). Thus, even though opioids may result in the client with CNMBP feeling better as a result of pain reduction, they may be withheld if there isn't a corresponding, significant improvement in functioning. According to Turk (1991), the practice of requiring both criteria be met raises a number of difficult ethical and practical issues, including the ethics of withholding treatment that has the potential to decrease pain severity, and the failure to prescribe opioids to relieve pain as grounds for malpractice.

Addiction remains another major issue in the debate, despite evidence that the likelihood of client's taking opioids for legitimate pain becoming addicted is considered to be low (Cole 1995; Fishbain

et al 1992). However, whilst the majority of CNMBP clients treated with LTOT are unlikely to become addicted they are likely to experience physical/chemical dependence and tolerance as a natural consequence of treatment (Savage 1996). The issue being that many practitioners confuse the entities of addiction, dependence and tolerance. Physical dependence to opioids is an expected neuroadaptation to continuous opioid use characterized by the patient experiencing withdrawal symptoms (e.g. yawning, anxiety, abdominal cramps, diarrhoea, muscle and bone pain) when the opioid is ceased abruptly (Savage 1996). Definitions of concepts such as tolerance, dependence, and substance abuse have been defined by schema such as Diagnostic and Statistic Manual, revised criteria (DSM-111-R). However, there is no clear definition of 'addict'. Addiction has been defined by Portenoy (1996) as a psychological and behavioral syndrome characterized by a) a strong desire for the drug and obsession regarding accessing further supplies; b) compulsive drug use e.g. unauthorized self medication including escalating dose; and/or c) evidence of one or more aberrant behaviors, including manipulating physicians for prescriptions to obtain extra drugs, drug hoarding and selling. Recent research in neurobiology has identified a gene A₁ allele (named the pleasure gene) (Lawford 2001). The euphoria experienced by substance users e.g. alcohol, cocaine, nicotine is mediated via mesolimbic D₂ dopamine receptors. Methylphenidate, a dopamine transport inhibitor, produces greatest euphoria in people having low mesolimbic D₂ numbers with euphoria declining as D₂ numbers increase (Lawford 2001). Subjects carrying the A₁ allele for the D₂ receptor possess on average 30% fewer D₂ receptors in their mesolimbic tracts than A₁ negative individuals (Lawford 2001). Lawford (2001) postulates that this results in an enhanced euphoric response to drugs of addiction and subsequently increased positive reinforcement of drug use. Thus addiction may have a biological as well as a psychological predisposition. Furthermore, practitioners fail to acknowledge that physical

dependence to opioids is not unique to chronicity, but can occur even with short term use after surgery i.e. >48 hours (Savage 1993). The addiction debate is further complicated by the unsubstantiated claims that addictive diseases e.g. alcoholism, smoking, are more prevalent among chronic pain patients than the general population (Savage 1993).

Tolerance is another issue regarding the long-term use of opioids in CNMBP management. Tolerance is a physiological adaptation phenomenon that results in either more medication being needed to maintain same desired effect or effect achieved from level dose appears to diminish (Cole 1995). LTOT is often associated with dose escalation over time due to this phenomenon (Savage 1993; Cole 1995).

Regardless of how LTOT is administered it is for most CNMBP clients a life-long, serious commitment to which they and their medical practitioner need to be "dedicated to making it work" (Schofferman 2000:139).

THE TECHNOLOGY OF LTOT

The discovery of spinal cord opioid receptors led to the initial trials of administering opioid drugs intraspinally to patients with chronic pain in the late 1970s (Wang et al 1979; Beechar et al 1979). Research relating to intrathecal infusional therapies has mainly concentrated on the treatment of cancer pain (Penn & Paice 1987; Krames et al 1985; Coombs et al 1983). However, there is now growing evidence patients with severe, chronic, non-malignant pain can be managed satisfactorily with long term (>six months) intrathecal opioids delivered via implanted programmable and non-programmable drug pumps (Coombs et al 1983; Penn & Paice 1987; Lamb & Hosobuchi 1990). A major advantage of intrathecal drug pumps is they

generally provide maximum pain relief from minimum amounts of opioids with minimal systemic effect, although incidences of amenorrhoea, polyarthralgia and spontaneous lactation associated with intrathecal morphine have been reported (Lamb & Hosobuchi 1990). A major concern relating to the use of drug pumps in the management of CNMBP is the risk of the technology becoming the focus of care rather than the person suffering CNMBP. For the growing number of CNMBP sufferers who are being implanted with intrathecal programmable drug pumps for pain control, their pain and life becomes beholden to a computer and the people who operate them, requiring frequent visits to the hospital for pump refills and reprogramming. In addition, they face an uncertain future in terms of tolerance, side effects, mechanical failure (rare) and inevitable surgery for the replacement of hardware every 4-8 years. Clients become entrapped in such 'techno/medico marriages' only after all traditional, conservative therapies have failed, further surgical intervention is contraindicated, psychological clearance obtained and an intrathecal trial has been successful (Krames 1993). These marriages, by their very nature, have the potential to foster passivity and an over reliance on medication as well as perpetuating the dominance of the medical 'sick/curative' model in CNMBP management. Thus, whilst intrathecal drug therapy can play a very positive role in the treatment of some CNMBP, it is essential that health care is centred on the client rather than the technology. In addition, access to this technology is limited especially clients who have no claim to a third party and is living on sickness/disability pensions. It has been stated that clinical capabilities ie LTOT administered through computerised pump drug delivery systems have proceeded faster than the scientific basis for these approaches (Hilderbrand et al 2001). There is a paucity of information relating to pump-drug compatibility, drug stability, and the effects of the pH and diluents on various outcomes (Hilderbrand et al 2001). These

unknowns become part of the uncertainty that CMMBP treated with LTOT via intrathecal drug pumps have to live with.

There are several models of external pumps, which deliver opioids either sub-cutaneously, or they are attached to a Hickman's catheter and delivered intra venously. Infection is a major risk factor with these systems.

PAIN & SUFFERING

Pain and suffering, although not the same, are related and share some attributes (Younger 1995: 55). The presence of agonising pain may not evoke suffering, if the cause is known and one does not perceive a threat (Younger 1995). However, suffering frequently accompanies chronic pain in a situation when the pain is overwhelming and the client feels out of control. (Cassel, 1991/1999). A client's suffering is not confined to physical symptoms such as pain. Clients suffer not only from their diseases and injuries but also from their treatment (Fagerhaugh & Strauss 1977). Pain is both a sensation and an emotional experience and suffering can occur in relation to any aspect of the person (Cassell 2001). *"Suffering is experienced by persons, not merely by bodies"* (Cassel 1982:639). It is associated with situations that threaten the integrity of the whole person (Cassel 1999). Hauerwas (1979:231) described suffering as: *"An anguish that is experienced, not only as a pressure to change, but as a threat to our composure, our integrity, and the fulfilment of our intentions"*.

Younger (1995) believes the basis of suffering is the notions of submitting or being made to submit to a particular situation, forced to accept an existence that is not under one's control. Pasqua (1977) identified three categories of suffering: (a) physical problems, pain and inevitable death; (b) relations with other people; and (c) the external world and its invisible forces. Baker and Keller (1978)

described the dynamics of suffering as the experience of loss. CNMBP clients have often suffered a number of serious losses as a consequence of their condition eg employment, finances, hobbies, self-esteem, relationships. Frankl (1963) who had suffered at the hands of the Nazis postulated that each person must answer for themselves the what and how of the concept of suffering.

In the past a narrow medicalized view of suffering, as solely defined as physical discomfort, ignores or minimises the broader significance of the suffering experienced by person experiencing chronic debilitating conditions like CNMBP (Charmaz 1983:168). The client with severe CNMBP experiences his/her body as the agent of the agony. This recognition can produce *"self-hatred, self-alienation and self betrayal (as well as the hatred of, alienation from, and betrayal of all that is contained in the self - friends, family, ideas, ideology)"* (Scarry 1985: 47 cited in Younger 1995:55). Suffering can not only alienate the sufferer from him/herself but it alienates them from others (Hauerwas 1979; Charmaz 1983; Morse & Johnson 1991). Those with a chronic condition causing suffering, like CNMBP, discover that people become strained in their company (Miller 1985; Morse & Johnson 1991). Thus, rather than feeling comforted by others, including health care practitioners, these sufferers feel alienated (Charmaz 1983). Sufferers, like CNMBP clients can either evoke compassion or alienation, the latter is more likely the longer the suffering continues (Nouwen et al 1982; Younger 1995). Pain is also 'ego-alien' (Bakan 1968). Part of managing pain is to make "pain distal to the ego" (Younger 1995:55) in that cannot distance itself from the body. This action permits the ego to relinquish that part of the body that is already separated from the rest (Younger 1955). This psychological process of relinquishing and transforming "me" into "it" is preparatory for actually getting rid of 'it' (Younger 1995:55). Suffering similarly has difficulty maintaining a distinction between

self, it and other (Younger 1995). Both these processes may lead to alienation from others.

Morse & Johnson (1991) have conducted qualitative research into the dimensions of suffering in relation to illness experience. In their Illness-Constellation Model, a theory of illness, minimising suffering is the core process which clients and family use to reduce the physical, psychological and social discomfort and distress associated with illness, including chronic pain (Morse & Johnson 1991: 338).

Suffering, like CNMBP, is subjective and ultimately a personal matter and reflects the client's personhood. CNMBP clients on LTOT not only suffer from their physical pain but can also suffer when health care practitioners fail to validate their pain and treatment (Fagerhaugh & Strauss 1977). Personhood has many facets and it is ignorance of these that may actively contribute to both the client's suffering and frustration on the part of practitioners to provide a service (Buzzell et al 1993). Personhood is at the root of individual vulnerability: *"when it is honoured we feel comfortable, when it is not taken into account by others we feel depersonalised (Buzzell 1989: 4).*

It is possible that CNMBP clients being treated with LTOT who become labelled 'difficult', 'manipulating', 'malingering' are suffering and demonstrating behaviours which reflect greater damage to their self concept than their physical pain. In order to understand and prevent such suffering practitioners need to know the 'person' that is the 'client'.

SUMMARY

CNMBP is a major health care issue in western societies and an increasing number of CNMBP clients are using LTOT as part of their pain management (Brameley-Moore et al 1998). However, the use of LTOT CNMBP management remains controversial resulting in those

using this form of treatment being at risk of being stigmatised and discriminated within the health care system (Cole 1995).

The causes and consequences of CNMBP are many and varied. Whilst chronic pain management is touted as an interdisciplinary endeavour, in Australia in the most part, it remains lodged in the medical model, especially in private practice and rural areas. However, the Australian Pain Society is setting down criteria by which to accreditate different levels of pain management being offered throughout the country. The nurses' role in the management of acute and cancer pain is well defined but remains an enigma in chronic pain.

The introduction of computerised, implanted, drug delivery systems is changing the way LTOT is administered but like other pain medications the cost is prohibitive to some clients, especially when there is not a third party insurer or litigator involve. In addition, these implants require regular invasive surgery to renew the pumps which adds to a number of additional risks of LTOT.

Pain and suffering whilst similar they are independent experiences which can result in not only alienation from friends, family and society but from oneself. Little is known how CNMBP clients treated with LTOT manage their pain, treatment and suffering to live credible, meaningful lives

The next chapter discusses the research approach utilised in this study in respect to the interpretative paradigm, symbolic interactionism and grounded theory. It also includes an introduction, background, outcome and rationale and philosophical and theoretical substantiation. It also broadly outlines and discusses methods needed for data collection and analysis.

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CHAPTER 2: METHODS OF INQUIRY

INTRODUCTION

This chapter describes the complimentary paradigms for discovering knowledge in respect of the research question, the reason for the study and the researcher's world-view. This discussion encompasses the research approach used to build a theory about the consequences of suffering CNMBP, which is treated, with LTOT and how clients manage them. To attain this aim a symbolic interactionism and grounded theory approach will be used. In addition, the role of the researcher, critical procedures and criteria utilized to evaluate grounded theories are discussed.

RESEARCH APPROACHES

There are two major criteria used to select an appropriate research method. The first criteria relates to how the research question is formulated and secondly, what the study hopes to achieve. The research process is also formulated by the worldview of the researcher (Guba & Lincoln 1994) whose beliefs have been shaped with respect to their life experiences and their opinions relating to the nature of knowledge (Annells 1996). There are a number of inquiry paradigms that are delineated by the responses to three interrelated, fundamental questions. They are: i) ontological (relates to what can be known about reality), ii) epistemological (relates to the relationship between the researcher and the known) and iii) methodological (how the researcher proposes to find out what he/she needs to know)(Guba & Lincoln 1994). According to Guba and Denzin (1994:109) there are four inquiry paradigms: positivism (received view), postpositivism (neo and modified positivism), critical theory and related ideological positions (value mediated findings) and

constructivist/interpretive (perceived view). Despite Guba and Lincoln (1994) categorizing the fourth paradigm as exclusively constructivist, Denzin (1994) adopted the term constructivist/interpretative. Basic beliefs and values that form the basis of each paradigm can be described in terms of their ontological, epistemological and methodological differences (Guba & Lincoln 1994).

The positivist has dominated research for nearly half a century and thus is further advanced than the other paradigms that are yet to be fully developed and accredited. The positivist paradigm ontologically assumes reality to exist driven by natural laws and mechanisms (Guba & Lincoln 1994). The basic stance of this paradigm is argued to be both reductionist and deterministic (Guba & Lincoln 1994). The whole can be understood by examining the parts (Guba & Lincoln 1994). Epistemologically the relationship between the researcher and the subject is one of objectivity, each representing separate entities. Biases are thought to be eliminated or minimized by rigorous attention to predetermined procedures. The methodology pertaining to this paradigm involves hypotheses testing using experimental and manipulative strategies which produces knowledge that is expected to be replicable and verifiable i.e. 'true' (Guba and Lincoln 1994).

Postpositivism is an adaptation of the positivist paradigm, in response, in part, to the criticisms made against the latter (Guba & Lincoln 1984). Reality is assumed to exist but it is not completely comprehensible due to humans' flawed intellects and unpredictable nature (Guba & Lincoln 1994). "Objective reality is seen to exist but in part or in all probability" (Fiveash 2000:53). Epistemologically Cartesian dualism is mainly discarded as not plausible, but objectivity remains a regulatory ideal, the emphasis being on the "guardians of objectivity" (Guba & Lincoln 1994:110) including reproducibility and peer review. Methodologically, the focus is on falsifying hypotheses using multiple, modified experimental strategies

in a more naturalist environment resulting in the reemergence of discovery as a part of inquiry resulting in contextual data from allowing those from the social sciences to determine the meanings of people's actions (Guba & Lincoln 1994). The third paradigm described by Guba and Lincoln encompasses critical theory and related ideological positions. *"Ontologically this paradigm views reality historically situated and value-determined"* (Fiveash 2000:53).

However, the ontological and epistemological components are somewhat intertwined (Guba & Lincoln 1994). From this perspective, people and knowledge are formed and transformed historically, socially, politically and culturally. The relationship between the inquirer and phenomenon constitutes reality. The knowledge is transactional, participatory and subjective, thus value mediated. (Fiveash 2000, Guba & Lincoln 1994). The transactional nature of inquiry necessitates data being collected through dialogue between the inquirer and the object of the inquiry. The participatory process can result in collective consciousness raising involving recognition of social, organizational, political, economic and personal constraints that underlay the phenomenon under study.

The constructivist (interpretive) paradigm differentiates itself by identifying reality as relative, in preference to realist, ontologically (Guba & Lincoln 1994). From this paradigm emerges multiple realities which are both individual and contextual. Epistemologically knowledge is developed in interaction between the researcher and the object of the research that is a 'co-participant' (Guba & Lincoln 1994). The term 'co-participant' is used to reinforce the stark contrast in this paradigm with respect of the relationship between inquirer and object in the positivist paradigm, as well as focusing on the type of knowledge sought, i.e. human experiences, feelings and the meanings they give to them. Working in partnership can only discover such knowledge with the subject. Methodology suitable to develop knowledge in the interpretive paradigm is hermeneutical and

subjective (Guba & Lincoln 1994). In partnership, through dialogue between and among inquirers and co-participants discover mental and social constructions and through this process the researcher compares and contrasts interpretations (Guba and Lincoln 1994).

Qualitative research can be traced back to the 18th century to two notable innovators Descartes (1596-1650) and Kant (1724-1804). Descartes' work 'Discourse on Method' (1637) founded the quantitative research field, stressing the importance of mathematics and objectivity in the search for 'truth'. However there were many dissenting views to Cartesian philosophy. Thus, Kant was inspired late in life by the writings of Hume, to publish his views in 'Critique of pure reason' (1781) thus laying down the foundations of interpretative inquiry and was influential in the subsequent development of such research methods as symbolic interactionism (Hamilton 1994). The tenets of Kant's work were in sharp opposition to Cartesian thinking. They were that perception involved more than seeing; human perceptions derive not only from sensual constructs but from cognitive processes and that, *"human knowledge is ultimately based on understanding, an intellectual state that is more than a sequence of experience"* (Hamilton 1994:63).

From this perspective truth is based not only on observation but also on the individual's ability to interpret the circumstance. Thus human claims about nature cannot be independent of intellectual processes of knowing the subject. Knowledge is augmented and modified by the relationship between the inquirer and the known. The researcher is pivotal to knowledge development because the inquirer acquires the knowledge and imposes their interpretation and understanding on the research process (Hamilton 1994). Kant's model of human reasoning thus built the processes of knowing and emergence of knowledge based on an epistemology that transcended the limits of empirical enquiry and distinguish between 'scientific reason' and

'practical reason' (Hamilton 1994). The opinions that apprise the tradition of the constructivist/interpretive paradigm today emanate from the seminal work of such intellectuals as: (August Comte 1798-1857, *Course de Philosophie*; positivist, John Stuart Mill 1806-1873), *A System of Logic*; Wilhelm Dilthey 1833-1911; Beatrice Webb 1856-1943, *My Apprenticeship*) (Hamilton 1994).

SYMBOLIC INTERACTIONISM

What has become known as the Chicago School refers to the social psychology of symbolic interactionism and related research methods that emanated from the University of Chicago between 1920-1950 (Bowers 1988). During the mid 20th century the Chicago-interactionist model of social psychology, influenced by the work of Mead (1934), focused on role, status, deviance as well as attempting to integrate with the phenomenologists Sartre & Husserl et al. (Denzin 1992). During the period of 1951-1962 attempts were made to link symbolic interactionism with Freud's work and European social theory which later resulted in the embracing of new concepts such as ethnomethodology and phenomenology. At the end of the 20th century interactionism was subject to review and critique which polarized thought leading to two schools of thought. These were the Chicago school (interpretive) and the Iowa school (positivist) the latter, which emanated from the works of Mead and Blumer and naturalist methodology (Denzin 1992).

Symbolic interactionism emerged to counter the grand functionalist theories, which were influential during mid 19th century. Talcott Parsons and Robert Merton were primarily responsible for the functionalist movement (Bowers 1988). Functionalist perceive the social world as a whole system made up of functioning, interconnecting units, and status of the units was determined only in relation to the unit's consequences on the entire system. The whole

social system took precedence over the individual (Bowers 1988). This is in stark contrast to symbolic interactionism where the individual is paramount. The primary interest of symbolic interactionism is how human beings experience their world. With symbolic interactionism the analysis begins with the individual and works up through the social groups and organizations rather than the opposite direction espoused by functionalist (Bowers 1988).

Symbolic interactionism's contribution to human research is through studying individual and/or collective human action (Lal 1995). This research requires the observer to also be the observed in order to understand the 'actors'¹ world (Bowers 1998). In addition, by entering the actor's world and assuming his /her role self-reflection is learned. The human ability of viewing one's self from another person's perspective gives the individual some notion of a reflective self (Mead 1934). The concept is learned during childhood through play and normal social interactions within their cultural context (Mead 1934; Chenitz & Swanson 1986:4,5; Lal 1995). Symbolic interactionism is a process primarily focused on how actors derive meanings through social interactions and how these meanings are interpreted and used to guide or predict theirs and others' actions (Blumer 1969; Chenitz & Swanson 1986; Schwandt 1994). The symbolic interactionists' thinking was propelled by the deliberations and postulations of Mead (1934) of a social process in preference to a structure or pattern (Lal 1995), whereby the human mind and body develop, through social interaction and society, into a rational self. Mead (1934) proposed a relationship between social interaction and the individual's mind (i.e. his/her ability to self reflect), thus proposing social interaction precipitated self-conscious thought (Bowers 1988, Fiveash 2000). Thus, via language and designated symbols used for meaningful interactions, individuals engage in processes of reflections and acts

¹ Term used in symbolic interactionism to denote research subject

(and/or predicts actions) on the basis of shared meanings (Bowers 1988).

- During the 1960s Herbert Blumer, whose work had been greatly influenced by Mead, refined, extended and named the concept of symbolic interactionism (Blumer 1969; Annells 1996). The notion of self, as espoused by Mead, became centralized within Blumer's theory of symbolic interactionism that was underpinned by three basic premises (Blumer 1969; Annells 1996). They are:
- The meanings that a person assigns to things (e.g. persons, feelings, and objects) will determine the actions made, or anticipated, towards those things.
- These meanings emanate from social interactions.
- The person to accommodate and modify the meanings encountered in situations uses interpretative processes.

Thus, based on these premises individuals experience their social world through their notion of self, which leads to intentional acts directed towards self and others (Fiveash 2000). Meaning is a social phenomenon determined by our relationships with others and self. Without self-interpretative process there is no meaning and thus no action (Blumer 1969). Humans act upon interpretation of a situation rather than in response to it, thus making human action purposeful based on meaning that the experience has for the individual. However, there is not total consensus amongst symbolic interactionists on the meaning of Blumer's three premises. For example, Lewis (1992) has identified differences in interpretation and postulated that it was plausible to suppose from the premises that all meaning is negotiated as well as to "*consider the existence of real, physical and structural constraints*" (Lewis (1992:284) cited in Annells 1996:382).

The occasion when a person has a reflex response to a situation, Blumer refers to it, as non-symbolic interaction where no interpretation is required (Blumer 1969). Symbolic interaction conversely requires interpretation of symbols/actions (Blumer 1969, Bowers 1988). *"The notion of symbols is intrinsic within Blumer's premises and according to symbolic interactionism, social life is expressed through symbols"* (Annells 1996:381).

The process of communication incorporates the use of both language and symbols to produce shared meanings. To attain a level of understanding of meaning, symbolic interactionism demands behavior at both the interactional and symbolic phases. *"Through a process of mutual interpretation of meaning and taking the role of the other that joint action arises. These interactions form the central basis of human society"* (Fiveash 2001:60).

Symbolic interactionism thus emphasizes social process rather than structure. Collective action results in the shared meanings similar to the notion of social norms that filter down through families, groups, organizations and societies (Lal 1995). Thus, meanings are continuously undergoing a process of change resulting from interactions and experiences with self and other (Blumer 1969; Denzin 1971).

There are three fundamental concepts that underpin the organization of symbolic interactionism theory, the self, the world, and social action (Bowers 1988). The self is socially constructed and composed of two elements, the "I" the reflector component and "Me" conceptualized as the object of self reflection (Mead 1934; Bowers 1988:36-7). "Me" is the public image of self, in that it can be defined, described and discussed with others. There are many "Me(s)" which emanate from internal conversations with self and changes with who "I" am in each social situation (Bowers 1988). *"The 'I' is the active, interactive, dynamic, interpreting part of self"* (Bowers 1988:37). It is a

process that interprets the social context through reflection of the situation and other relevant dimensions of self, both past and present (Bowers 1988). Thus the self-changes as it continuously evolves in response to varying social situations, thereby the individual and the social self are the same (Mead 1934; Stryker 1980; Katovich & Reese 1993).

"The world" is the second central concept of symbolic interactionism which refers to the social or object world as it is experienced by the individuals in it (Bowers 1988). The object world encompasses anything that can be attributed to self or reflected on, including emotions, physical objects and abstract concepts (Bowers 1988). A person's social (object) world is defined by the process through which that individuals assigns meaning to objects based on the way others act towards them and the objects (Bowers 1988). Thus, a person's reality is constructed by the meaning that the situation holds for him/her. The individual may experience multiple realities of the same situation, giving rise to the possibility, that what is reality for one person may not be reality for another (Fiveash 2000). The acquisition of culture plays the vital role of orientating the individual in his/her activities by a pattern of symbolic meanings (Lal 1995). These meanings are continuously evolving as old objects take on new meanings and new objects are encountered which give rise to new patterns of symbolic meanings.

Determining the social world requires explicating what objects are important to the individual's experience in addition to understanding the meaning of the object. According to Bowers (1988) the interactionist as researcher is mainly interested with determining the realities of the participants, the nature of the objects in their world, and how they define and experience their world (Bowers 1988).

The object world, like self, is continually going through the process of evolution.

The third principal component of symbolic interactionism is social interaction. According to Bowers (1988:41) symbols which incorporate "*both verbal and non-verbal gestures*" specify the object world. It is the shared understanding of these symbols that permits us to interact in specified or purposeful ways (Bowers 1988). The process of interaction entails adopting the role of other that is central to social action (Bowers 1988). Each individual responds to each other's symbols, which communicates to each other how they act towards the object world. Social structure is determined through the union of purposeful actions of individuals who utilize shared symbols and construct the social structure and formation of the social world. Society is also a process and it is continuously evolving in response to individual's use of shared symbols (Bowers 1988; Lal 1995).

Research using symbolic interactionism necessitates the researcher to enter the natural setting and explore the complete arena of the various interactions and behaviors. Thus, the inquirer embarks on a journey of discovery relating to the setting and all relevant factors (e.g. physical environment, policies, and ideas) that impact on behavior (Chenitz & Swanson 1986). In order to understand the participant's world the researcher takes-on-the-role-of-other. This requires participating in the natural setting and exploring participants' interpretation of self in the interactions with others and the meaning that incidents have for them (Blumer 1969). Such an approach aims to identify symbolic meanings in a range of situations (Chenitz & Swanson 1986).

From a symbolic interactionism perspective individuals are understood in respect to their self-reflective interpretations and social interaction within their social and historical context (Fiveash 2000). This processes underlying symbolic interactionism that occur simultaneously and continuously, help individuals to discover who they are 'now', how others perceive them and to predict their actions,

and how to act (Bowers 1988). According to Blummer (1969:70) joint action, from a symbolic interactionism perspective, represents a dynamic series of social processes whereby there is the *"fitting together of lines of behavior of the separate participants"*. Thus, one cannot understand group or individual behavior outside their social context.

Research methods are determined by the underlying philosophical stance taken by the inquirer. The philosophical perspective determines the kind of research questions, how data are collected and how to make meaning of the findings (Blumer 1969, Fiveash 2000). A symbolic interactionism conceives exploration of interactions/situations as a valid way to study aspects of society because interactions represent the foundations of societies.

GROUNDED THEORY

Grounded theory is a general research method developed by the sociologists Glaser and Strauss who emphasized theory as process (Glaser & Struass 1967). It's generality and focus on process are compatible with an interactionist perspective because of how it views and conceptualizes data for developing theory as well as permitting one to explore the interactive nature of situations (Strauss & Corbin 1994). *"Of all the paradigm features, actions and/or interaction lie at the heart of grounded theory"* (Strauss & Corbin 1990:159).

Grounded theory method offers a set or processes to discover patterns and their relationships as well a rigorous scheme to develop an explanatory, substantive theory (Strauss & Corbin 1990).

Background of grounded theory

Grounded theory was initially developed by Glaser & Strauss (1967) in an attempt to counteract the prevailing structuralist and

functionalist theories predominating social inquiry, considering qualitative studies *"either too abstract or too poorly to be developed and tested"* (Wells 1995:34). Thus social inquiry during 1960s produced theoretical explanations that lacked rigour and were considered impressionistic rather than scientific (Robrecht 1995). Using this method, theory evolves during the actual inquiry resulting from the constant comparison between data collection and analysis (Strauss & Corbin 1988:158). Grounded theory offers a method of constructing sociological reality (Charmaz 1990) by data gathering that considers not only text and data but also time and space (Benoliel 1996). When Glaser was undertaking some qualitative research he expressed the need for *"explicitly formulated, and systematic set of procedures for both coding and testing hypotheses generated during the research process"* (Strauss & Corbin 1990:25).

Thus, when Glaser and Strauss published their methodology in a book entitled *The Discovery of Grounded Theory: Strategies for Qualitative Research* (1967a) they had been collaborating on a number of research studies related to different aspects of dying which were published in a number of texts (e.g. *Awareness of Dying* (1965), *Time of Dying* (1967) *Anguish: Case study of a dying patient* (1970). Their professional, collaborative partnership was halted when Strauss & Corbin (1990) developed axial coding. Both Glaser (1978, 1992) and Strauss & Corbin (1990) have espoused coding as a necessary modality for changing raw data into theoretical constructs of social process (Kendall 1999). Glaser identified two forms of coding, substantive (open) and theoretical, whilst Strauss & Corbin developed three: open, axial and selective (Kendall, 1999: 746). Glaser (1978) described substantive (open) coding as a means of, *"generating an emergent set of categories and their properties which fit, work and are relevant for integrating into a theory"* (Glaser: 56).

Whilst Strauss & Corbin (1990) described open coding to be, the process of dismantling, examining, comparing, conceptualizing, and

categorizing data. The only difference between the two is that Glaser puts more credence in the necessity of letting codes and theoretical concepts emerge than do Strauss & Corbin. Whilst there is general agreement amongst all grounded theorists that codes and categories are determined by the inquirer's interpretation of the data. According to Glaser (1978, 1992) emergence relates to the process whereby the inquirer generates codes and categories directly from the data and he affirms that *"data should not be viewed through a predetermined framework"* (Kendall 1999: 746). Furthermore, whilst Glaser, Strauss and Corbin have similar definitions for the final coding process, they use them differently in their theoretical constructions and thus generate different theoretical products (Annells 1996; Kendall 1999). The main controversy between Glaser and Strauss and Corbin relates to the latter scholars' development of another intermediary set of coding procedures, called axial coding. Strauss & Corbin (1990:96) define axial coding as *"a set procedures whereby data are put back together in a new ways after open coding, by making connections between categories. This is done by using a coding paradigm involving conditions, context, action/interactional strategies, and consequences"* (Strauss & Corbin 1990:96).

The paradigm model is a management tool that helps link the sub-categories of the data to the phenomenon under study. Thus, Glaser assessed the Strauss & Corbin approach as too prescriptive and that the codes should be driven by conceptual interests that have emerged from the data and not 'forced' into any particular scheme, such as Strauss & Corbin's paradigm model (Glaser 1982:3). Anselm Strauss died in 1996 and prior to his death, Strauss co-authored the second edition of his text with Corbin entitled *Basics of Qualitative Research*, which was published in 1998.

The discourse at the beginning of this chapter on the gamut of research paradigms provides the foundation for the discussion of

grounded theory method being utilized for both qualitative and quantitative data (Glaser & Struass 1967, Strauss & Corbin 1994). Grounded theory emanated at the time positivist research was believed by many to be the only 'real' research (Annells 1997). During this period the beliefs and customs of the positivism continued to be incorporated into qualitative research in an determined effort to try and establish scientific merit for qualitative methods (Annells 1997). The strategies adopted by qualitative inquirers focused on objectivity and the role of the researcher, as well as issues of validity and reliability. There were divergent views regarding the role of the researcher, in that the positivist stance postulated that in order to find 'truth' necessitated the researcher to be detached, neutral and dispassionate (Annells 1997). During that positivist phase Glaser and Strauss (1967) manifested mainly postpositivist (neopositivist) received view of science, grounded theory method of inquiry (Denzin & Lincoln 1994; Annells 1997; Fiveash 2000). In the mid sixties it was suggested that Strauss & Corbin's (1990) grounded theory method had moved away from the positivism and postpositivism and was now more akin to an interpretive inquiry paradigm (Annells 1996).

It has been argued (Miller & Fredericks 1999) that grounded theory has not been adequately scrutinized from an epistemological perspective as to its structure as a theory i.e. what type of theory does it produce. The notion of what theorizing ought to be in qualitative research, remains a central focus of debate among leading scholars and researchers in this area (Miller & Frederick 1999). For example, Morse (1997) has recommended that the role of theory in qualitative research should be critically examined in relation to type of theory produced and its structure. Two criteria described by Morse (1997) relate to generalizability and utility, the first being relevant to the core debate as to whether grounded theory is predictive or accommodationist.

The difference between the context of discovery and the context of justification in the philosophy of social sciences is regularly attributed to Rudner (1966) (Miller & Fredericks 1999). Rudner's tenet is that any scientific activity is associated with applying specific techniques and protocols (Rudner 1966). Such techniques and protocols are the foundation from which to evaluate subsequent claims, hypotheses or theories. Rudner's thesis was that the social sciences could not simultaneously lay claim to a unique methodology whilst at the same time engaging in scientific endeavor regardless how narrowly or broadly construed (Miller & Fredericks 1999). Furthermore, although the process of discovery is distinct from that used to validate (justify), according to Rudner (1966), they are routinely combined. What he states is that a logic of discovery is necessary to distinguish between the context of discovery and context of justification. For grounded theory these two issues set the stage for "evaluating the viability and utility of the process of human science research" (Miller & Fredericks 1999:540). Glaser & Strauss's (1967) original description of grounded theory did not rule out further empirical tests of theory. In addition, Strauss & Corbin's popular model (1990: 96) uses the phrase "*causal conditions*" as a relevant construct in the development of a grounded theory. Hence, there is the possibility of testing a grounded theory empirically, even though the theory originated in the qualitative domain (Miller & Fredericks 1999). Furthermore, Strauss & Corbin's (1990: 96) acknowledgment that 'causal conditions' can result in the development of a phenomenon gives rise to the notion of causality as a valid aspect of grounded theory. This being the case, contrary to common belief, grounded theory may be in the same "business" of any other theory of predicting and explaining (Miller & Fredericks 1999). Those who belong to this school of thought denounce grounded theory as being interpretive (or *verstehen*) and see it rather as explanatory. Given grounded theory is the end product of a process, it is prudent for it to

be examined to evaluate its status in terms of the predictivist or accommodationist issue. It appears that grounded theory is closer to accommodationist stance in that the inquirer seeks support for the theory by referring to some other relevant body of literature that concerns other theoretical frameworks (Miller & Fredericks 1990). However, according to Miller & Frederick (1999: 550) "*grounded theory provides inductive arguments for inductive explanations.... and it need not either accommodate or predict, although it may do one or the other in principle*".

The logic of discovery is heralding as a new area of theorizing about how theories come to be developed and evaluated which may give a more definitive answer to the question as to what kind of theory does grounded theory produce (Kantorovich, 1993).

Classic grounded theory can be differentiated from contemporary grounded theory in that the former focuses on a substantive area whereas the latter focuses on phenomena (Annells 1997). Changes between the classic and contemporary modes have resulted in changes in the development of the interpretive paradigm and accompanying recognition of the usefulness of qualitative findings to human science knowledge.

APPLICATION

Because of the intended product of this research and a philosophical stance that embraces naturalism with the need to understand from the perspective of the other, I intend to use as a method of inquiry the symbolic interactionist perspective of Mead and Blumer with Strauss and Corbin's version of grounded theory. Historically, the classical model of grounded theory method has been conflated with the symbolic interactionist perspective (Wells 1995). Symbolic has undergone some changes and whilst it is usually associated with the classic mode of grounded theory because of its interpretive

redevelopment (Denzin 1992; Annells 1997), it can be used to inform qualitative studies. *"The works of both Mead and Blumer with the philosophical perspectives of meanings and interactions and the self reflective nature of both the participant and the researcher support an interpretative view of micro and macro interactions at both the individual and shared meaning level"* (Fiveash 2000:64). Thus symbolic interactionism is conflated with Strauss and Corbin's interpretation of grounded theory. Strauss & Corbin was chosen for this study because it emerges out of the interpretive paradigm and will defend knowledge to be discovered that is more reflexive and subjective in nature and facilitate the research process to be more interactive for both the researcher and the research subject. In addition, the knowledge it develops has utility for both the researcher and the participant.

Grounded theory method² is purssuant to the goals of developing an accurate understanding of the phenomena under study from the participants perspective (Strauss & Corbin 1990). It aims to discover and conceptualize the essence of complex interactional processes (Hutchinson 1993). Grounded theoriests search for the processes that underpin social interactions related to a particular phenomena or situation. It is primarily concerned with:

- (a) the need to get out into the field, if one wants to understand what is going on;
- (b) the importance of theory, grounded in reality, to the development of the discipline;
- (c) the nature of experience as ongoing and continually evolving;
- (d) the active role of persons in shaping the worlds they live in;
- (e) an emphasis on change and processs, and the variability and

² Thereafter grounded theory method will refer to the Strauss & Corbin (1990) version unless otherwise stated

- (e) complexity of life; and
- (f) the interrelationships among conditions, meaning, and action
(Strauss & Corbin 1990:25)

This study will use the fundamental research strategies as outlined by Strauss & Corbin (1990) including open coding, enhancing theoretical sensitivity, axial coding, selective coding, theoretical sampling, memo writing, identification of a core category(ies); and theoretical saturation and development of a theory. This method facilitates the aims of this research study because it focuses on social processes, social structures and social interactions and views the social world as constructed by the individual in his/her social context. This inductive method can inform both the researcher and the participants with regard to interactions and social conditions in situations of interest.

OUTCOME OF METHOD

The outcome of this study should offer a theory that has emerged from the reality of participants that explains the main issues for CNMBP patients coping with their pain and treatment and how they address them. The utility of theory relates to its potentiality to determine consequences and the conditions that underpin them (Strauss & Corbin 1994).

In the past grounded theory has been used for patient centred research by both nurses and sociologists (Glaser & Strauss 1986; Fagerhaugh & Strauss 1977; Charmaz 1990; Swanston & Chenitz 1993). The focus of some of the grounded theory research have included regaining a valued self, individual adaptations in chronic illness, the illness experience, politics of pain management and passages and process of vulnerable people (Benoliel 1996). How

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CNMBP clients cope with pain and treatment may fall into the domain of individual, group/interactional processes and practices.

GROUNDING THEORY PROCEDURES

Sources of data

Data are collected from the field, the practice setting and other relevant sources, for example the literature. The setting is selected on the basis that it will provide the data while accommodating the physical limitations of the participants. Focus groups³, in-depth interviews, observers' comments (field notes), memoing⁴, emails, poetry and historical documents from comparison groups are sources of data (Benoliel 1996). Multiple perspectives helps in the identification or cross referencing for any inconsistencies in theory development and assists in richness of data (Lincoln & Guba 1985).

The role of the researcher in grounded theory is one of active participant in order to try and take-the-role-of-others, thereby attempting to define the object world and understand the meanings players give to shared symbols (Bowers 1988). Spradley (1980) defines four types of participation the researcher can adopt in the field, ranging from passive, moderate, active or complete participation. Complete participation requires a high level of involvement by the researcher in the research setting. For example, in the health care setting, the researcher may take on the role of the patient or the nurse (Spradley 1980; Bowers 1988; Fiveash 2000). Given my personal circumstance being a CNMBP patient being treated with LTO, using grounded theory legitimized my adopting complete participation as a patient during field research.

³ Focus groups can be defined as carefully planned discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment (Krueger 1988).

⁴ Written records of analysis related to the formulation of theory (Strauss & Corbin 1990).

Preliminary periods of observation and informal discussions permit the inquirer to get a perspective of the field and the various players (Chenitz & Swanson 1986). Keeping a daily journal including specific records of the participant observations, made soon after the event as possible (Chenitz & Swanson 1996), not only aid in maintaining a "heightened level of awareness" and accurate recall (Hutchinson 1993:187), but form part of the data (Fontana & Frey 1994). The more time spent in the field allows the inquirer to become familiar with the physical environment and emotional climate, typical, atypical interactions and procedures. The direction of the observations take and the time taken is determined according to theoretical need (Adler & Adler 1994). Participant observation is congruent with symbolic interactionist perspective because one is exploring the other's concepts of meaningfulness through observation and interaction, requiring high degree of empathy and compassion (to be with the participant and imagining their suffering and thus their reality) (Hutchinson 1983). *"Suffering is experienced by persons, not merely by bodies"* (Cassel 1982:639). The word compassion is derived from the Latin words pati and cum which combined mean "to suffer with". (Nouwen et al 1989:4). *"Compassion requires us to be weak with the weak, vulnerable with vulnerable and powerless with the powerless. Compassion means full immersion in the condition of being human"* (Nouwen et al 1989:4).

During the early stages of observation the inquirer is speculative, and follows clues, intuition of informative data (Charmaz 1990). Also during this period one identifies participants for focus groups and individual formal interviewing. Focus groups have been successfully used to examine people's experiences of disease, health care services and staff attitudes (Jillings 1992; Strong et al 1994; Murray et al 1994). Self disclosure is facilitated through group processes and participants are encouraged to explore and express their views and

experiences relating to CNMBP treated with LTOT using their own language and communication styles (e.g. jokes, teasing, argument). Such processes and styles mimics social reality, as well as identifying both shared and common knowledge it also provides insight into not only what they think about a particular experience, but the reasoning behind their thoughts (Kitzinger 1995). Each focus group discussion can help facilitate participants experiencing a shared sense of reality as they may become conscious of their concerns being shared by others in a similar situation i.e. "*making the personal political*" (Rudge & Cheek 1994: 59). The focus groups are audio and transcribed. In addition there is a research assistant who does not engage with the group but changes tapes, and observes and notes any significant group or individual behavior and/or comments, actions, gesture. The transcriptions and field notes and other documents herald the beginning of data analysis with analysis being congruent with data collection.

Initially participants are asked to sign a consent form and to complete a short demographic questionnaire. The discussion is commenced using broad open questions, that do not include any preconceived ideas or definitions about the experience but serves as a beginning focus (Strauss & Corbin 1990; Fiveash 2000). The same format and process, minus the research assistant, was used for the individual interviews.

Participants who resided in rural Victoria and in other states of Australia were asked to complete a questionnaire which was based on issues that the focus groups and interviewees had highlighted and some additional questions raised from the literature that the focus groups and interviews had directed me to. The internet was also used to communicate with one participant in Perth over a period of several months.

Record keeping is an essential element of the grounded theory method, in addition to field notes one writes "records of analysis related to the formulation of theory" (Strauss & Corbin 1990:197) which are called memos. Memo writing records the progression of initial code development and discusses chronologically how the data have been analysed from beginning ideas to the construction of categories and their relationships (Strauss & Corbin 1990). Furthermore, memo writing acts as a "tool for engaging in an extended on-going dialogue with self" (Charmaz 1990:1190). Memos are dated and it is permissible to use them in the research report (Bowers 1988). In addition, drawing diagrams that show preliminary relationships between concepts and diagrams that reflect analytical thinking and the evolution of the logical relationships between categories and their subcategories, in terms of the paradigm features are referred to as logic diagrams (Strauss & Corbin, 1990). The analytical processes recorded in memos and diagrams informs theoretical sensitivity and sampling.

Theoretical sampling

Theoretical sampling refers to the process of sampling on the basis of relevant theoretical concepts to the emerging theory, thus selection of participants is reliant on the analysis. It determines which participants are selected on the basis of their utility in developing theory, thus it directs data collection but focuses on sampling incidents rather than people. (Strauss & Corbin 1990; Fiveash 2000). It is important that the research sample not be insular (Bowers 1988). Theoretical sampling is cumulative, enhances depth of focus, adds to consistency in data collection and ensures variation as well as density of data (Strauss & Corbin 1990). Issues and hypotheses that emerged from previous focus group discussions, interviews, observations, and memoing are raised with the participants to clarify and reflect in order to ensure accurate interpretation of the participants' meaning. The sample size can not be predetermined.

Because the inquirer continues to explore, asking questions until he/she is content that a conceptual framework has emerged and that it is integrated, examinable and addresses the problem (Stern 1985). Constant comparisons between interviews are made to substantiate or invalidate assumptions and to achieve a multidimensional view of the same phenomena from similar or different contexts. When the research reaches the point where no new information is forthcoming, then the situation is explored for different experiences that offer other ways of viewing the phenomena (Strauss & Corbin 1990).

Theoretical Sensitivity

Theoretical sensitivity refers to the personal qualities of the researcher that enables him/her to elucidate the "*subtleties of meaning of data*" (Strauss & Corbin 1990: 41) at a theoretical level. One's sensitivities to the situation is not only based on personal and professional experiences both prior and during the research project but also from the literature. Theoretical sensitivity utilizes the researcher's ability to have various insights into the nature of the situation, which is based on professional and personal knowledge and experience of the phenomena and participants under study. It also relates to one's relationship with co-participants which calls for good communication skills, creativity, theoretical analysis and the ability to find meaning in data (Strauss & Corbin 1990). Theoretical sensitivity is like an 'insurance policy' guaranteeing that the theory that is developing does emerge from the data. Theoretical sensitivity is a challenging task of balancing reality, personal experience and using one's imagination and one often needs one to move away from the data to ask certain questions in addition to "*maintaining an attitude of skepticism*" (Strauss & Corbin 1990:45). The fundamental objectives of data collection in grounded theory are:

- (a) repeatedly refining research questions according to data gathered;

- (b) sampling according to theoretical need;
 - (c) collecting the range of data from various sources;
 - (d) gathering data from a diverse range of those available experiences of the phenomena including both negative and positive;
 - (e) cross checking ideas, hypotheses and that then becomes data"
- (Fiveash 2000: 70)

Constant comparison

In grounded theory method there are two analytic procedures that underpin the coding processes, they are (a) making comparisons and (b) asking questions. Data analysis incorporates the constant comparison of data and the selection of co-participants who provide the various dimensions to develop theory. The process of constant comparison requires the researcher to compare substantive analysis from one section of the data obtained through theoretical sampling in other substantive area (Charmaz 1990). The researcher remains mobile in the field in an attempt to gain variation. A comparison is made between data collected from various sources (e.g. participant observations, answers, literature). *"In addition it incorporates a process that describes how categories, subcategories, dimensions, and subdimensions interrelate"* (Bowers 1988:49). The constant comparative method continues until categories are 'saturated' i.e. no new insight into the phenomenon can be achieved through further data collection.

Coding

Data analysis in grounded theory utilizes three coding methods: open, axial and selective coding (Strauss & Corbin 1990). The process of grounded theory is combination of intensity and being systematic because it involves the researcher simultaneously collecting, coding and analyzing the data for the outset (Strauss 1987; Hutchinson

1993). According to Hutchinson (1993) the different types of coding produce three different levels of codes, level one refer to in vivo or substantive codes, level two codes refer to categories and level three codes are theoretical constructs.

Open Coding

Open coding is the process undertaken by the researcher of dismantling the data, interpreting, examining, conceptualizing and categorizing data (Strauss & Corbin 1990: 91). Whilst taking apart field notes one labels relevant concepts to represent categories of phenomenon, thus making conceptualizing the first stage in grounded theory analysis (Strauss & Corbin 1990). After disintegration of the data through open coding, the data is then reintegrated through the procedures of axial coding.

Axial Coding

Refers to a combination of procedures that reintegrates the data in various forms after open coding, by making connections between sub-categories and categories using a paradigm model involving conditions, context, action/interactional strategies and consequences (Strauss & Corbin 1990: 96). The objective is to identify a phenomenon (category) in terms of causal conditions, context, how it is managed and the consequences of these strategies (Strauss & Corbin 1990). Both categories and subcategories have properties which are "dimensionalized" (Strauss & Corbin 1990: 98) giving them various specifications which are important when it comes to integrating the theory. A variety of phenomena is constantly and simultaneously identified, revised and verified, thus alternating between open and axial coding (Strauss & Corbin 1990: 98).

Selective Coding

A process of determining the core category and systematically identifying the relationships with other categories, verifying those

relationships and refining those categories as necessary (Strauss & Corbin 1990). A core category is the crucial element in the integration of theory and reflects the major phenomena in the data and is the fundamental analytic idea that combines all categories.

According to Strauss (1987: 36) "a core variable (category) has six essential characteristics:

1. the phenomon recurs frequently in the data;
2. it links the various data together;
3. because it is central, it explains much of the variation in
4. the data;
5. it has implications for a more general or formal theory;
6. as it becomes more detailrd, the theory moves forward;
7. it permits maximum variation in analysis".

One of the procedures in selective coding is conceptually explicating the story line about the central phenomena being studied (Strauss & Corbin 1990). The story line emerges as the core category and its' properties are apparent from the story line. Then the sub-categories, including their properties and dimensions are integrated in relationship to the core category (Strauss & Corbin 1990). According to a sub-category's contexts, conditions, strategies and consequences the researcher decides which section of the paradigm it belongs to (Strauss & Corbin 1990). The story line gives direction to the inquirer as he/she starts to organize and reorganize the categories in relation to paradigm until they seem to fit the story (Strauss & Corbin 1990). As the theory develops, patterns and connections emerge or are deduced to systematically refine and develop sub-categories and their relationships (Strauss & Corbin 1990). The inquirer is continuously examining the categories, properties and dimensions for theoretical gaps and via a process of discriminate sampling it may be found necessary to return to the field and co-participants to find missing data (Fiveash 2000). Selective or discriminate sampling continues

until theoretical saturation of each category is reached (Strauss & Corbin 1990). Saturation only occurs when:

1. "no new or relevant data seem to emerge regarding a category;
2. the category development is dense, insofar as all the paradigm elements are accounted for, along with variation and process; and
3. the relationships between categories are well established and validated "(Strauss & Corbin 1990:188).

Theory generation is complete when i) the emerging theory is validated against the data and it fits the phenomena under study; ii) both practitioners and clients can comprehend what the theory is saying; iii) it has the ability to inform a range of contexts; and iv) it has the ability to determine action in respect to the phenomena (Strauss & Corbin 1990, Fiveash 2000).

Process is central to the analytical procedures in grounded theory. It refers to linking of sequences of action/interaction as they relate to, *"management of, control over, or response to, a phenomenon"* (Strauss & Corbin 1990:143). The linkage of sequences is achieved by noting:

- change in the conditions influencing action/interaction over time;
- the action/interaction response to change;
- the consequences that result from that action/interaction response, and
- describing how those consequences become part of the conditions influencing the next action/interactional sequence (Strauss & Corbin 1990).

Process is discovered analytically by engaging in asking how and why questions and examining and explaining how events alter under certain circumstances and with time (Strauss & Corbin 1990). Thus,

coding for conditions and consequences rather than the subject matter alone helps in defining process (Charmaz 1990). Reasons are sought for why phenomenon alters or remains static under the conditions, actions and consequences of events. According to Strauss & Corbin (1990: 157) there are essentially two ways that process can be conceptualized in grounded theory research. One is to perceive it as stages and phases of journey, together with an explanation of what facilitates transversing, halting or taking a downward turn. The alternative way to conceptualize process is as *"action/interaction that is flexible, in flux, responsive, changeable in response to changing conditions"*.

Coding procedures

Focus group and interview transcripts and other relevant documents can be analyzed either on a line-by-line, sentence, paragraph or whole document basis (Strauss & Corbin 1998) using the constant comparative analysis method. During this process the data is dismantled, conceptualized and reconstituted in new ways (Strauss & Corbin 1990). The nature of the data substance determines the coded labels attributed to them (substantive codes) (Stern 1985). The data are coded with respect to their action and simultaneously coded data are compared with each other. Progressively the inquirer translates via analytical coded paradigm into categories incorporating their various properties and dimensions including determining actions and their actual/potential relationships. Through the constant comparative method categories are arranged in a conceptual formation from coded data. The development and positioning of categories elevates the coded material to a higher level of conceptual abstraction that incorporates the diversity of the data (Glaser & Strauss 1967). Categories are classifications of concepts when compared appear to relate to a similar phenomenon (Strauss &

Corbin 1990:61). A grounded theory emerges from the formation of these conceptual categories and includes not only their properties according to the paradigm but also relationships between categories (Charmaz 1990). Again the researcher is promoting the analysis to an abstract level and by identifying the relationships between the categories begins to develop a framework that can ultimately explain and predict the process under study (Charmaz 1990). The constant comparison within each level of analysis continues whilst the researcher makes suppositions about which data fits into which category if at all, thus proving or disproving the categorization (Stern 1985; Chenitz & Swanson 1986; Bowers 1988, Fiveash 2000). The paradigm features of a category prompts further exploration to discover new features of the phenomena which may result in validating or invalidating or enriching the known information. These processes continue until data collection renders no more new information and theoretical saturation is reached (Glaser & Strauss 1967).

The Six 'C's

Glaser (1978) identified the 6 Cs of theoretical analysis using grounded theory method: cause, consequences, covariance, contingencies, context and conditions.

- Cause refers to the source of the phenomena.
- Consequences are the ramifications of the phenomena.
- Covariance refers to the variation relationship between phenomena, contingencies; and the direction of the variance (Strauss & Corbin 1990).
- Context relates to the social circumstances influencing the phenomena.

- Conditions refer to a range of pre-requisites that must operate in order for a phenomenon to occur and be influenced (Glaser 1978, Charmaz 1990: 1168).

During theoretical analysis the researcher is not attempting to describe phenomena but to elicit the meanings and concepts hidden in the data for future exploration (Charmaz 1990). Following identification and interpretation of ideas the researcher explores the field and relevant literature for answers to analytical questions (Strauss & Corbin 1990). After coding and analyzing the data using the constant comparative method the researcher develops concepts, categories and hypotheses. Assumptions are continuously suggested and tested. The researcher is looking for patterns within the data that may suggest categories and/or relationships between concepts and categories (Hutchinson 1993). The properties of concepts and categories and their relationships are continuously defined and redefined and *"in addition to incidents, the researcher compares the behavior patterns of different groups within the substantive area"* (Hutchinson 1993: 201).

Thus data analysis in grounded theory occurs simultaneously with data collection using the constant comparison method. The analysis moves through three levels, descriptive, conceptual and theoretical. Conceptual categories are developed, identifying their properties and relationships. Eventually a central core category emerges, which is usually a social process. This provides the framework for the integrating the sub-categories in the development of a theory that has a systematic structure, is testable, accepted by research participants and is useful to practitioners (Strauss & Corbin 1990).

Data Management Strategies

The constant comparative method requires an effective data management system be set up before commencement of data

collection. This can be a manual or computerized system or a combination of both. Data management involves secure storage of data analysis, quick retrieval system to documentation. It is the University's policy that the data is retained for a period of 5 years post completion of research and those interview tapes be destroyed at that time under supervision.

The place of the literature review in grounded theory research

Literature in the grounded theory method includes both technical and non-technical material. Technical literature refers to published books and refereed journal articles. Non-technical literature includes memos, correspondence and reports (Strauss & Corbin 1990). Unlike verification research when the review is only written prior to data collection, in grounded theory literature review is an ongoing process throughout the study. Literature review is used during data analysis to elicit alternative perspectives on phenomena and a source of data comparison. At this juncture the literature assists in heightening theoretical sensitivity (Strauss & Corbin 1990). On completion of data analysis a full literature review is conducted and can be utilized in several ways, including helping the researcher generate theory from the data (Strauss & Corbin 1990). Other functions include a way to extend existing theory; a further source of data; to stimulate questions and hypotheses; theoretical sampling; and augment validation (Strauss & Corbin 1998). Undertaking a literature review during analysis not only sensitizes the researcher to properties of phenomena but elicits alternative variables that have the potential to influence the phenomena under study (Strauss & Corbin 1998). After the theory has been developed and further literature review is undertaken, which review links with extant research and theories on the study topic (Hutchinson 1993).

ROLE OF RESEARCHER

In grounded theory the researcher does not remain a passive observer, but must be capable of entering the world of the participant (*"taking the role of other"*) in order to gain their perspective (Hutchinson 1993, Bowers 1988:43). In order to understand another person's perceptions of his/her reality requires personal reflection and acceptance of one's own preconceptions, values and beliefs. *"If such bracketing (of values) is not done, the scientific enterprise collapses and what the (researcher) then believes to perceive is nothing but a mirror image of his own hopes and fears, wishes, resentments or other psychic needs; what he will then not perceive is anything that can reasonably be called social reality (Hutchinson 1993a: 187).* This becomes paramount when the researcher is a sufferer of the condition under study. Thus, the researcher is straddling two worlds, a position that Park (1950) refers to as 'marginality'. Marginality requires the researcher to keep a degree of intellectual distance to give 'a helicopter's view' of the situation whilst simultaneously asking analytical questions, reflecting on assumptions relating to the categories and their properties under development (Bowers 1988). *"It not only exposes us to a new and different world but, at the same time, causes us to become more sensitive to our own world" (Bowers 1988:44).* To maintain marginality the researcher uses the constant comparative method, i.e. constantly comparing the accounts of participants with each other, researcher and literature (Bowers 1990). Thus, the researcher is central to a grounded theory study and their philosophical beliefs and values, personal and professional experience tend to permeate the data collection and analysis (Denzin 1971; Charmaz 1990). During the constant comparative method the researcher makes the choice of questions which the researcher considers relevant to the study situation. The more apparent involvement of the researcher in the discovery process is the notions and questions they raise after interacting with the data (Charmaz 1990:1169). It is important that

the inquirer's beliefs and values are made explicit so that the reader can judge the extent to which they influence the study.

EVALUATION CRITERIA

The criteria used to evaluate quantitative research in terms of it being "good science" are considered by most qualitative researchers to be inappropriate for evaluating their research. However, many grounded theorists believe that *"the usual canons of 'good science'"* should be retained but redefined in order to accommodate the realities and complexities of qualitative research and its' subject matter. Such "scientific canons" include generalizability, reproducibility, and verification (Strauss & Corbin 1990). Strauss & Corbin (1990) have developed seven evaluative criteria that they put forward as guidelines relating to a variety of data collection and analysis procedures (Appendix 3/4). Each mode of discovery produces its own set of standards and processes for achieving them which need to be clearly articulated to reduce confusion when using positivistic labels (Strauss & Corbin 1990). For example, in empirical studies reproducibility refers to the study being replicated and if by doing so reproduces the same results then it assumes more credibility (Strauss & Corbin 1990). When researching psychosocial phenomena no resulting theory in reality is reproducible, given the contextual nature of the research and whilst major conditions may be similar they can not definitively correspond to the original research (Strauss & Corbin 1990). However, reproducibility from a qualitative perspective can be denoted as: *"Given the same theoretical perspective of the original researcher and the following the same general rules for data gathering and analysis, plus a similar set of conditions, another investigator should be able to come up with the same theoretical explanation about a given phenomenon"* (Strauss & Corbin 1990:251).

Morse (1997) has categorized qualitative research relating to the level of theoretical development and strategies to evaluate methods. The levels are referred to as descriptive, interpretive, disclosure and explanatory. According to Morse (1997) grounded theory is disclosive, i.e. a theory that explicates the structure of knowledge and the intricate linking concepts and delineating stages and phases of a process. These disclosive theories are transferable to other contexts and to other cohorts experiencing similar phenomena (Morse 1997). Evaluative criteria for disclosive theories incorporate *"fit, relevance, be able to work; it must be modifiable' and it must be transcending. To transcend it must be presented at a higher level of abstraction than the substantive area being studied"* (Morse 1997:179). However, Morse (1997) cautions scholars to remain flexible and open in relation to theory evaluation in order not to jeopardize losing the insight and creativity necessary in quality theory development.

SUMMARY

Given the purpose of this research is to develop knowledge about how clients manage the consequences of their CNMBP and LTOT such insight is individual and contextual as well as psychosocial in nature, then participants need to be studied in relation to their unique situation (Bowers 1988; Schwandt 1994). Such an approach allows the researcher to gain an understanding of people in their specific circumstance from their unique viewpoint and to study the interrelationships between participants. To gain insight, understanding and knowledge of specific phenomena necessitates entering the participants world and to interpret their behavior and language.

The development of such knowledge is supported philosophically and epistemologically by symbolic interactionism and methodologically by grounded theory. Symbolic interactionism (Mead 1934; Blumer 1969)

is a theory of social interaction concerned with self, the world and social action (Bowers 1988). Social action is structured by the integration of purposeful actions by those who utilize shared symbols and construct the social structure and pattern of the social world. Society is formed by individuals who act towards and respond to a set of shared symbols, thus society only exists through the individuals that construct it. Society is not static but continuously changes resulting from the individual's utilization of shared symbols (Bowers 1988). Symbolic interactionism corroborates naturalistic inquiry and individuals in respect to their self-perceptions of their social and historical context. Using these processes symbolic interactionism facilitates the researcher's exploration of CNMBP client's knowledge of themselves and their situation through their social world and their behavior that is demonstrated in social interaction. Interactions are viewed by symbolic interactionists as the foundations of society and thus they are a valid way to study society.

Grounded theory supports a symbolic interactionist view because it is a method of analysis that facilitates the exploration and examination of the interactive nature of events (Strauss & Corbin 1990). Grounded theory method with its emphasis on process facilitates interpretations of actions, strategies and procedures to identify social process. It provides a systematic set of procedures for data gathering and interpretation from which a theory can emerge about psychosocial processes that is accessible to the research participants (Strauss & Corbin 1990).

A grounded theory emerges from the data collected in the field with analysis being undertaken simultaneously with data collection. This approach can be used to search for factors such as 'stigma' in addition to determining the social processes involved and cause contexts, contingencies, consequences, covariances and conditions (Stern 1985; Fiveash 2000). Data is collected from a variety of

sources including focus groups, interviews, field notes, memos, and literature, personal, organizational and historical documents (Benoliel 1996). Grounded theory is evaluated by using a range of criteria developed by Corbin and Strauss (1990) which although may include quantitative language but are redefined to fit the unique ingredients and processes of qualitative research.

The next chapter describes the application of the method of inquiry outlined in this chapter to an actual research study. This discussion includes data collection and analysis procedures, how the original sample was selected and some of the events and actions that indicated some of the categories.

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CHAPTER 3: THE STUDY

INTRODUCTION

This chapter contains a description of the procedures used in the study to investigate the research question: How do CNMBP clients treated with LTOT manage the consequences of their pain and treatment? The chapter describes and discusses the procedures used to collect, analyze and manage data. This discussion includes the setting, the selection criteria and strategies used for the recruitment of participants, the procedures used for collecting data through focus groups, participant observation, interviews and postal survey. Data management and analysis are described including coding procedures and actions used to add rigor to the study.

THE RESEARCH SETTING

The initial and latter stages of the study were undertaken in metropolitan Melbourne, Victoria, Australia involving five private hospitals and four medical pain specialists in the northern and eastern suburbs of Melbourne and one medical pain specialist in Perth, Western Australia. Three of these hospitals were chosen because they actively promoted their facility as specializing in pain management and the others were where two of the pain specialists had admitting rights. The medical specialists were accessed through personal contact and via the Australian Pain Society and the three 'pain units'. The postal survey was undertaken in all States and Territories of Australia.

Accessing appropriate health care facilities.

Entry into the field was negotiated initially with the Directors of nursing/CEOs and the medical specialists attending the facilities, then the Unit Managers of the areas where the study would be undertaken. Such negotiations involved explaining the aims of the study, under whose auspices it was being conducted and what involvement in the study meant for that particular institution. For example, needs were different from conducting focus groups to undertaking participant observation. All facilities were interested in supporting the project generally and they were keen to have access to the results.

PARTICIPANT RECRUITMENT

Given the controversy surrounding the use of opioids in the long-term management of CNMBP there was a limited population from which to recruit participants.

Following ethics approval from Monash University, the five private hospitals, one public pain unit and four pain medical specialists gave permission to conduct the study using their facilities and/or accessing their patients on the basis of the aforementioned University approval.

- ♦ Upon ethics approval, clients who met the selection criteria of having suffered chronic back or referred spinal pain for six months and had been legally prescribed opioids to manage their pain for six months or longer were initially selected by purposive sampling (Patton 1990). Thereafter recruitment was according to theoretical sampling, i.e. on the basis of concepts that have proven relevance to the evolving theory (Strauss & Corbin 1990: 176). A purposive sampling technique was used

for the selection of the initial 20 focus group participants. This technique ensured that participants were well conversed with the phenomena. Eye-catching notices advertising the study were strategically placed in the waiting rooms of four medical pain specialists' practices and day rooms and/or nursing stations of three private and one public hospital pain unit. A psychologist and an occupational therapist working with two of the pain specialists in the study were offered invitations to have their clients participate in the study. At no time were clients coerced into participating in the study. The fact that the researcher also experiences CNMBP which is managed with LTOT had a positive influence in relation to recruiting clients to the study, many verbally expressing the view that I understood what they were going through and that I had integrity. After they had provided written consent to participate, this was verbally confirmed prior to the conduction of focus groups, participant observations and interviews and clients were reminded that they could withdraw from the study without any negative implications to their on going care. Interested clients were asked to obtain a study information pack from the designated distribution points e.g. doctor's reception, nurses' station. The study pack contained:

- ◆ a General Explanatory Statement (Appendix 5) outlining the focus and object of the study, under whose auspices it was being conducted, what participation entailed and the guarantee of privacy and confidentiality, and
- ◆ a Expression of Interest Form (Appendix 6), which set out the options of how they could participate in the study (e.g. focus group, private interview, observation and/or survey).

After reading the General Explanatory Statement they were invited to complete the Expression of Interest Form and leave it in the

study envelopes at the nurse's station or with the Specialist's receptionist, or hand it in to the psychologists or occupational therapist, which kept them in sealed envelopes. The researcher collected the Expression of Interest Forms after the due date and each interested client was contacted by telephone by the researcher who introduced herself and the study and what involvement in the study meant. Those who agreed to participate in the study were forwarded either a Specific Explanatory Statement (Appendices 7/8/9/10) for the mode of involvement that they had selected, together with a written Consent Form (Appendices 11/12/13) or a survey questionnaire with a return stamped addressed envelope.

The decision to run separate focus groups for female and male sufferers was made because the researcher did not want participants to feel embarrassed or intimidated. In addition, it was important to discover any gender differences in relation to the experience of CNMBP treated with LTOT. Whilst ten participants were initially recruited for both female and male client focus groups, unfortunately a number of clients were unable to attend the focus group because of their pain levels on that particular day. There were four male and seven female participants, all being treated in the private sector. The inability to attract participants from the public sector may be due to their emphasis on behavioral-cognitive therapy rather than pharmacological approach, especially the use of opioids. Seven clients consented to be interviewed privately and fifteen clients agreed to participate in participant observation. Participants for the postal survey were recruited through a variety means. These included displaying bright bold notices in the reception areas of the original Victorian pain units and specialists, Australian Pain Society Members and through a national radio broadcast on the Australian Broadcasting Commission's night program.

During the client focus groups I learned that participants wanted to focus on the enormous impact of CNMBP treated with LTOT on their lives and self. In particular, the stigma and discrimination they had experienced relating to being on LTOT and the issue that people, particularly family members and nurses had no idea of their pain and suffering. This knowledge influenced my selection of participants and initial questions for informal and formal interviews. It appeared important to engage participants of all ages, including both sexes, those who have family members and sufferers who had been hospitalized, thus interfacing with nurses, in the last twelve months. Respondents to the study notices and radio program were contacted by telephone in order to determine their suitability. In addition it led to seeking participation from family members and nurses working with clients who suffer CNMBP treated with LTOT.

Theoretical sampling allows one to sample *"on the basis of concepts that have proven theoretical relevance to the evolving theory"* (Strauss & Corbin 1990:176). This technique propels the development of categories, their properties and processes. Participants were also sought from a range of settings (outpatient/inpatients, urban/rural) ages, including both male and female participants, although more females showed interest in the study and followed through that interest than did the males. In order to get a wide range of experiences participants were recruited who had their pain management coordinated by different medical specialists i.e. anaethetists, psychiatrists and those who were cared for in a designated pain centre to those cared for on medical/surgical wards when hospital admission was required. The centre and wards were staffed by both registered and enrolled nurses, whilst none had any formal qualification in pain management, many had attended in-service education on chronic pain. Only two facilities employed a clinical nurse

specialist in pain management, both were employed on a part-time basis and were responsible for acute and chronic pain nursing management.

Later there was the transition towards developing categories and sub-categories and theoretical sampled participants. The theoretical trail led to the community and as expected home environments varied from person to person. Theoretical sampling allows comparisons across cohorts and the acquisition of the necessary depth to start understanding the contexts and meanings of participant's experiences. Participants were selected to follow up specific issues as they emerged according to theoretical need and variation. The selection of individuals and settings was dictated by where the actions/interactions being studied were most likely to be found.

THE STUDY POPULATION

The participant profiles for each of the methods of data collection are presented in the following tables.

Gender	Male n4	Female n7
Age	Range 41-57 Mean 48 years SD 6.7	Range 34-57 years Mean 43 years SD 7.9
How long had CNMBP	Range .6 - 19 years Mean 6 years SD 8.1	Range 5 - 20 years Mean 9.3 years SD 5.06
How long on LTOT	Range 1 - 8 years Mean 3.2 years SD 3.2	Range 1 - 7 years Mean 3.6 years SD 1.9

Table 2. Patient Focus Group Participant Profiles

Gender	Female n 8	Male n 7
Age	Range 30 – 64 years Mean 48 years SD 11.2	
How long had CNMBP	Range 2.6 – 21 years Mean 9.9 years SD 5.8	
How long on LTOT	Range .6 – 15 years Mean 6.7 years SD 4.7	

Table 3. Participant Observations Participant Profiles

Gender	Male n17 (34%)	Female n33 (66%)
Age	Range 30-65 years Mean 47.5 years SD 8.6	
How long had CNMBP	Range 1-26 years Mean 10.5 years SD 6.2	
How long on LTOT	Range .6-15 years Mean 5.9 years SD 3.5	

Table 4. Survey Respondents Participant Profiles

Gender	Male n2	Female n5
Age	Range 45 – 63 years Mean 50.8 years SD 6	
How long had CNMBP	Range 2.6 – 13.4 years Mean 6.9 years SD 4.4	
How long on LTOT	Range .60 – 12.4 years Mean 5.4 years SD 4.3	

Table 5. Interviewees Participant Profiles

Gender	Male n4	Female n2
Age	Range 30 - 75 years Mean 55 years SD 18	
Relationship to sufferer	Spouse	n 3
	Daughter	n1
	Mother	n1
	Father	n1
How long family member suffered from CNMBP	Range 5 - 21 years Mean 12 years SD 5.3	
Employment status	Full-time	n 3
	Retired	n 2
	F/T Carer	n 1

Table 6. Family Members Focus Group Participant Profiles

Gender	Male n0	Female n9
Age	Range 28 to 49 years Mean 41years SD 6.7	
Nursing Experience	Range 7 - 28 years	Mean 19 years SD 6.6
Nursing CNMBP Patients	Range .3 - 11 years	Mean 5 years SD 3.4

Table 7. Nurses Focus Group Participant Profiles

DATA COLLECTION

Given the purpose of this research is to develop knowledge about CNMBP client management strategies related to their pain and LTOT such insight is individual and contextual, as well as psychosocial in nature and thus requires methods that facilitate such exploration. In addition, given that LTOT remains controversial in the treatment of CNMBP, there are not a plethora of subjects that meet the selection criteria and a number of those

who do meet the selection criteria reside in rural Australia. Upon ethics approval, focus groups, individual formal interviews, participant observation, postal survey and relevant policies and State regulations relating to the administration of Schedule 8 drugs (morphine).

1. Time Table

The focus groups were conducted in October 1997. Participant observation occurred as complete participant - as a member of the group, during six admissions that the researcher had during the period September 1998 - March 2000. The periods of observation varied from 3 days to 6 days depending on my health status. During the process of participant observation, data was also collected through informal interviews and field notes. The survey was undertaken during the period August 1998 and August 1999. The survey was undertaken in stages in response to the various recruitment strategies employed. Further interviews were undertaken following analysis of current data during 2002. The final stage of the analysis and writing was conducted during the period 2002-2003 on a part-time basis, taking into consideration my own pain management.

Phase 1	1997	Focus groups
Phase 2	1998 - 1999	Postal surveys
Phase 3	1998 - 2000	Participant observations
Phase 4	1999 - 2002	Interviews

Table 8. Data Collection Timetable

2. Methods

i. Focus Groups

The focus groups were held at a private pain unit in the eastern suburbs Melbourne. The hospital was selected because it had a designated 'pain unit' and the hospital was located close to transport as well as access to disabled parking. It was a 36 bed acute medical and surgical private hospital with eight beds designated for pain patients. There was a specified 'pain unit' room which was normally used for group counseling and physiotherapy, which was where the focus groups were conducted as it provided facilities for participants to lay down if they had difficulty sitting for prolonged periods. In addition there was a psychologist in attendance at the hospital at the time the focus groups were conducted should the discussion cause a participant particular distress that the participants and/or researcher considered needed professional intervention. Whilst 10 participants had initially been recruited for each focus group, only 7 female and 4 male participants attended on the day. The non-attendants were contacted and all gave their high levels of pain on the day as the reason for not attending. In consultation with participants, it was decided to conduct the focus groups in the early afternoon. Transport was arranged for those who required it. Permission was granted to display a 'do not disturb' sign on the door of the pain unit 'treatment room' where the focus groups were to be conducted. The 2-3 hour focus groups discussions were conducted with a 30-minute refreshment break after one hour to allow participants to move and take medications if necessary (client focus group). An independent research assistant was also present; who took notes of critical issues and scenarios, gestures and group dynamics as well as audiotaping the discussions. The hospital's 'pain clinical nurse specialist' and senior administration were very supportive of the study and

endeavored to make the environment as comfortable and conducive to participants being relaxed. However, for some client participants who had been inpatients at the hospital in the past expressed some discomfort visiting the unit again. The client focus groups were conducted in the afternoon, and the nurses' and family members' focus groups were conducted in the evening. On arrival at each focus group participants were:

- given a name badge
- asked to complete a short questionnaire (Appendices 14/15/16)
- introduced to each other, and
- the researcher briefly outlined the aim of the focus group, and some basic ground rules which would facilitate achieving the aim.

The participants were advised at the time of the focus groups that a synopsis of the discussion would be sent to them, together with an evaluation form (Appendices 17/18/19/) for them to complete and return in a pre-addressed, stamped envelope. The focus group interview schedules are outlined in Appendices 20/21/22.

ii. Participant observation

Participant observation allows the researcher to collect data in the field by observing the participants when they are inpatients. Spradley (1980:58) has identified four types of participant observation based on the degree of participation with people and activities by the researcher in the field. The four types are:

- a complete participant when they become a member of the group;

- a participant as observer when activities and participation is active and involvement is high but not as complete as being a member of the group;
- an observer as participant open about their presence and the influence of the researcher on the setting is acknowledged and participation with people and activities is low; and
- a complete observer having complete freedom to observe without influencing the group observed and the participation does not exist.

Participant observation involves a range of informal interviews, comprising every day conversation after or before a particular activity. These informal interviews occurred with CNMBP patients receiving LTOT. These informal interviews were later documented as field notes as soon as practical, and became a source of data. These conversations were in part constructed by the participant's concerns and the necessity to explore issues according to theoretical need, including those arising from the focus groups. Participant observation was conducted in 350, 137, 36, 40 bed private hospitals where 3 pain management specialists had admission rights and the hospitals provided pain management services. All the hospitals offered acute medical and surgical care as well as day procedures units. Whilst all hospitals had designated pain management beds they were generally located on a medical/ surgical wards. For example in the 350 and 137 bed hospitals the designated pain management beds were based in 33 and 30 bed wards, respectively, where nurses also looked after general surgical, vascular, urology and general medical patients. The observations occurred during six admissions that the researcher had during the period September 1998 – March 2000, thus according to Spradley's classification I became a complete

member of the patient group. The observations were undertaken when my pain was well controlled and I was either being stabilized on a new medication regime, or after recovering from having a new Medtronic synchronized computerized drug pump implanted. I was highly sensitive and aware of it being crucial that I withhold my personal views and experiences (as far as is humanly possible), so that theory emerged from the data and not from prior knowledge. However, because prospective participants identified me as 'one of them' it was helpful in developing gaining their trust and their participation. In addition, the fieldwork was not undertaken until after the focus groups were conducted where client issues, experiences and concerns had been elucidated and these were initially used to focus the participant observation, rather than issues and concerns based on my own personal experience. Since I was a member of the patient group, I did not participate in nursing ward routines, except those directly organized for 'pain patients' (for example, attending the occasional morning 'pain patient group' meeting conducted by the pain clinical nurse specialist at one of the hospitals). In the larger hospital permission had been granted for me to conduct the research on a particular ward to which pain patients were generally admitted by one of the Pain Specialists who was participating in the study. During the period of participant observation 15 clients were observed and participated in the study. The participant observation schedule is outlined in Appendix 23.

Field notes relating to these observations included verbatim quotes, critical incidents, insights, interpretation and self-reflection. This analysis directed further data collection. When categories were reaching theoretical saturation I gradually ceased participant observation whilst at the same time, negotiating with interested and relevant participants, setting up formal interviews.

iii. Postal Survey

Due to the controversy surrounding the use of LTOT in the management of CNMBP it was decided to use the survey method to access those that met the entry criteria who resided in the rural communities and in other States and Territories. Data from focus groups, participant observation and the literature was used to develop postal survey questionnaire seeking theoretical saturation. The 24-page questionnaire (Appendix 24) was tested on focus group participants. This method was another way to ensure that my own personal experiences and views did not dictate data collection. The questionnaire contained five sections a) personal profile b) chronic pain profile c) disability profile d) pain management profile, e) suffering & chronic pain). Whilst a number of questions involved ticking appropriate boxes, many were open-ended and required the participants to express his/her response using their own language. Generally, these questions produced a very valuable source of data, with many participants writing on any piece of clear paper on the page (for example writing in margins and using their own paper). All interested participants were sent an Explanatory Statement (Appendix 9), a questionnaire to complete by a specified date (two weeks from receiving the questionnaire) and a pre-stamped, addressed envelope to return the questionnaire. Two hundred questionnaires were distributed to CNMBP receiving LTOT throughout Australia using Pain Specialists and allied health professionals who were members of the APAS. Fifty-four were returned, four of which were not completed and thus were not part of the study. One inter-state participant had voluntarily included their e-mail address and subsequently agreed to be interviewed using e-mail. Whilst the majority came from Victoria, each State and Territory were represented in the sample. The return of completed

questionnaire was interpreted as consenting to participate in the study.

iv. Formal Interviews

Interviews were undertaken by engaging the person in conversation, dealing with environmental distractions and barriers and utilizing verbal and non-verbal strategies to promote communication. Such strategies include attending, active listening, and attending to verbal and non-verbal cues. The utilization of reflecting, clarifying and re-framing, where relevant, facilitated better understanding of participants' meanings and understandings on issues/experiences being explored (Minichiello, Aroni, Timewell & Alexander 1990).

Seven participants agreed to be formally interviewed, three were interviewed on numerous occasions (4,3,2 respectively) during the period 1998-2002. Interviews varied in length in response to participant's pain level and focus of discussion. Four participants were in hospital at the time of their interview. One interview was conducted using e-mail from a participant who lived in another state and had completed a survey and voluntarily included his e-mail address in his survey form saying he would like to be involved in anyway possible. The interview involved eleven emails over an 18-month period 1999-2001. Each of four participants who were interviewed in hospital had private rooms and a 'do not disturb' sign was placed on the door after seeking authorization and to ensure privacy. Other interviews were conducted either at the client's home or at the researcher's home. Each interview was conducted when the patient was feeling comfortable and it was not commenced until approximately 1hr after their last medication for pain relief. The interviews, except the e-mail interview, were audiotaped and notes were taken during the course of the interview after receiving written consent from the participant

(Appendix 13). A psychologist was either in attendance at the hospital or contactable by phone, at the time of the hospital and home interviews, in the event that the interview may have raised feelings to a level that the interviewer felt that professional intervention was required. However, these circumstances did not arise.

A number of issues shaped the construction of the interview schedules. Guidelines for the initial interviews were drawn from the focus group discussions. The schedule of interview questions based on previous data collected is contained in Appendix 25. The emerging theory, current issues, survey responses and my relationship with the participants also influenced the questions or sequence. In addition, I was continually cognizant regarding my own and participant's pain levels and its' influence on concentration and thus the necessity to structure in appropriate breaks in interview schedules. The interviews generally lasted 1.5 hours real time but conducted over approximately 3 hours when one includes breaks. Whilst participants either knew, or were told by me that I too suffered CNMBP treated with LTOT, I at no stage focused on my perceptions and experiences. However, participants often stated that I understood what they meant, when others "had no idea". In this scenario I used it to ask the participant who 'they' were, and 'what' did they have no idea of? Often exploration of negative incidents facilitated clarification of criteria used by each individual to evaluate a positive experiences and/or outcomes. Strauss (1987) refers to this process as 'flip/flop'. What ever the participant said was accepted and at no time were they coerced or pressured to agree to a predetermined phenomena or structure. At the closure of the interview, which was negotiated with the participant, permission was sought to contact the participant at a later date if further clarification was found necessary.

The definition of concepts dictates theoretical need, the development of hypotheses and their subsequent relationships, thus the need to be continually simultaneously redefining concepts and their relationships (Strauss & Corbin 1990, Fiveash 2000). Constant comparisons across incidents and participant's experiences necessitated that the interview process was continuously responsive to accommodate such scenarios. In a continual effort to achieve theoretical saturation and advance theory, there was constant comparison of data and cross validation of field notes and existing literature. Whilst acknowledging the context of the individual's experience, simultaneously the researcher was also attempting to discover the diverse natures and aspects of the same situation. At the completion of the interview process all participants thanked me for doing the research and for 'telling their story'. They all expressed interest in receiving a copy of the findings of the study.

Data was gathered from various sources, focus groups, participant observation, informal and formal interviews, field notes, memoing, personal documentation, and institutional statements of philosophies. This data was compared athwart sites and sources.

All data was considered confidential and stored in a locked cabinet. Anonymity was maintained by not using names of clients or facilities. Participant's names were coded and the codes were placed on transcribed material, field notes and memos. Transcriptions were stored on computer and protected by a password, tape recordings, field notes and memos were stored in a locked filing cabinet in my home office, to which I was the only one to have access to the key. Participants were informed that apart from my supervisors the transcriber and myself no other person would listen to the tape recordings or read the transcriptions and field notes. The individual experiences of each

participant were amalgamated during the analytical process that no individual or his/her experience could be identified.

Participants were asked permission for the researcher to disseminate the findings of the study through journal articles and conferences for health care practitioners and consumers. In accordance with university requirements the computer files and a hard copy will be stored for five years after publication in a locked cabinet. Once the study has been completed transcripts and tapes will be destroyed.

Emden's (1993) guidelines for qualitative research were adhered to in this study which included that a) participants being partners, not subjects; b) claim only realistic outcomes of the research; c) comply with ethic's committees; and d) acknowledge all contributions.

DATA ANALYSIS

The aim of data analysis in this research is to develop a substantive theory of how people with CNMBP who elect to use LTOT manage the consequences of their pain and treatment. Data from focus groups, interviews, participant observation, postal survey, documentation and literature were analyzed through a process of open coding, axial coding, theoretical coding and the development of the core category or process (Strauss & Corbin 1990). This was achieved through the process of manually coding data, comparing and contrasting codes, raising questions, collating the codes into categories and integrating categories and their properties into a theory. Comparison of data obtained from different groups, settings, interviews, and participant observation was undertaken to identify differences and commonalties. Through this process maximum variation and diversity is achieved. Memos writing together with further theoretical

sampling (directed by emerging theory), and theoretical sensitivity a diagram of the categories and their relationship emerged.

Coding was commenced as soon as possible after collection and continued until categories and properties emerged. Axial and selective coding was also utilized to develop and integrate emerging categories. This process was continuously refined until categories were reduced in number which were more abstract higher level concepts and their relationships apparent. Each analysis determined additional data collection until saturation was attained.

Data Coding

Before commencing open coding and listening to the audiotaped focus group discussions I first discussed with the independent observer the notes that they had recorded noted the body language and emotional responses to specific issues. In addition, in order to become immersed in the data, the transcriptions of the focus group discussions, interviews and field notes were read a reread before open coding commenced. Open coding is a process by which data is dismantled allowing the phenomena to be re-conceptualized through axial and selective coding permitting alternative views of the phenomena to be discovered. Transcribed focus groups discussions, interviews and field notes were coded manually line by line and sentence by sentence and code by code. Simultaneously, where possible, the analytical concepts were formulated using the participant's own language ("in vivo" codes). These were noted in the margins of the transcripts. What appeared to be critical incidents from the data were coded with accompanying theoretical notes reflecting my initial interpretations and ambiguities. Data was continually coded for process movement. Numerous concepts and theoretical notes

emanated from the initial data. Table 9 shows the development of one conceptual label

Data	Conceptual label
"It (CNMBP) changes not only your personality but your whole person. I just want me back". (Participant FG.1.97)	Losing self

Table 9. Open coding

Manual coding and analysis of data was adopted in preference to utilizing qualitative data computer programs to record and manipulate the data allowed me to develop a greater sensitivity to emerging themes. Following dismantling the data memos were generated that contained summaries of concepts, themes and ambiguities that were used to explore the features of these concepts and themes. The constant comparative method was used as new data was collected and analyzed. The data was examined to elucidate similarities and differences among conceptual labels and ambiguities explored. As analysis proceeded codes and concepts were formulated that represented the diversity of data which, where applicable, categories were merged with other categories. This process resulted in the development of concepts by either verifying or negating them in relation to new data.

Through a strategy of conceptual abstraction a varying number of conceptual labels were classed into categories. Table 10 illustrates the development of Vulnerability. This category subsumed 'Losing Self'.

Table 10. Conceptualization of the category 'Vulnerability'

Life changing
Losing self
Losing self esteem
Losing self worth
Losing income
Grieving losses
Damaging personhood
Stereotyping as addict, malingerer
Not being believed
Uncertain future
Black periods (in vivo)
Suicide thoughts
Shattering
Crushing
Overwhelming
Soul destroying

Axial coding was undertaken concurrently with open coding. The categories became the axis through which relationships were explored. Categories were analyzed to determine the conditions under which they occur, intervening conditions, and relationships to other categories and the consequences of such events. It is through axial coding that one relates sub-categories to categories. This strategy permits a way of analyzing the inter-relationships between categories and sub-categories in relation to causal condition, the context, related action and interactional strategies and their consequences (Strauss & Corbin 1990).

The discovery and development of the basic social process and core problem is achieved through selective coding. In addition, this strategy facilitates the systematic development and integration of the theory. It is the core social process forms the nexus, connecting all categories. Simultaneously with data analysis the literature was reviewed to explore designated categories. The regular review of the transcripts and codes by my co-supervisor facilitated comparison of emerging themes as well as obtaining a more in-depth and broader view of the findings.

Using the constant comparative method, data from focus groups, interviews and surveys were analyzed and contrasted with previous findings. Through theoretical sampling further participants were selected for observation and interview. Using Strauss and Corbin's (1990) Six C's combination of codes categories were structured into theoretical codes that gave density and meaning to the theory. These strategies determined the questions that I asked of the data, for instance why do some clients try and conceal their pain and suffering? How do they conceal their pain and suffering? What conditions led to this action/interaction? These questions emanate from the grounded theory paradigm model (Strauss 1987), that conceptualizes conditions, interactions, strategies and consequences. Theoretical memos facilitated the process of theory development and determined further theoretical sampling to test the embryonic ideas about the process of struggling/reconstructing. The total process of analysis gradually evolved as numerous categories and sub-categories were reduced, subsumed and discarded, whilst simultaneously a framework of a substantive theory emerged with one major category became the core problem while another major category was considered the basic social process. The remaining categories underlay either the basic social process or the core problem.

Memoing

Throughout the study the research process is documented using memos which record theory development (Strauss & Corbin 1990). Memos are an integral part of the grounded theory method. They can take a number of forms: code notes, theoretical notes, operational notes, and variations of these (Strauss & Corbin 1990). Memos are critical elements of analysis and they are written at the inception of the research project and continue until the final writing of the theory (Strauss & Corbin 1990). Memos recorded embryonic ideas/concepts to the formulation of categories and their relationships. Thus memoing informed theoretical sensitivity and sampling and determining the questions to be explored in other interviews and periods of observation. (Appendix 26)

Field Notes

Field notes encompassed detailed records of periods of participant observation and thus were a rich source of data (Fontana & Frey 1994). Informal interviews which were undertaken during participant observation were documented as soon as was practical after the event (Chenitz & Swanson 1986). An example of field notes is provided in Appendix 27, written on 3rd March 2000 after a period of observation on a medical ward, which also specialized in pain management. Field notes were an important source of data.

The discovery of a core problem, an experience shared by all participants in the study and a basic psychosocial process (core process) that elaborates on how the core problem was addressed. The core process connects and explains for all phenomena, including the change in conditions that manipulate action over time and demonstrates the consequences of these actions over time (Strauss & Corbin 1998). In this study the core process

slowly emerged while other categories were still being deliberated on. Not all categories were fully inter-related and totally explanatory in accordance with Strauss & Corbin (1990) that not all data has to be used.

Literature

A review of the literature was initially undertaken to provide a rationale for the study and to place the findings of the study in context (refer Chapter 1). The main literature review was undertaken to connect existing research and theory to the characteristics of the emerging theory. This review included psychological, medical and nursing literature. The literature was utilized for facilitating theoretical sensitivity, as a secondary source of data, theoretical sampling and for supplementary validation (Strauss & Corbin 1990).

Ethical considerations

Traditional ethical issues of informed consent, confidentiality and anonymity, accessing participants, lack of coercion, protecting participant from harm, maintenance of client's rights during focus groups, interviews and participant observation, in addition to the appropriate storage and disposal of data needed to be addressed.

SUMMARY

This chapter described the research setting, participants and the procedures used to collect, analyze and manage data. Focus groups were conducted in 1997 with 4 males and 7 female participants. Six participant observation periods and 7 interviews were conducted from 1998-2000. A postal survey undertaken from 1998 to 1999 attracted 54 respondents. In addition one participant in Western Australia was interviewed by Email. Data collection and analysis occurred simultaneously. The next four

chapters describe in detail the findings of this study, and relate the findings to the current literature in the field.

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CHAPTER 4. THE CORE PROBLEM - FRAGILITY (Part 1)

INTRODUCTION

The core problem for participants was fragility. This chapter will present, describe and discuss the causes fragility. In the next chapter (Fragility (Part 2)) the characteristics, contexts and consequences of the fragility will be presented. Fragility is characterised by the category vulnerability. As a consequence of feeling fragile participants may either become overwhelmed by feelings of hopelessness which entraps them to the depths of an existence which is focused increasing pain and suffering, loss of hope and risk of suicide. However, through successful pain management and medical/family/social and/or spiritual support they find hope and engage in authenticating and repairing personhood (core process).

Chapters six and seven address the core process - authenticating/repairing personhood. This involves the internal and external ways that participants address feeling fragile. Participants who struggle to authenticate/repair their personhood are able to live, rather than merely exist with their CNMBP and LTOT.

Within each of the following chapters the data is presented and explored and related literature discussed to contextualize the findings. This exploration facilitates development of the theory authenticating/repairing personhood, allowing concepts to be further defined, refined, expanded and understood within the current body of knowledge in the area (Glaser & Strauss 1968).

The findings of this study are described in this thesis using text, transcript excerpts and diagrammatic form. This process included my own interpretation and reactions to the data. The intention is to explain a theory of authenticating/repairing personhood that shows

how CNMBP treated with LTOT manage their fragility. Many categories and sub-categories have been identified as elements of this theory. These categories will be defined and their relationship to each other explained. The aim is to explain a theory of authenticating/repairing personhood, the conceptual categories, how they relate and illustrate concepts that support theoretical decisions, grounding each concept and explaining the decision trail. The paradigm model (Strauss & Corbin 1998) has been utilized to develop categories by exploring the causes, characteristics of the phenomena, the conditions and context within which it occurs, strategies for its use, consequences for its occurrence and relationship to other categories.

The use of long term opioid therapy for CNMBP remains controversial. Those sufferers electing to choose this form of therapy are susceptible not only to being labeled a malingerer as a result of their CNMBP, but also being stereotyped as an addict for taking opioids to manage their pain (Marks & Sachar 1973; Porter & Jick, 1980; Watt-Watson 1987; Lander 1990; McCaffrey et al 1990; Freidman, 1990; Cohen et al 2002). Most participants expressed having been especially fragile when they interfaced with the health care system and also with some family members. There was a general sense that substantial damage to personhood accompanies CNMBP itself. An individual's sense of feeling fragile varied in relation to causal, contextual and intervening conditions, the strategies used to cope, and the consequence of the experience. The development of fragility is listed in Appendix 28.

CAUSES OF FRAGILITY

Fragility emanates from a number of experiences related to CNMBP treated with LTOT. These include **being discredited**, and **'not being believed'** (in vivo code) by health care practitioners, especially nurses

and family members of clients struggling with CNMBP who are prescribed LTOT to manage their pain. Other causes of fragility relate to **'losing me'** (in vivo code), **undergoing losses/changes**, and **experiencing compromised health**.

The experience of suffering CNMBP appears the initiating factor that first arouses the client's awareness of feeling fragile. The degree of fragility felt varies according to a number of factors including the cause of their CNMBP, for example a workplace injury versus sports injury; how long they have suffered CNMBP and ethnicity. Taking opioids to manage their pain also adds to the degree of fragility felt, which can vary according to the length of time that they have been taking opioids and how they are administered. The longer their CNMBP and LTOT biography then the more likely the client is more likely to feel a greater sense of fragility. Furthermore, the data showed that if there was a third party involved relating to litigation and compensation the participant was at greater risk of experiencing fragility.

A variety of forms and degrees of fragility were evident in the data, as were the initiating factors and strategies employed to mitigate and repair their sense of fragility. Fragility may be directly or indirectly associated with either CNMBP or LTOT and a combination of both.

Causes of fragility are discussed in this chapter under the following headings **being discredited**, **'not being believed'** (in vivo code), **'losing me'** (in vivo code), **undergoing loss/changes** and **experiencing compromised health**.

BEING DISCREDITED

The data

Discrediting causes fragility. Chronic non-malignant back pain and/or the use of opioids initiate the discrediting process. Participants verbalized feeling discredited when they perceived having been negatively stereotyped and felt disgraced and demoralized by a particular dialogue, behavior and/or organizational policies relating to negating CNMBP and its treatment with opioids. The development of discrediting is listed in Appendix 28.

Many participants made comments on feeling negatively stereotyped, stigmatized and thus discredited. The initiator for the stigma was experiencing persistent back and referred pain and/or the taking of opioids to manage it. The experience of feeling stigmatized appeared most intense when they requested their prescribed opioid analgesia from nurses whilst in hospital. They interpreted nurses' comments and lack of concern as reflecting the nurses' perceptions of them as malingerers and drug addicts. Participants identified nurses, medical practitioners and extended family members as the main perpetrators of stigmatization.

The participant who made the following succinct quote was very agitated and overwhelmed with embarrassment as she acknowledged suffering CNMBP and taking opioids to manage it. She was acutely concerned about what other people thought about her; thus she was extremely disturbed after experiencing being stereotyped and stigmatized as a 'drug addict' which was a source of extreme embarrassment, guilt and immense suffering.

Ffg1 They (nurses) just think you're a drug addict and that's it.

The following quote reflected the trauma still felt by a participant who had been an inpatient at the hospital where the focus group was

being conducted. The initiator for feeling stigmatized was the lack of care shown when the participant was in pain and required analgesia.

Ffg3 I didn't want to come back here (hospital)...I spent seven weeks here and when I needed and was due for some analgesia I was always being told someone's at tea/lunch and you will have to wait and then I was forgotten about altogether. Your pain has low priority in relation to other patient's needs. They just see you as malingerers and drug addicts.

The following participant had referred to many occasions when she had felt stigmatized by nurses in relation to her taking opioids for her CNMBP. Whilst in the following excerpt the participant refers to the nurse's age, the focus group participants didn't believe the age of the nurse made any difference in respect to how they interacted with them in relation to their pain and analgesia.

Ffg7 My worst experience was when an older nursing staff member came down and said, "I'll fix her" and slammed two Panadeine Forte down in front of me and said, you're not having any more morphine". She made me feel like a child (even though I was her age), and a drug addict.

The following participant recalls her feelings when collecting her prescriptions for opioids at the pharmacy.

SI5 Even sometimes when I go into the pharmacy to get an Endone script filled I feel self-conscious. Once she (the pharmacist) looked me up and down and asked why I needed the large amount. It's a bit of a stigma.

The following field note was written after my first session of participant observation on a designated 'pain' ward of a large private

hospital that recounts my first impressions of how this designated pain ward managed CNMBP clients treated with LTOT.

FN. The ward was very cluttered and odorous. The 33-bed ward was managed by splitting the ward into two sections; one section treated cardiovascular clients and the other general medical and pain clients. Nurses were rotated through the two sections and allocated 4-6 patients each depending on the patients' levels of nursing dependency. Their work was task orientated and they relied heavily on verbal hand-overs rather than reviewing histories undertaking their own assessment of the client in relation to planning their nursing care. There was not a strong sense of teamwork. For example, if a patient buzzed and their particular nurse was at tea it was rarely answered by another member of staff. If it was answered they were told they would have to wait for their nurse to return from tea unless it was a call relating to an intravenous infusion or an emergency. A 'pain nurse' has recently been employed and works four days a week from 8am - 2pm and when she was on duty she was responsible for the all pain patients regardless of numbers. She was expected to run a group 'therapy' session with pain patients once a week, which in reality served mainly as an arena for airing grievances about the lack of care and understanding from other nurses. She has a psychiatric background and experience in conducting group therapy but has not received any in service education in relation to chronic pain and its treatment with LTOT. Due to staff shortages she was occasionally assigned non-pain patients as well, thus the group sessions often had to be canceled due to her heavy workload. This contributed to my general impression that

pain patients were a low priority in relation to receiving nursing care. The pain nurse verbalized that she felt isolated from the other members of the nursing 'team' and unsupported by the unit manager and that there was a lot of negative feelings amongst other nurses towards both pain patients and her role which was being trialed. Most of the other ward staff have received in-service education on chronic pain management including LTOT, although during my participant observations this was not always reflected in their interactions with CNMBP clients receiving LTOT.

The following field note relates to the impact of nurse's beliefs and attitudes towards a particular pain patient on this ward and the distress experienced by a participant's daughter. It also raised the efficacy of the in-service education on changing entrenched stereotyping and stigmatization of CNMBP and the use of opioids for non-cancer pain. It also relates to the issue raised by participants of them (nurses) 'having no idea'.

FN. I was interacting with a CNMBP female patient who was a widow, in her mid forties who had been on opioids for her chronic pain for 10 years. Her husband who had been a pharmacist had died from bowel cancer 3 years earlier. Currently her opioids were being administered through a Hickman's catheter which her 26-year-old daughter, a trained nurse, managed, as she was now requiring full-time care. She had had multiple admissions to this hospital and ward for management of renal and liver failure, and was well known to most staff members. Whilst I was talking with the participant the daughter arrived in the room very distressed and angry. I asked if I could be of any assistance and if it would help to talk about what had made her so distressed. She said the

source of her distressed state was that she had overheard a couple of the nurses referring to her mother as the pethidine addict in room XXX and that her husband had been a pharmacist and now she is ruining her young daughter's life. Her daughter stated that it had always been a constant struggle to have her mother's pain and disability taken seriously by certain nurses on this ward. She believed that if it were not for Dr. X her mother probably would not be alive. She believed her mother received better care and understanding on another ward where they don't regularly admit CNMBP clients and she was going to advise Dr.X that she didn't want her mother admitted to this ward ever again. The participant herself, who was very frail, said she had got to the stage where she no longer cared what they (nurses) thought about her, she knows Dr X believes in her pain and disability and his continuing support and care was all that mattered. She talked freely about her daughter's decision to become her full time carer. "We get on great and have a good time. We go to the Gold Class cinema regularly and have had several good holidays. My only wish is that one-day she will meet someone and get married and have a family. I want to be a grandmother".

The following field note and quote demonstrate the relationship between stigmatization and the issues of lack of trust and control between staff and CNMBP receiving LTOT. The first relates to another field note following a further participant observation period on the same unit as described above.

FN. I have been asked by the unit manager to critique a proposal for a Pain Management Patient Pamphlet which would outline certain protocols for pain patients. It mainly outlines restrictions on CNMBP being treated with LTOT

behavior on the ward. Stating if they were having an IV opioid infusion they are not allowed to leave the ward to visit the coffee shop or to have a cigarette. Smokers are to be chaperoned to go down for a cigarette by a member of staff and are not allowed to smoke between 10pm and 7am in the morning. Televisions are to be turned off at 10pm and not used overnight. These restrictions appeared not to apply to other non-pain patients admitted to the ward and thus seemed very paternalistic and discriminatory.

The following excerpts from an interview with one of the patients on the ward that summarizes her perceptions of, and reactions to, the nurses' attitudes to chronic pain and opioids.

Int.M. They (nurses) have got control over us, more so than other patients. I have had nurses' say to me, Oh how come you can walk around and have a cigarette if you are in so much pain? I have said, it is just as painful for me to lie in bed. It doesn't go away when I lie down, you know. I mean it does help to rest, and I'm tired for sure, but I can't lie down all day. It's got that stigma, the chronic pain...the pethidine.

The discrediting associated with CNMBP treated with LTOT contributes to sufferers' resisting the behavioral modification chronic pain management therapy that is the basis of many pain clinic programs (Jackson 1992; Speldwinde 2003). The consequences of discrediting can be demoralizing that can result in inadequate pain management, intense suffering and fragility.

The literature

Discrediting refers to the process of harming the good reputation of somebody. The term 'stigma' refers to *"any persistent trait of an individual or group which evokes negative or punitive responses"* (Susman 1994:16).

A number of chronic illnesses and disabilities have been explored in relation to their stigmatization. These include AIDS (Laryea & Gien 1993), psychiatric disorders (Brunton 1997), epilepsy (Iphofen 1990) and chronic pain (Fagerhaugh & Strauss 1977). Intrinsic to these conditions is that the sufferer is perceived to be different in a negative sense i.e. deviant, evoking an adverse social response (stigma) (Goffman 1963).

The original work on stigma undertaken by Goffman (1963) identified three types of stigma. First physical deformity, character blemishes e.g. dishonesty & weakness and tribal sigma, when a particular group is perceived differently from the norm. Goffman deduced that a person is discredited if they show any visible signs of difference, until then the person is only discreditable (Joachim & Acorn 2000). Thus, some CNMBP sufferers being treated with opioids fall into this 'category' and thus in certain circumstances they are in control of disclosing their condition. The research literature that examines chronic illness and stigma define social values and their enactment, as the source of stigma thus concluding that stigmatization is not within the jurisdiction of the sufferer (Joachim & Acorn 2000). Illness and disability are social constructs, thus changeable, and that it is the stigma associated with certain illnesses and disabilities, rather than the conditions themselves, that pose the greatest challenge for the sufferer to overcome. Charmaz (1983) study of the chronic illness experience using grounded theory identified being discredited as one of the major sources of suffering.

a therapeutic relationship based on trust. Participants agreed that there was a role for opioids in the management of some CNMBP but they had major concerns regarding tolerance, dependence and addiction.

Physical evidence constitutes an important part in the legitimization of pain for CNMBP sufferers. While in other conditions positive tests will be feared, for CNMBP sufferers a positive result affirms 'real' pain which is an acceptable condition worthy of treatment (Coulehan 1985; Seers 1996). The issues of testing, legitimization and visibility are closely linked. As a respondent said:

S26 I'm so healthy, and people look at me and they can't see and understand the severity of pain I am in.

"Because doctors just don't pay attention. They don't, they're not listening to what you say...they try and tell you that backaches are psychosomatic and your back couldn't be hurting, that there's nothing, no reason for it to hurt. X-rays don't show anything and you don't really have a backache. Oh yes I do, yes I do. But backaches are hard to see. Unless there's something that's a visible thing, it's kind of your word against who's looking" (Rhodes et al 1999:1191).

The experience of 'not being believed' appeared to be contingent upon whether a definitive organic cause for the pain could be found and a corresponding level of disability observed. Given that 'pain' is not visible some nurses continue to rely on 'pain behaviors' to assess its existence and severity despite the plethora of pain assessment tools and the "gold standard" of pain assessment being the patient's self reporting of pain. This continuance to rely on 'pain behaviors' amongst this cohort appeared to reflect their level of trust in patients suffering chronic pain being treated with opioids. Sufferers are more likely not to be believed when there is an imbalance between the

known pathology and the level of pain behaviors being demonstrated. Given that a majority of CNMBP patients receiving LTOT strive to be 'ordinary' in order to avoid dependence and minimize the stigma they often fail to exhibit the behaviors that the health care practitioners seek in order to validate their pain and disability and thus need for opioids. Furthermore, CNMBP sufferers whose tests are negative or inconclusive must confront *"a disjunction between their inner experience of the reality of a body that has become an ongoing negative and constraining influence in their lives and the 'normality' of their test results"* (Rhodes et al 1999:1196). They remain alienated from the health care system health care practitioners and themselves. Thus, this questioning of legitimacy is also related to the category of 'losing me' (in vivo code).

The literature

The need to be believed has been highlighted by Reid et al (1991), (Hitchcock et al (1994) and Seers (1996). Likewise, the literature emphasizes how common it is for health care practitioners and family members to question the authenticity of the patient's pain (Kleinman 1988; Bowman 1991). If, as a consequence of these doubts, the pain is described as 'imaginary' this can result in stigmatization (Bendelow & Williams 1995). Issues of validation and legitimation are critical for people with chronic illness (Kleinman 1992; Seers 1996). For CNMBP sufferers these issues are magnified by the fact that the pathology may be invisible both externally and internally (Jackson 1992). CNMBP, especially when it is the result of a work place injury, has attracted much attention with respect of legitimacy (Leavitt & Sweet 1986; Jayson, 1992; Tarasuk & Eakin 1995). Sufferers are reported as encountering suspicion in their workplace regarding the severity of their pain and disability and compensation entitlements (Ison 1989, Greenough & Fraser 1989; Tarasuk & Eakin 1995). An enormous

amount of literature has emerged which focuses on "compensation neurosis" in order to assist general practitioners to differentiate between 'real' and 'un-real' pain (Jackson 1992; Binder 1992; Jayson 1992; Leavitt & Sweet 1986; Ogden Niemeyer 1991; Skerritt 1987).

The problem of legitimacy that is experienced by CNMBP sufferers is potentiated by the current state of medical knowledge and treatment with respect of back disorders (Tarasuk & Eakin 1995). Whilst there has been major advances relating to imaging with the use of CAT and MRI scans, what constitutes appropriate treatment remains ambiguous and contentious. Furthermore, a definitive scan and diagnosis does not always provide immunity from accusations of malingering (Fagerhaugh & Strauss 1977; Rhodes et al 1999).

Illness that cannot be seen or affirmed by 'objective signs' threatens a crisis of meaning which most CNMBP patients will embark on a long pilgrimage to resolve (Kleinman, 1988). Thus CNMBP sufferers invest a lot of time and emotion into trying to objectify their pain through diagnostic tests (Rhodes et al (1999). According to Good (1994), *"one of the central efforts in healing is to find an image around which a narrative can take shape"*(p.128-129).

Rhodes et al (1999) study on the meaning of diagnostic tests in chronic back pain found that tests that demonstrated pathology were a positive experience for these patients because it gave them entry into the medical system and treatment. In addition it affirms to the patient that the CNMBP is 'not in their head' and they are not mad. When no pathology is visible CNBMB sufferers are further alienated not only from their body but also from the health care system and treatment. The importance of the pilgrimage undertaken by many CNMBP sufferers to gather proof that their pain is real through subjecting themselves to numerous x-rays and scans has been found to be related to a number of factors (Rhodes et al 1999). They include the:

Strong historical connection between visual images and the medicalization of the interior of the body, a set of cultural assumptions that make seeing into the body central to confirming and normalizing patients' symptoms and the sensuousness of diagnostic images themselves (Rhodes et al 1999:1193).

Although pain assessment and control is acknowledged in the literature as a high priority within nursing it is often under-assessed and unrelieved (Baillie 1993; Rutledge & Donaldson 1998). The literature also reaffirms that the patient's report of pain be considered the "gold standard" of pain assessment (Rutledge & Donaldson 1998). There are a plethora of reliable and valid pain assessment tools (for example McGill Pain Questionnaire) for the variety of pain experiences and patient ages (Baillie 1993, Rutledge & Donaldson 1998; Gloth et al 2002). Many authors have documented nurses' lack of knowledge relating to the use of opioids in pain management and the resultant under-medication of pain patients (Porter 1980; McCaffery, Ferrell, O'Neil-Page, & Lester 1990; Ferrell et al 1991; McCaffery & Ferrell 1994; Ferrell et al 1992; Wright & Bell 2001; Twycross 2002).

Chronic non-malignant back pain patients are not accorded the social recognition afforded to other patients with chronic conditions and trying to communicate ones pain and suffering can be as challenging as the pain itself (Rhodes et al 1999). The loss of feeling understood and lack of validation of their pain and suffering by family members, employers and health care practitioners is also well documented (Brooks et al 1989; Raymond & Bergland 1994; Henriksson 1995).

Pain is one of the most private of all human experiences; severe CNMBP can be responsible for the disintegration of the normal relationship between self and society, together with adversity of trying

to convey this pain experience to others (Gaddow, 1982; Scarry, 1985). Garro (1992: 102) states:

"Illness transforms the 'lived body' in which self and body are unified and act as one in the world, to the 'object body' where the body is a source of constraint and is in opposition to self".

'LOSING ME' (in vivo code)

Another fundamental form of suffering in relation to CNMBP treated with LTOT that causes fragility is the experience of *'losing me' (in vivo code)*. Chronic non-malignant back pain patients receiving LTOT, like other chronic ill persons, frequently experience erosion of their former identities without concurrently developing equally valued new ones (Charmaz, 1983; Thorne, 1993). Thus, consequently these loss of personal and social identities and self-images results in an altered and diminished sense of 'me'. The development of *'losing me' (in vivo code)* is listed in Appendix 29.

The data

Many participants reported enormous suffering with respect to the negative impact that CNMBP treated with LTOT had had on their personhood. Their negative self-images appear related to the stigma associated with CNMBP and opioids including inferences of addiction and malingering. A major impact appears related to the negative impact on their self-esteem.

IntC When I have been lying in bed for days in unrelenting pain, knowing that things aren't likely to change, knowing that I am alone in my pain, and knowing that I have made myself a social leper, my perception is that my pain has

Fagerhaugh & Strauss (1977) in the 'Politics of Pain Management' used the qualitative methodology of grounded theory and provided some important insights into the nursing care of chronic pain sufferers. In this study CNMBP clients with long medical/surgical biographies were found to be not highly desired clients.

"Their illness trajectory is unpredictable, difficulties in validating their pain and its source, associated with suspicion on its degree, and the limited relief options when the pain appears intractable lead to staff frustration and helplessness" (Fagerhaugh & Strauss 1977:117).

Furthermore, nurses strongly upheld the view that psychological factors were an important source of back pain that affected their interpretation of pain expressions and nursing care. The unequal division of power between nurse and client adds, because of the stereotyping of CNMBP clients as malingers and manipulators, to the nurse's problem of making accurate pain assessment and the client's task of legitimating pain (Fagerhaugh & Strauss 1977). Nurses' interactions with CNMBP clients were also found to be influenced by treatment choices with the "interlocking" of patient and doctor/treatment reputations. If the treating physician is considered by nurses to be too liberal with opioids then this had a negative impact on the care the clients received (Fagerhaugh & Strauss 1977:128). In addition, CNMBP seeking relief through surgery tended to be negatively stereotyped when nurses felt they would do better just "learning to live with it (pain)" (Fagerhaugh & Strauss 1977:18). Other nursing studies which have compared nursing attitudes towards, and assessment of, acute and chronic pain clients have consistently found a significant tendency for nurse to underestimate the pain of chronic pain sufferers, in contrast to acute pain clients (Teske, et al 1983; Halfens et al 1990). Another consistent finding is that the patient's medical diagnosis and underlying physical pathology predominantly influence a nurse's judgment

regarding pain (Fagerhaugh & Strauss 1977; Taylor et al 1984; Halfens et al 1990). The patient's ethnicity can also influence a nurse's judgement in relation to the administration of opioid analgesics (McDonald 1994; Bates et al 1997).

These results support other nursing studies which have suggested that it is stereotypic people, behavior and illnesses which determines nursing practice rather than individual client needs (Moss 1988).

Although there have been efforts to improve nurses' pain management knowledge, lack of understanding about basic pain management concepts remain (McCaffery & Ferrell 1997; Wright & Bell 2001). Given, as McCaffery & Ferrell (1997:175) state that nurses are the "*cornerstone to pain management*", nursing undergraduate curriculum should dedicate more time to this area of practice, which research conducted in America has shown that it can be as low as 8 hours (Zalon 1995). This knowledge deficit is especially troubling in relation to opioid analgesics. A Canadian study of 164 senior nurses found that 75% of nurses were unaware of both the beneficial and harmful interactions of opioids with other drugs nor did they know the duration of action of a number of common opioids (Romyn 1992). It has also been noted that this knowledge deficit in relation to pain and its management is further compounded by the lack of good role models in practice (Wright & Bell 2001; Twycross 2002).

The experience of feeling discredited was made worse when their pain was not well controlled, a time when they felt most vulnerable. Circumstances that increased the likelihood of being stigmatized included multiple admissions to hospital for pain management, being associated with a particular doctor who was considered by some nurses as being too liberal with prescribing opioids (Fagerhaugh & Strauss 1977; Gardner 2000). Discrediting is prejudicial and

detrimental to all aspects of treatment. To feel discredited is, in fact, to experience a number of negative consequences, from *"not being seen, to not being heard, to a sense of deficiency and shame....these patients betrayal occurs at a deeper level than merely the personal"* (Rhodes 1999 :1201).

'NOT BEING BELIEVED' (in vivo code)

A dominant cause of fragility is *'not being believed'* (in vivo code). Issues of legitimacy underlie the experience of *'not being believed'* (in vivo code).

Participants reported that doctors, nurses, families, friends and/or work-mates either do not believe their pain is real or they do not believe its intensity and its subsequent disabling effects. The implications and accusations that their CNMBP was not severe enough to warrant opioid therapy constituted a moral assault to them. The resulting shame and anger made establishing their credibility a major goal. The participants describe circumstances that invariably led to disbelief and invalidation, which they have to purposively, although sometimes to no avail, protest if they are to retain a sense of integrity of their own experience of CNMBP treated with LTOT. The development of *'Not being believed'* is listed in Appendix 29.

The data

Credibility issues from *'not being believed'* (in vivo code) was considered by some participants to reflect having been stigmatized which then impacted on the nursing care they received. Participants said that sometimes it wasn't just what they said but how they said it.

Mfg5 When I have buzzed for an injection I have had nurse say "why don't you try and wait another hour and anyway where does it hurt?" You know they don't believe your pain and you are made to feel like you're a malingerer and drug seeker.

Int.H People don't understand chronic pain and analgesics. It angers me the way chronic back pain is depicted in the Workcover (television) advertisements. Nowhere do this group of patients get depicted truthfully. I have had doctors say that it (pain) is in my head. You sense the nurses judging you, you get very good at reading faces of those that believe and care for you.

The participants also spoke about the issue of 'not being believed' with respect to the general lack of understanding by both professional and lay persons and the consequences in terms of their self-concept. Participants' reports of pain severity and disability was more likely to be questioned when there was no demonstrative pathology to account for their symptoms. However, even when there was organic pathology some still did not receive empathy and appropriate pain management due to ambiguity relating to severity of pain and level of disability and reluctance of general practitioners and specialist medical practitioners to refer them to doctors and centres who specialized in pain management. Many regarded it a struggle to get their total suffering acknowledged and to receive appropriate pain management.

S46 The years of having doctors tell me that my pain was psychological in origin (now proven wrong) has had an enormous effect on the way I view myself as a person. At the time, it created a lot of self-doubt, which I have had to really 'work' on. It severely affected my sense of self worth. I felt totally worthless and useless. Although I am

much improved in this area now (due in large part to an extremely supportive doctor who actually totally believes in me and my pain, and a lot of 'work' on my part), I still have issues in this area i.e. of how I see myself, as well as issues of mistrust of both doctors and nurses.

IntCS My pain has devastated my existence. It has resulted in my integrity being discredited by those who do not understand or believe my pain and disability.

Some sufferers reported experiencing a sense of abandonment and when the treating doctor could not find any definitive cause of their pain.

Ffg1 I had doctors who were telling me there was nothing wrong with me at first, and that's the hardest part, you are suffering and they are saying nothing is wrong. Until you find the right doctors you struggle.

S36 I wished the medical profession would not blame the patient for their inadequacies. If they can't fix it then it doesn't exist. They sit in judgment when they have no idea what you are going through and how low your self-esteem is already. They leave you feeling lost with no where to go.

S27 Because I can't show people my pain I have experienced a lack of understanding and some times disbelief from other people.

Often the original cause of a person's CNMBP remains the focus of medical attention and as a consequence they are sometimes reluctant to explore other reasons for persistent pain following 'successful' surgery.

S34 When my injury first occurred my general practitioner seemed disinterested. I finally managed to see an orthopaedic surgeon and had a myleogram that showed two bulging discs. I had surgery but had severe pain when I came home from hospital. The local GP told me it was 'mind over matter' and that I couldn't have severe pain any more. Seven weeks later a 3/4 of a hypodermic needle was removed from my back. After this incident my GP has never challenged my pain level.

I invited a group of nurses who cared for CNMBP sufferers who are treated with LTOT to discuss any issues they had related to caring for this group of patients. The following is a summary of excerpts from the taped discussion, which particularly relate to the issue of pain legitimacy and patient credibility.

Nfg. Participants generally associated CNMBP with failed surgery, compensation and stigma. Whilst it was generally acknowledged that many CNMBP patients are courageous there was also a prevailing view that a significant number of these patients tended to be depressed, egocentric, manipulative and defensive unlike the rest of the community. Validating a CNMBP patients' levels of pain and need for opioids was considered by all to be difficult and problematic. The majority relying on the patient's physical appearance and level of functioning rather than what the patient say is their level of pain. A number of participants expressed a lack of trust in relying on patient self-reporting of pain and 'pain tools' which is not consistent with medical/nursing literature. One nurse said she never believed anything a 'pain patient' said which she acknowledged was problematic professionally when one is supposed to be referring to patients as persons rather than by their diagnosis as well as creating

devastated my very existence. It has resulted in my integrity being discredited by those who do not understand my pain, destroyed my self-esteem because due to the disabling pain I am unable to work and to contribute to society, thus I have lost my identity.

S35 I have low self esteem, lack of confidence, am withdrawn, depressed, anxious and frustrated as a result of needing morphine to manage my back pain.

S27 I have low self-esteem, feelings of worthlessness and failure, lack of confidence and usefulness and general frustration due to my circumstances healthwise.

A number of respondents refer to their lack of utility as contributing to their fragility. This perceived lack of utility is often associated with feelings of guilt. The following is an example of such perceptions:

S09 Being less active means I do less, go out less, meet less people - this means I feel I contribute less to humanity and I feel useless. I don't like being dependent on anyone else and so feel that I am now a problem, I don't know myself being different. I feel I am boring, as pain is such an overpowering influence on my everyday life. I don't like myself because I can't do what I used to do and what others can do.

S45 Due to the severity of my back pain and the need to take narcotics to control it I now feel inadequate, guilty, useless and irrelevant.

S20 Decreased usefulness, lack of confidence and low self-esteem.

S34 I have experienced low self-esteem and guilt because my wife had to do everything for five years.

S18 I no longer contribute, it doesn't matter whether I am here or not.

This perceived lack of self worth and value is disturbing when it reaches a level when the sufferer questions the relevance of their existence. Over fifty percent (58.5%) of survey respondents (n=50) reported that feelings of 'not being believed' and stereotyped had provoked serious thoughts of suicide. Other respondents perceived they were less valued by society and not seen as equals within the health care system compared with general members of society.

S19 I am not paying my way and I am no longer a valuable member of society.

S23 It (CNMBP treated with LTOT) has decreased my ego and feel I am no longer treated as an equal.

FFG1 We want to be treated as individuals and not just a group of chronic pain patients. To be assessed as an individual and not have us being stereotyped.

S36 My self worth is declining, I am not as outgoing, less confident and more sensitive.

'Losing me' not only referred to their changed identities as a result of their respective pain journeys but some felt that it was a concept that related not only to the 'who' they felt they had become but the 'who' they had been and the 'who' they had wanted to be. The following participant felt that it was a concept that some health care practitioners did not fully comprehend.

Ffg5 I went to a psychiatrist who asked me what I wanted back and I said I just want "me" back. He couldn't understand what I meant by it.

For some participants they talk about "losing me" with regard to their pre-morbid and future personhood. For example:

Int5 I think the fact that I am no longer able to work has meant the loss of "me". In my work I was able to identify myself as one of the workers. I played a role. I contributed to society. Not only did I do an important job where I helped others, but I also had a social life at work. Now that I am not longer able to do anything, in particular I am not able to do anything to help others; I feel I am no longer important.

Ffg1 Losing me is losing who I was and who I was going to be. I have lost my sexuality, passion and spontaneity. I lost my social network and identity. I lost my ability to engage in physical recreational activities. Nobody is interested in who I was and what I was hoping to be. It's like losing your soul.

The issues of loss and struggling to reconcile with their new personhood and lives emerged as major categories in the core process, which are discussed fully in chapter seven.

The literature

People with serious chronic illnesses struggle to have valued lives and selves (Charmaz, 1987; Thorne, 1993). The struggle is for control and self-worth. Chronically ill people want to be persons first and reject identities founded in invalidism (Charmaz, 1987; Thorne, 1993). In a qualitative study of 57 chronically ill persons with varied diagnoses 'loss of self' was found to be a fundamental form of

suffering as persons see their former identity disintegrating without being replaced with an equally honored self-image (Charmaz 1987). Thus, one becomes alienated from self. Younger (1995: 56) describes alienation as *"a sense of homelessness, a lover's quarrel with mankind"*. According to Seeman (1985) alienation alters one's relationship with self, that can be manifested in three forms: 'despised self', 'disguised self' and 'detached self'. Fromm (1976) believed that the alienated do not perceive themselves to be centre of their world and the conductor of their own 'music'. The alienated sufferer is incapable of being an authentic self when interacting with others (Younger 1995). Experiences of being discredited ignored and devalued also contribute to the isolation of chronically ill individuals and to their subsequent reappraisals of self (Schneider & Conrad 1981; Charmaz 1987).

For many it may not be possible to restore or salvage their old self and thus they begin a pilgrimage of reinventing themselves in terms of identity. However, according to Gannon & Gold (1988) the loss of self requires a mourning process that incorporates the 'rebirth' of the adapted self. In a phenomenological study undertaken by Leder (1990:76-77) he notes that a pain free body is 'absent' to perception. However, when experiencing pain, the body is perceived, becoming an 'alien presence'; *"aversive, involuntary and disruptive, the painful body emerges as a foreign thing"*. This may account, in part, for participants' reports of 'losing me' as a result of their CNMBP.

In a qualitative study of people with genital herpes participants were found to first try and protect themselves from devaluation due to the stigma connected to the disease (Swanson & Chenitz, 1993). They then try to renew their sense of self by balancing their lives through managing symptoms, changing life style and refocusing their lives. The final stage involved in preserving oneself related to adopting a management style that helped them regain control of information

about self (Charmaz & Chenitz, 1993). This process of adaptation to genital herpes with its' emphasis on regaining control, is similar to that of persons adapting to CNMBP treated with LTOT that will be addressed in Chapter seven.

UNDERGOING LOSSES/CHANGES

The losses and changes related to CNMBP treated with LTOT makes the sufferer vulnerable to feelings of fragility. The development of 'undergoing losses/changes' is listed in Appendix 29.

The data

The losses/changes associated with CNMBP treated with LTOT tend to be numerous and often permanent. They can occur abruptly (loss of job and income) or insidiously over extended periods of time (loss of self, memory, and relationships). The losses/changes can be intrapersonal, interpersonal and/or concrete. Many participants reported loss of 'me', work, sexual relationships and ordinary relationships the most difficult to reconcile and transcend. (*'Losing me'* has already been addressed separately in this chapter).

When the participants of the female focus group were asked to think about the changes that CNMBP treated with LTOT had had on their lives they initially responded with succinct words and statements as: GIGANTIC, MASSIVE, TOTALLY and COMPLETELY LIFE CHANGING. They were then asked to expand on what they meant by these words. The following quotes emanated from the discussion in the female focus group and issues again related to changes to their personhood including their pre-morbid identities and impact of losing their employment.

Ffg6. It just changes you, not just changing your personality but the whole person has to change.

Ffg2. It changes your whole life. I mean you stop work and this takes away your self-esteem.

Ffg5. I think the devastation of having to stop work, I think that was one of the worst things. I don't think a lot of people in the community understand that.

Ffg4. You lose your confidence. At social gatherings even if I do see someone I know I feel inadequate, I've got nothing to talk about. They're talking about maybe work, films and shows they've seen.

Ffg1 Work is actually part of who you are and so you've lost another part of you for which you grieve. It changes your identity and who you are.

The following excerpt from an interview with a male participant highlights the effects of subtle changes and losses and how they impact on his fragility.

Int.D It is not just the big things that you lose or that change but it's the little things. I don't ask anybody for anything, I'd rather do it myself. For example my wife wanted a blanket box, an old Baltic pine one, so I thought I am not paying the price they want for them, I'll make one. It gets me out into the workshop on my good days, I can't bear being idle. But I tell you it cost me a few bob, because I break things, drop things, throw things. I have a shocking temper, only personally, not with other people, except myself. I'm my worst own enemy. I get so frustrated with the pain because it affects your concentration.

The following quotes from part of the discussion in the male focus group where they openly discuss the impact of loss of sexual performance and how they felt this to be strongly tied to their altered perceptions of themselves as men.

Mfg2 There's a number of things that you loose. Like working and bringing home the money, taking care of your family, physically and sex is who you are as a man. I think it (sex) is part of who you are. What destroys you is not just the physical enduring stuff relating to the pain, it's the impact on your relationship, especially sex or rather lack of it. Also the pain and the drugs effect who you are as a person and what other people think of you and how much you think of yourself.

Mfg4 It's a hell of a reminder that our relationship and it (sex) isn't the same as it was before. It's a constant reminder every night.

Seventy-seven percent of survey respondents also felt that CNMBP treated with LTOT had negatively changed their perception of themselves as a sexual being negatively changed their sex life in regard to diminished or loss of libido, reduction in sexual activity and satisfaction.

The following transcript is from an interview I had with a young mother of two young daughters who had suffered chronic pain since the age of 10 due to scoliosis. Her losses/changes have in the main been gradual, although up to four years ago her pain was intermittent but since then it has been constant.

- I What impact has your scoliosis and resulting pain and need for narcotics had on your life?
- P *Oh a huge impact because it affects everything that I do every day.*
- I Is there any aspect of your life that hasn't been touched due to your chronic pain and its treatment with narcotics?
- P *No. It's pretty much all consuming. I talk about my 'previous life' - when I used to go skiing, play tennis, work and feel resentment. It seems to get harder each time you lose something else because it's like losing chunks of you. Your life gets smaller and more insignificant and you grieve for your former life.*

The following excerpt from an interview with a man who had been forced to retire because of his CNMBP gives insight how frightening, even for males, to undergo the losses and changes associated with CNMBP.

Int.D. Before I injured my back I had a "bloody" brilliant life...great business, great kids, great family, everything going for me. We own our own home and everything and all that, and now that has all changed and even now I am frightened. I am frightened about the future, especially financially and also that I may do something stupid when the pain gets out of control. Before I had the pump I overdosed on Endone or whatever I was taking for the pain. I don't think I meant to kill myself. I think it was mainly to control the pain, and must have taken too many. Like I've got a nice family to commit hari-kari, although I have often thought about it, very often, but I don't, no I don't think I'd do it but you never know, you can't say no, you never know. Because I live out in the sticks, and

because Dr X knows I get frightened at what I might do, that is why he makes me come into hospital when my pain gets bad. I know I am a man and I might look tough but I get very emotional and I get hurt very easy, you know, I really do.

I met this young woman during a period of participant observation. She had recently been married after a "whirlwind romance" and had had to be hospitalised due to breaking her arm after a fall at home and acute exacerbation of her chronic pain. She had fractured her radius and her arm had been set in plaster and her chronic pain was responding well to treatment. We talked about how she was finding married life given the added challenge of suffering CNMBP treated with LTOT.

Int.H It (CBMBP treated with LTOT) adds a whole murky dimension to married life. J has to do so much around the house. He does basically everything and in some ways I feel a little bit like I am a guest. He doesn't make me feel that way, but I feel that way because I can't participate in running the house, and J has his difficulties living with chronic pain because he hadn't seen me like this and feeling so powerless to help me. It puts a crimp in our life like planning to do something and then at the last moment having to cancel or, me not being able to sleep at night. On thinking about it, the little things mean as much as the bigger changes. I'm, in a state of constantly apologizing for not being able to do something and I find also that I grieve. I don't openly grieve, I don't inflict that on J but I am in a state of grief all the time for the things that I want and can't do, and for the life we are living because of what has happened to me.

The changes and losses experienced by CNMBP treated with LTOT, like other chronic illnesses, can transform the 'ordinary' into the 'extraordinary' with respect to people and lives (Kralik, 2002). Such transformation often leaves the person extremely fragile.

The literature

Historically, the word loss has been traced back to the thirteenth century English when it was synonymous with death and destruction (New Oxford Dictionary of English (2001)). It was later influenced by the word lose which originally meant, *"to be deprived of"* (New Dictionary of English, 2001). Shapiro (1993:4) defined loss as: *"the disruption of an attachment – an attachment to other people, body parts, to inanimate objects, to fantasies, to habits, and to life styles"*.

Persons suffering chronic pain experience loss (Roy, 1939; Shapiro, 1993). Loss can take a variety of forms (Harvey, 1996; Kelly, 1998). These include personal losses of physical activity; loss of memory and ability to think clearly; loss of interest and enjoyment of sexuality; loss of life as it used to be and loss of a future (Kelly 1998). Rando (1988) suggests two basic types of losses: physical losses, (for example, death) and symbolic losses (for example, losing self-esteem as result of CNMBP). Kelly (1998) posits that persons suffering chronic pain experience a sense of loss at the personal (for example, loss of self) and interpersonal levels (for example, loss of employment).

The personal loss experience of persons suffering chronic pain is well documented in the literature (Armentrout, 1979; Lebovitz 1979; Flor, Turk, & Scholz 1987; Holland, & Beeson 1993; Shapiro, 1993; Lewis, 1994). Siefer Abrams (2001) uses the concept 'ambiguous loss' to describe *"incomplete or uncertain loss"*. For example, people who suffer chronic conditions such as chronic pain may appear physically normal but radically changed in mind and body (Boss, 1999).

Chronic pain sufferers who lose control of their pain and lives, sexual desires and energy, lose their sense of self, need to mourn their old selves and reconcile it with their new identity (Armentrout, 1979; Lebovitz, 1979; Kelly, 1998).

Chronic non-malignant back pain sufferers, like others with a chronic illness, experience incremental losses which according to Lindgren et al (1992) result in chronic sorrow. In addition, for those like CNMBP sufferers treated with LTOT whose coping resources are already extended a further loss can overwhelm their capacity to cope (Murray, 2001).

The interpersonal and social losses of chronic pain are well documented in the literature (Brooks & Matson, 1982; Flor et al 1987; Manne, & Zaurtra 1989; Payne, & Norfleet, 1986; Raymond, & Bergland 1994; Roy, 1989; Shapiro, 1993; Kelly, 1998). Shapiro (1993) notes that interpersonal losses are closely related to personal losses given our sense identify, which incorporates our beliefs about our physical abilities and our sense of worth as a person, is molded over a lifetime of interactions and personal growth. A critical loss for CNMBP sufferers treated with LTOT is loss of family relationships (Henriksson, 1995; Kelly, 1998). Loss of family role with the inability to fulfil their pre-morbid duties and maintain the general feeling of intimacy with children and spouses was considered to be due to a lack of understanding by family members regarding their pain and treatment (Flor 1987; Henriksson, 1995; Kelly 1998).

EXPERIENCING COMPROMISED HEALTH

Experiencing compromised health also causes fragility. Chronic non-malignant back pain treated with LTOT with their related physical

and psychosocial disabilities results in feelings of fragility. For the development of 'experiencing comprised health' refer to Appendix 30.

The data

For the majority of participants CNMBP was a multi-sensory experience that involved more than one distinct pain experience in more than one location. Radiating pain was prevalent among participants. Their pain(s) was variously described as either burning, stabbing, deep ache, "like an electrical shock", "like a toothache" and/or "like an earache". The majority (92%) of participants reported that their pain was constant. Using an ordinal pain scale of 0=no pain 10=worst pain you can imagine, their worst pain ranged from 7 to 10 mean 9.70 SD .65 and the best pain relief they achieved ranged from 0 to 8 mean 3.77 SD 1.96. The majority of participants had a negative response to being asked to rate their level of pain by assigning it a number. The following excerpt from an interview with a male participant summed up the general view of participants in relation to being asked to rate their pain intensity using a 0 to 10 scale.

Int.D. I hate it when you are asked to give your pain a number. Don't get me wrong, I know why you are asking me but I have a problem with it all. First of all what I mean by my pain being a number seven might be totally different to what the doctor or nurse imagine what pain rated at number seven feels like. What you rate as 5 might be seven to me. Also it doesn't seem to matter what you rate your pain as because nothing happens. For example, once I had rated my pain as 9, I had just come into hospital and I was climbing the walls and ready to jump out the window. Yet the nurse didn't do anything except continue asking me all the questions that they do when you first come in. Even when I said, "can I have

something for pain?" She said, "I'll just finish filling out your admission forms and do your 'obs' first, then I will see what you are ordered". So what's the point in asking you in the first place? When you are admitted is often the only time you get asked to give your pain a number so I probably shouldn't grumble so much.

Many participants also reported loss of sensation, pins and needles and motor loss or weakness along various dermatomes. When the latter involved the lower limbs it put some at risk of falls requiring them to use some form of mobility aid, with a number confined to a wheelchair or reliant on an electric scooter.

Physical and psychosocial problems related to CNMBP treated with LTOT can be permanent or transient and/or permanent with intervals of exacerbation of symptoms. Participants reported a moderate level of physical disability, including those surveyed whose mean pain disability index score was 38/70 (SD 1.3), being most disabled in relation to occupation, sexual behavior and recreation. Sexual behavior emerged as a major problem for both men and women when they discussed 'losing me' (in vivo code), seeing it as critical part of personhood.

Sleep disturbance and fatigue were major health issues that participants related to either their CNMBP and/or LTOT, which negatively impacted on the ability to cope with their CNMBP and any adversity, thus increasing their fragility. All participants reported experiencing adverse effects from their LTOT (which often involved them taking more than one opioid (mean 3)). The adverse effects of LTOT, the most commonly being constipation, nausea, diaphoresis and memory loss, added to the participant's feeling of fragility. Memory loss was the most frequently reported side effect and the one that concerned participants and family members the most, thus increasing their sense of fragility. However, whilst participants

related these adverse reactions to their LTOT, the majority were taking a 'cocktail' of non-opioid medications as part of their pain management regime which could also account for some of these adverse effects. In addition, CNMBP and life style (diet, lack of exercise) could also be contributing factors to these 'adverse effects'. Some of the participants who were receiving their LTOT via an intrathecal pump reported experiencing joint pain, diaphoresis, lactation and premature menopause in females, and loss of libido with reduced testosterone levels in both male and females. These symptoms appeared to be associated with morphine and a number of participants had changed from morphine to another opioid because of them being unable to tolerate some of these adverse effects.

The following quote from a male participant expressed his dismay at the apparent lack of knowledge regarding the adverse effects of LTOT and how despite his continual complaints regarding loss of libido which certainly contributed to his fragility went un-addressed for nearly a year.

S.16 I think there needs to be an education program for doctors and nurses regarding the side effects of the medications now being used for chronic pain, especially morphine. They just seem to concentrate on constipation and nausea in addition of warning you of that taking too much can stop you breathing. I complained for nearly a year regarding the loss of libido even when my pain was well controlled but it was just brushed aside. It was a major problem, affecting my marriage and in the end my GP did a blood test to check my testosterone levels and when they came back they were below normal. He sent me to specialist who told me that it was related to the morphine and prescribed replacement testosterone that has made such a difference to both my marriage and my self-esteem. I consider lowering of testosterone a

significant side effect that should have been picked up earlier. Also that sexual problems related to experiencing chronic pain should be taken more seriously and investigated, rather than just accepting it as a consequence of having chronic pain because it can be a source of immense suffering for both partners.

The following quote from a woman who had an intrathecal pump that had been filled initially with morphine expresses how the adverse effects made her both physical and emotionally fragile.

Int. M. I had never had any problems with morphine when having injections but when it was put in my pump it was horrendous. The joint pain, especially in my wrists was agonizing and used to keep me awake at night. And sweat, I would have to change my clothes and the bed. I would drench everything and you felt so sick with it. Not nauseated sickness but feeling ill. It's hard to explain, but it became unbearable. Also I felt like I was permanently pre-menstrual and had a very short fuse. Although the pain control was good, I couldn't live with the side effects.

A number of both male and female participants said they were receiving testosterone replacement therapy in order to try and improve their libido. Infection was also a problem for some participants receiving their LTOT through an implantable device. Whilst they were infrequent, when they did occur they tended to be serious, even life threatening. One young nurse who was receiving her LTOT via a Hickman's catheter required open-heart surgery to remove an infectious growth emanating from the catheter that had attached to the atrial wall.

Int S. I live alone and was lucky that I had a friend visiting at the time I collapsed. He called an ambulance

and was able to tell them my history where to send me. Also I was fortunate to be looked after by an extremely good doctor who was convinced that something serious was going on and it wasn't until he order an echo-cardiograph that they found the growth. I was so shocked as I was always so particular with my aseptic technique when handling my Hickman's catheter. Whilst I hadn't been feeling 100%, I wasn't aware that I had a temperature and felt that it was my pain that was the cause of my lethargy and loss of appetite. Although it was terrifying to have to face open-heart surgery at the age of 35 I would still prefer to have my pain managed using a Hickman's catheter. At the moment I am waiting to have a intrathecal pump trial and in the meantime I am controlling my pain with hydromorph injections.

The majority of participants said that the pain relief they received from their LTOT out weighed any of the negative effects. Weight gain and inability to participate in any form of physical exercise was reported by a number of participants as a major concern with respect to them being at risk for cardiovascular disease. The majority of participants were taking anti-depressant medications for their analgesic effect and/or for treating depression. Depression was the most talked about psychological problem that participants discussed. Whilst most participants appeared to respond well to their anti-depressant treatment which constituted mainly taking medication, the majority of participants reported having suicide ideation at some stage. A number of participants had either been referred to or had sought out a psychologist/psychiatrist for professional help when they became depressed.

The literature

Bonica (1990) has long argued that chronic non-malignant pain is seriously misleading contending that chronic pain is never benign. He describes chronic non-malignant pain as a "*malefic force*" that can destroy sufferers lives and even lead to suicide (Bonica, 1990; Liebeskind, 1991). Chronic pain patients have been shown to experience significant reductions in physical, psychological, and social well-being, as well as in their Health-Related Quality of Life (Atkinson et al, 1991; Skevington, 1998; Becker et al, 2000; Clark & Cox 2002).

While the side effects of opioids are generally well known among medical practitioners and nurses, the adverse effects of LTOT are not so well documented. Pituitary dysfunction's such as hypogonadism and metabolic disorders including diabetes and thyroid dysfunction have been reported in clients receiving LTOT (Hockings, et al 2001). It has been known for two decades that intrathecal morphine can produce a syndrome characterized by amenorrhoea, polyarthralgia and spontaneous lactation (Lamb & Hosobuchi, 1990).

The medications being used for CNMBP listed on page 42 have a range of adverse effects including blurred vision, hypotension, hallucinations which, along with other adverse effects can further compromise CNMBP sufferer's health (Bramley-Moore et al 1998).

Studies of patients attending pain clinics have been found to be more likely to present with affective and anxiety disorders than any other psychiatric disorders (Reich et al 1983). Between 8% - 50% of chronic pain patients attending a multidisciplinary pain clinics for assessment are reported to have a current major depression (Smith, 1992; Ruoff, 1996). A negative correlation between coping activities in CNMBP and depression has also been reported (Weickgenant et al 1992). The literature also reports an association between both depression and antidepressant medication and sexual dysfunction

(Woodrum & Brown, 1998; Kennedy et al 1999; Phillips & Slaughter 2000; Zieba et al 2000; Baldwin 2001; Coyne et al 2002; Nurnberg & Hensley 2003).

The relationship between pain and depression remains controversial (Gray, 2001, Clark & Cox 2002). Clark & Cox (2002) cite two studies where approximately 60% of patients with depression report pain symptoms at time of diagnosis (Von Knorring 1983; Magni et al 1985). In another study of 211 patients with chronic pain attending a pain clinic major depression was significantly related to self-reported disability and negative thoughts about pain (Geisser et al 2000). *"Depression is not simply a co-morbid condition but interacts with chronic pain to increase morbidity and mortality"* (Clark & Cox 2002:82). The consequences for CNMBP sufferers who suffer depression that goes undiagnosed or under-treated can be devastating, with reports of increased rates of suicidal ideation, suicide attempts and suicide completion (Fishbain et al 1991; Fishbain 1999). The long-term use of codeine has been found strongly associated with dependence and depression (Romach et al 1999). These issues also highlight the importance of monitoring LTOT, so that unused drugs are not left unaccounted for in the patient's home where they could become lethal to the depressed person (Westerling et al 1998).

Anxiety disorders are also common among chronic pain sufferers (Clark & Cox 2000). Chronic non-malignant back pain sufferers have increased rates of both anxiety symptoms and disorders (Weissman & Merikangas 1986, Polatin et al, 1993).

Psychological factors have been reported to be predictive of long term disability in many chronic pain syndromes (Boothby et al, 1999; Johansson & Lindberg, 2000). Burton et al (1995) found that psychosocial variables accounted for 59% of the variance in disability associated with chronic pain. However, Turk and Okufuji (2002)

advise caution with respect to interpreting these results due what they believe to be intrinsic methodological problems. However, there is a plethora of research related to the successful use of psychological modalities in the treatment of CNMBP, especially when it is an inherent component of a multidisciplinary program (Hildebrandt et al 1997; Goossens, Rutten-van Molken et al, 1998; Vendrig van Allerveeken & McWhorter 2000).

SUMMARY

Fragility is caused by **discrediting**, **'not being believed'** (in vivo code), **'losing me'** (in vivo code), **undergoing losses/changes** and **experiencing comprised health**. CNMBP sufferers who experience stereotyping/stigmatization received prejudicial care within the health care system. The literature indicates stigma is a social construct and thus not within the jurisdiction of the sufferer. Furthermore, it adds to the problem of health care practitioners making accurate pain assessment and CNMBP sufferers legitimating their pain. Having one's pain dismissed, as not real has a negative impact on how CNMBP patients perceive themselves as persons and enormous source of suffering, sometimes even greater than their physical pain. The literature supports the notion that people with severe chronic conditions struggle to have valued lives and selves. Regaining control is an essential part of the process of 're-inventing' oneself, and it has been reported that CNMBP sufferers who feel in control of their pain experience less pain. The next chapter presents characteristics, contexts and consequences of fragility. Data is presented and explored in relation to the literature to contextualize findings.

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CHAPTER 5: THE CORE PROBLEM - FRAGILITY (Part 2)

INTRODUCTION

The core problem for participants in this study was fragility. This chapter continues to present data and literature in respect to fragility. This includes the characteristics, conditions, context, consequences and relationship to other categories of fragility. Fragility emerged early in the data. Fragility relates to feeling threatened, easily damaged, and destroyed, frightened and extremely vulnerable. Comments made throughout the interviews and on survey forms reflected these characteristics. Fragility is a threat to the individuals' sense of control over their pain and life especially during periods when their pain is exacerbated and they come into contact with the health care system, in particularly nurses.

FRAGILITY CONTEXTS

Background

Fragility is moderated by the context. Fragility may be transient or sustained, life threatening or trivial, manageable or unmanageable. Fragility may overwhelm some CNMBP sufferers to the point of incapacity and thoughts of suicide, while for others it can be perceived as a challenge and an opportunity to grow. Given that CNMBP is a life long experience for most sufferers, some learn to reconcile themselves to their chronic condition and circumstance; their expectations become more realistic, fear subsides and fragility is diminished. Fragility is more likely to become a major issue when the CNMBP patients' pain is out of control and they interface with the health care system or doctors working for a third party's interest. The core problem may range from a minor sense of feeling embarrassed when having opioid prescriptions dispensed by chemist with low or minimal feelings of fragility. In contrast to a critical

incident associated with uncontrolled pain feelings of loss of control over pain, self, life, personal credibility, fear, despair and hopelessness that produces high feelings of fragility. Some individuals who have a strong sense of self and connectedness are able to embark on a journey of repairing and authenticating personhood. For others who are unable to self-advocate, have low self-esteem and limited social support, endure a miserable existence void of hope.

The nature of the context of fragility can be quite complex.

Several factors influence the experience of fragility. These include the cause of the CNMBP, whether a definitive diagnosis can be made through diagnostic imaging, if there is a third party involved e.g. insurance companies, lawyers. In addition, the opioid dosage, route of administration, the prescribing doctor and the hospital unit to which they present or are admitted to can impact of their sense of fragility. If CNMBP patients have had negative experience in a particular unit, readmission to that unit may result in a high degree of fragility. Several issues may influence this response they include, nursing staff who have a negative attitude towards CNMBP and/or LTOT and hospital and unit policies. The CNMBP patient being admitted to a unit that does not usually care for CNMBP being treated with LTOT may experience less fragility due to the staff having no pre-conceived prejudicial attitudes towards these cohorts of patients. In addition, the reason for the admission can moderate the level of fragility experienced as can the level of family support. The individual attributes of the person moderate the experience of fragility including their ability to self-advocate as well as their social-cultural status, their values, beliefs, interests and medical biography. If CNMBP patients treated with LTOT are cared for by people who acknowledge their pain and respect their personhood fragility is

diminished. Temporal concerns may influence the individual's experience of the context. Not having ones pain believed and ones personhood not respected increases fragility.

At a state level factors that influence the context of fragility resulting from CNMBP treated with LTOT includes having to be registered with the state Health Department as an Schedule 8 (S8) opioid user. It is a legal requirement in all Australian States that regular prescribing of S8 drugs to any individual for prolonged periods require an authority. The authority specifies whether the opioids are to be used for treatment of cancer or non-cancer pain. Authority applications to administer LTOT are reviewed by a medical panel and are issued for a designated period of time, after which a new Authority must be obtained. Authorities to prescribe S8 opioids are issued by a relevant body within each State Health Department. For example, In New South Wales the Pharmaceutical Services Branch (PSB) of the State Health Department is responsible for the issuing of S8 Authorities and in Victoria they are issued by the Department for Drugs and Poisons (Bell 1997). The government monitoring of type, amounts and points of dispensing of opioids, including the government campaigns related to illicit drug use and addiction to opioids influences community attitudes towards opioids and concern regarding drug abuse and addiction that can impact on the context of fragility. Also at the State level worker's compensation Acts and advertising campaigns often compromise CNMBP sufferers that can also influence the context of fragility.

The literature

Fragility has been discussed in relation to a variety of topics. These include economics (Benick 1995), archeology (Hylands (1996), ecology (Smith 1990) the human condition (Kramer 2002), psychiatry (Koide et al 2002), orthopaedics (Seeman 2002). Fragility in these studies

generally referred to a threatening circumstance that put something or someone at risk of breaking or being destroyed. Fragility has only been discussed in relation to back pain in one Canadian ethnographic study of the experience of work-related back problems (Tarasuk & Eakin 1994). This study found back injuries left many workers with a sense of fragility and vulnerability (Tarasuk & Eakin 1994).

Perceptions of fragility and increased susceptibility to re-injure added to workers' feelings of heightened physical vulnerability and to the belief their back problems would in some way be lifelong problems (Tarasuk & Eakin 1994:60).

Fragility implies a position and condition of extreme weakness. The Oxford Dictionary of English (2001) defines fragility "*easily destroyed, damaged, threatened; not strong, delicate, vulnerable*".

A qualitative study undertaken by (Charmaz 1983) using the grounded theory method explored the source of suffering in people experiencing a variety of chronic illnesses. She found that the primary source of suffering amongst these chronically ill patients was their extreme concern regarding loss of pre and post morbid self that resulted in them perceiving "*themselves and their lives as fragile*" (Charmaz 1983: 190).

In the literature there are several studies that have been conducted over the past two to three decades on the subject of vulnerability (a characteristic of fragility) and health that will be reviewed separately.

CHARACTERISTIC OF FRAGILITY - Vulnerability

The data

A characteristic of fragility is vulnerability. The development of vulnerability is listed in Appendix 30. According to the data

participants feel vulnerable because they have minimum control of the pain, life and are emotionally and physically exhausted. Dimensions of vulnerability vary with the importance it has for each individual. Characteristics of vulnerability include the nature of threat and harm and the extent to which the sufferer has control over his/her pain, personhood and life.

Vulnerability is experienced and problematic when:

- Pain is out of control;
- Fear that pain cannot be controlled and that it will get worst;
- There is suicidal ideation;
- Perceive loss of control over pain management regime;
- Experience loss of independence;
- Discredited by nurses, doctors and family members as malingerers and addicts;
- There is a lack of family/social support;
- There is a lack of trust;
- Not being believed;
- Reliant on technology (implanted computerised drug pumps) and doctors; who control it;
- There is no definitive diagnosis;
- Their personhood is damaged;
- There is a third party involved eg insurance company, lawyers, and
- CNMBP sufferer is a smoker.

Vulnerability decreases when the pain is well controlled and the sufferer is in control of his/her pain management regime. It also decreases when the sufferer's pain, suffering and LTOT is acknowledged and validated by health care practitioners, especially nurses, and family members. A strong sense of self and connectedness also decreases vulnerability. As does being engaged in

diversional therapy. For example, art, handcrafts, education. Furthermore, the absence of a third party, such as solicitors and insurance companies also decreases vulnerability. For some faith in a transcendent spiritual/religious being can decrease vulnerability.

Strategies that maintain vulnerability include, giving up control of pain to another person, for example, nurses, doctors, family members; fear of engaging in pain provoking activities and disclosing their condition and treatment to people who lack empathy and understanding. Being poorly informed in relation to LTOT and its' long term effects and the support available to them increases their vulnerability. The consequences of vulnerability are sliding into depression, dependency, and lack of normalcy and fragility.

The following transcripts are participants' report on their experiences of vulnerability.

Fear that the pain will not respond to treatment and that in the long term it will get worse is evident in the following quote:

Int.H It worries me greatly because I wonder how much worse can I get. It's horrendous and scary leaving me feeling very vulnerable and without much hope.

The following excerpts are from the parents of young divorcee who lives alone and whose CNMBP is treated by a cocktail of oral medications as well as high dose, intramuscular morphine. Their concerns relate to their daughter's vulnerability of becoming addicted to the morphine and home security.

P It's (LTOT) something that I can understand from the point of view of her problems that she needs something of

that strength, but it worries me with all the other medications she takes. It does worry me as to.....you read things in the popular press about the fact that people sort of started off on it because of the need, then carried on taking it because they couldn't do without it, and that concerns me.

P It is a concern that she lives alone and she does have a lot of stuff (medication) at home which could make her a target for a break in. Since her specialist had a heart attack about a year ago and she only had a weeks supply, she now has at least an extra two weeks supply in the house, which does concern me. She really did have a psychological drama about it (specialist's heart attack) because she knew the local general practitioner wouldn't prescribe the dose she was on.

The following excerpts from the female focus group discussion refers to the lack of understanding shown by families when sufferers return home after hospitalisation. It reflects a lack of acknowledgment of their pain and the re-adjustment necessary when making the transition from hospital to home and often from one pain regime to another that reflects their vulnerability and heightened fragility.

Ffg8...once you've come back home they think Mum is home again..... so things are back to normal. I did a stupid thing I went home and couldn't stand the mess so I tidied up, swept the floor....their standards are not mine, and that's the part I hate.

Ffg4 I'm all right when I am in hospital, but it's when I go home. Oh my God I'm suicidal. Hospital I think becomes

a cocoon where you are protected and thank God I get some relief. It's the lack of support when you are discharged.

Ffg7 Last time (I was discharged) I was so close to knocking myself off because the way I felt physically & mentally. You've got to get your strength (physical) up as well as your mental strength to fight it again. It takes me so long to get myself together.

The following quote reflects the fear and uncertainty that those CNMNBPs sufferers who have their LTOT administered through an implanted, computerised pump.

Int.HG Well never knowing, never knowing with the pump. There is the possibility of things going wrong with the pump.

S50 Having a pump is like a techno/medical marriage, you are totally dependent on the doctor or nurse who controls the computer. You have to trust that they are fully concentrating on you when they are programming the pump because they could inadvertently knock you off by either incorrectly filling the pump or incorrectly programming the pump. It has happened. You feel vulnerable. It requires trust.

The following quotes highlight the issue of 'lack of understanding' amongst health professionals, families and the community that not only negatively impacts not only on the sufferer but on family members trying to come to terms with their situation.

S35 GPs need to complete a course in back pain management. Huge ignorance amongst a lot of them. You are fearful at what has happened to your back without them telling you "it's all in the mind".

S27 Great pressure has been put on my marriage and has affected my children who are withdrawn especially the youngest. Lack of understanding of other people, especially those close, because you can't see pain.

S23 On Workcover I nearly lost everything, including my house - I didn't know my rights then but I do now.

S35 I saw Workcare doctors, one was tremendous the other one an animal that lacked any understanding and patience. I tried rehab to get back to work and was treated like a moron. Stripped of any meaningful work. Almost had a breakdown because of the callous treatment.

Int.HG It angers me the way CNMBP is depicted in the Workcover ads; nowhere does this group of patients get depicted truthfully.

The following excerpts from sufferers and family members relate to the uncertainty of CNMBP treated with LTOT which, they believed increased their vulnerability.

P It's difficult planning things ahead because you don't know from one day to the next how bad your pain is going to be. It appears to have a life all of its own.

P It (CNMBP) goes up and down, better some days than others, you can't predict. So it does make planning difficult which can be pretty frustrating, as you slowly become socially isolated.

All these participants speak of their experience of vulnerability resulting from suffering from CNMBP treated with LTOT. As previously discussed many experience suicide ideation from not being believed and lack of understanding from nurses, doctors, employers, insurers and family members.

The literature

In the context of this study vulnerability is about being feeling threatened, scared and/or harmed by a particular health care experience. Vulnerability is a complex phenomenon that may be actual or potential. According to the Oxford Dictionary of English (2001) vulnerability refers to *"exposed to the possibility of being attacked, harmed either physically or emotionally"* (2001:2073). In the literature vulnerability has been defined as a gauge of distress (Lazarus 1966), irresolute of health care outcomes (Tahan 1998) and regard for risk of iatrogenic events and the inherent lack of control relating to them (Ellett & Young 1997). Whilst the literature on vulnerability emanates from a number of disciplines, the majority arises from nursing where it has been discussed in relation to *"health, control, measurement and other theories"* (Fiveash 2000: 148). Three Australian nursing studies have made reference to vulnerability and clients (Irurita 1996, Lawler 1991, Fiveash 2000). The perceived degree of control over ones condition or circumstance impacts on how vulnerable one senses (Rogers 1997). The greater sense of control over ones pain the less vulnerable one becomes.

Vulnerability is contextual and fluctuates along a continuum from nil to high state of vulnerability according to personal and social circumstances (Ellett & Young 1997; Murphy & Moriarity 1976; Kessler 1979).

There have been a number of tools and models developed to assess an individual's risk of vulnerability (Ellett & Young, Rogers 1997). Uncertainty was deemed to be the major risk factor for vulnerability by Tahan (1998) in a study of patients awaiting heart transplant. Many CNMBP sufferers treated with LTOT live with uncertainty in relation to their pain trajectory and response to various pain regimes including opioids. According to Fiveash (2000:149) *"Vulnerability is shaped by the individuals' perception of illness-related events, characteristics of the experienced events, ability to process information, availability of resources and psychosocial support, ability to recognise and classify the experienced events and efforts to reduce uncertainty"*.

The concept of vulnerability has been incorporated into a number of nursing theories. Irurita (1996) an Australian nursing scholar developed a grounded theory of preserving integrity that had vulnerability as its core problem. In this study vulnerability was found to be associated with a number of factors, including compromised health state, nurse/patient interactions and equitable relationships and age of patient (Irurita 1996). The core process for addressing vulnerability was preserving integrity (Irurita 1996). In another Australian nursing study (Lawler 1991) vulnerability was linked to uncertainty, pain, diagnosis and treatment in an alien environment. Fiveash (2000), using grounded theory, had vulnerability as the core problem in relation to addressing how clients achieve and maintain a sense of control over their health whilst recipients of health services. The core process for addressing

vulnerability was purposefully activating being initiated by finding hope.

Vulnerability and invulnerability have been denoted as a psychological condition (Rose & Killen 1983). The degree of vulnerability experienced or perceived varies for each individual. This variability is, according to a number of scholars (Rose & Killen 1983; Murphy & Moriarity 1976; Rogers 1997) due to vulnerability being dependent on the combination of two factors physiological/psychological traits and life events.

How individuals respond to vulnerability can have a negative impact of their health and well being (Seligman 1992). Situations or events that provoke feelings of stress, apprehension and fear have been shown to have a negative affect on the endocrine and immune systems predisposing vulnerable persons to life threatening health problems (Peterson et al 1993; Leibeskind 1990).

CONSEQUENCES OF FRAGILITY - PASSIVELY RESIGNING

The data

The consequences of feeling fragile are that individuals may decide to attempt to address fragility and work toward repairing and authenticating personhood or passively resign. The development of passively resigning is listed in Appendix 30. Passively resigning is seen as accepting and surrendering something undesirable. For participants in the study passive resigning was illustrated by despairing comments such as *"death can't come soon enough"* feeling their situation is completely hopeless and overwhelmed by their intractable CNMBP. Conversely hope was illustrated by comments such as *"I look forward to being a grandmother"*. Individuals who

passively resign are either incapable or elect not to address fragility. Participants can be divided into two groups. One group who passively resign to being fragile and another group that find a sense of hope. Those sufferers who find a sense of hope and have the will and ability to take control of their life and pain are able to repair their damaged personhood and live a life where pain is not in control.

Passive resigning

Passive resigning occurs when a sufferer does not have the will, ability, health care resources and has a sense of hopelessness to control their pain and life. Passive resignation occurs when the sufferer's:

- Pain is poorly controlled,
- self esteem is low,
- is fearful of engaging in activities that might exacerbate pain,
- is uninformed and unaware of treatment options,
- experiences no hope of CNMBP improvement,
- experiences sorrow,
- is treated by others as invisible, drug dependent, and
- allows others to take control of the situation.

Individuals who passively resign themselves to their current condition and circumstance may not possess the personal and/or social resources to take control of their pain and life. Furthermore, the CNMBP sufferer treated with LTOT may be resigned to being less active excused and/or excluded from the daily responsibilities of life for the rest of their lives. Passive resigning may be expressed

physically by refusing to engage in physical activities that may help improve or maintain their mobility and strength, eg hydrotherapy, for fear of 'pay back pain' (in vivo code). Sometimes the unpredictable course of CNMBP treated with LTOT fosters uncertainty and fear, resulting in some sufferers voluntarily restricting their lives more than they need to be. Strategies that support passive resignation includes family coercion, focusing on medical evidence of their situation, catastrophizing, adopting pain behaviours, associating with other CNMBP sufferers who have also passively resigned.

Several participants speak of their experience of passive resigning.

This woman aged 50 is cared for by her eldest daughter aged 26 who is a qualified nurse. She requires 24 hour care, her LTOT is administered via a Hickman's catheter. She believes if it wasn't for her daughter she would be in a nursing home. She refuses to try any other medication or engage in any ongoing supporting therapies (eg. Physiotherapy, Relaxation).

FN She stated she had got to the stage where she no longer cared what the nurses thought about her, (referring to her as an addict). She also no longer wanted to try any other medication as she was sick of being used as a guinea pig and suffering when she is found to be sensitive to the new drug. She still engaged in certain recreational activities eg. Going to the movies but had totally withdrawn from engaging in any home duties eg cooking. She was reluctant to engage in any ongoing physiotherapy due to it increasing her pain. The Hickman's catheter now precluded hydrotherapy but she stated she had never used the pool at home even when she was physically able. She and her daughter's life now revolved around managing her pain and activities of daily living.

The following quotes demonstrate how for some sufferers pain controls their existence to the point when they question the relevance of continuing their existence.

S18 I no longer contribute and it doesn't matter whether I am here or not.

S09 Being less active, means I do less, meet less people – this means I contribute less to humanity and I feel useless. I feel I am boring, as pain is such and overpowering influence on my everyday life. Death cannot come soon enough for me.

For some they just focus on each day and express no hopes for the future in terms of their pain and quality of life.

S48 I take my life day by day with limited expectations and ruled by my chronic pain.

S46 Pain – severe, constant pain is so limiting in every aspect of life – ADLs, through to recreational outings; and of course the fatigue and lack of tolerance to activity that goes along with it. I think the lack of participation in life in general that becomes depressing, and the fact the future seems bleak- more of the same.

Int.HG My continuing deterioration, there is a lot that can possibly can go wrong and I will end up in a wheelchair which has been a fear and phobia of mine.

A woman who was admitted for acute exacerbation of her CNMBP talks of her inability to self-advocate and consequently passively resigning herself to an intolerable situation.

Int.S I was so exhausted from not sleeping and the pain that when the nurse refused to give me my prescribed medication because she thought the dose too high I could not take control of the situation. For example by asking to speak to the nursing supervisor or to ask her to ring the doctor. I lost complete control, gave up and layed there sobbing my heart out feeling totally abandoned, humiliated and hopeless.

The literature

In the literature the act of passively resigning in relation to chronic pain is discussed in terms of coping (Jensen et al 1991). Coping has been defined as active efforts to manage or impair the negative impact of stress (Burish & Bradley 1983; Lazarus & Folkman 1984; Jensen et al 1991). It is also talked of in terms of being active ie. responses requiring sufferer to initiate something to manage their pain, whilst passive strategies involve withdrawal or giving up control to another person (Brown & Nicassio 1987). Patients who believed they had no control over their circumstance were more likely to resign themselves to the status quo and become depressed and distressed about their pain (Skevington 1983). Studies have supported the relationship between internal locus of control and positive adaptation to chronic pain (Skevington 1983; Laborde & Powers 1985; Rudy & Turk 1988). It is also suggested that locus of control is related to various coping efforts (Jensen et al 1991). Strong et al (1990) found a positive relationship between ones' sense of control over pain and level of functioning.

Having negative thoughts has been found to be useful in predicting long-term adjustment to chronic pain (Jensen et al 1991).

Furthermore self-efficacy beliefs influence the initiation and persistence of behaviour (Bandura 1986). The research on self-efficacy beliefs gives compelling evidence that sufferers are more likely to do what they believe they are capable of doing and that this is associated with positive psychological outcomes eg. improved self-esteem. Thus, those CNMBP sufferers who have strong self-efficacy beliefs are more likely to engage in authenticating and repairing, in contrast to those with low self-efficacy beliefs that probably would embark on a journey of passively resigning.

Research on outcome expectancies, which refers to the judgement of the consequences of a specific action, support the social learning theory model that patients are more likely to engage in behaviours that have a positive outcome than those who do not. This can be likened to what patients call 'pay back pain' (in vivo code) behaviour. Whilst some CNMBP sufferers who actively resign themselves to their situation are more likely to engage in pain provoking behaviours than those that passively resign themselves to their condition. Council et al (1988:323) hypothesised that *"self-efficacy expectancies may mediate the relationship between outcome expectancies and functioning"*. That is, if CNMBP sufferers believe that the outcome of an activity will increase their pain this may influence their beliefs about their ability and or willingness to engage in that activity, which then influences the actual initiation of that behaviour.

The literature reviewed indicates that complex relationships exist among pain appraisals, resigning strategies and adjustment to chronic pain.

HOPE

The data

The individual who has hope find means of living with their pain and reconciling themselves in order to regain their self esteem and live valued lives. Striving to regain control over their pain is not always possible without medical intervention and when this situation arises the sufferer is more likely to take on the responsibility to seek out what they consider appropriate intervention. They may also at some stage consciously decide to resign themselves to a particular situation because they perceive it to be in their best interest. Seeking hope happens and is encouraged when there is no further surgical intervention is warranted and pain management is the focus of care that requires the sufferer to accept that there is no cure and to take responsibility for their pain and its management. Not passively resigning can be problematic for the sufferer who needs not to lose hope that their pain can be managed successfully thus to some extent they remain fragile.

Strategies for seeking hope include acceptance of pain and disability and living within ones limitations and coming to terms with 'pay back pain' (in vivo code). The consequences of hope are acceptance of self and the amount of 'pay back pain' (in vivo code) one is able to cope with and life which is governed by the individual and not their pain.

The following participants were commenting on their experience of having CNMBP that was treated with LTOT. They had spoken very positively about their treatment they eventually received and the resultant quality of life. They had particular, made reference to the importance of having hope to be able to self-advocate and obtain the treatment they needed and the importance of being self-reliant.

S6 I have good quality of life and much less pain due to morphine, able to do what I can when I can. In relation to the future, I hope they find better ways of fixing back problems rather than fusions and good natural pain-killers and that I can be more useful. But in the long run it is entirely up to the sufferer to demand that the help is always forthcoming.

S17 A lot of people are under the misapprehension that each time you have a nerve block or some other procedure this will be it, cure everything. Pain is a lonely road and only you own it, feel it, live with it and only you can come to terms with it.

S36 I wish the medical profession (some) would not blame the patient for their inadequacy. Eg. When an operation goes wrong or the results are not good they say the patient must have done something wrong. They always try to hide what went wrong instead of letting you know they are human to. They sit in judgement when they have no idea what you are going through and how low your self-esteem is already. They also have the habit of washing their hands of you when their area of expertise has failed without sending you to someone else that may give you some help or hope. They leave you feeling lost with no where to go. I have found this to be mainly neurosurgeons. I had sought out the pain management side of chronic pain (which has given me the best help). I honestly don't think I would be here today. I have found communication is a very important part of healing and helping yourself.

The following person spoke about the best things about her life at present and her employment opportunities in the future.

S46 I am managing a tertiary course (Masters in nursing) although this does aggravate my pain, I believe the positive benefits in self-esteem far outweigh the negatives. I hope to successfully complete my Masters and continue studying (possibly a PhD) to be able to contribute again ie. Consulting work.

Resigning oneself to the fact that to engage in some meaningful behaviour requires careful planning, pacing and a certain amount of 'pay back pain' (in vivo code) is highlighted in the following quotes.

Ffg4 its whatever you plan, you have to be prepared to suffer the consequences:

Ffg6 If I decide to have some sort of social activity I enjoy it to the fullest, because I know I'm going to pay the price.

Passive resigning and finding hope may occur at any time during the fragility experience or any phase of the authenticating and repairing personhood process. Although finding and nurturing hope helps CNMBP sufferers to move on to develop a new life, there remains a degree of fragility.

As a consequence of fragility, individuals may passively resign to the status quo or find and nurture hope within the reality of their pain and disability allowing them to move on with their lives and diminish their fragility. Individuals who find hope move out of their fragile positions. They do this through a process of authenticating and repairing personhood.

The literature review relating hope is presented in chapter six with respect to it being the catalyst for CNMBP sufferers treated with LTOT

addressing their fragility by the core process of authenticating and repairing personhood.

SUMMARY

Chronic non-malignant back pain sufferers treated with LTOT experience fragility, especially when they interface with the health care system. Fragility impacts on the individual according to his/her level of pain, effectiveness of his/her pain management regime and personal and social resources. Given that the person experiencing it can only measure fragility and it is their perception which guides how they feel, the person's perception of fragility is central and needs to be addressed both in the community and hospital setting. Such experiences of fragility may decrease an individual's adaptation to their pain and disability to the extent that they may countenance thoughts of suicide.

A characteristic of fragility is vulnerability. The CNMBP sufferer treated with LTOT may be rendered emotional and/or physically vulnerable by their condition and treatment. Sufferers can feel vulnerable when they have minimum control over their pain, life and are emotionally and physically exhausted. Dimensions of vulnerability vary with the importance it has for each individual. Characteristics of vulnerable include the nature of threat and harm and the extent to which the sufferer has control over his/her pain and life.

The consequences of fragility vary. Some may passively resign themselves to their current situation and may remain in the sick role for life with their CNMBP controlling their life rather than the reverse.

Others may find hope and embark on a journey of reconciliation through the process of authenticating and repairing personhood. Authenticating and repairing personhood is the core process those individuals use to address fragility allowing them to maintain a sense of hope and worth.

The next two chapters describe the core process – authenticating and repairing personhood and how finding hope is a critical element in initiating this process to address fragility.

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CHAPTER 6: THE CORE PROCESS - AUTHENTICATING & REPAIRING PERSONHOOD CYCLE

INTRODUCTION

In this chapter the core process - authenticating and repairing personhood, is described together with its phases and relationship to other categories. The core process engaged in by participants to deal with the problem of fragility was identified as authenticating and repairing personhood. Finding and sustaining hope is central to authenticating and repairing personhood. Subcategories of finding hope include faith, positive thinking, self-development and connectedness. This chapter describes the cause of authenticating and repairing personhood, **finding hope** and the core process. These aspects of the theory are presented and explored in relation to the literature. In the next chapter the three phases of the authenticating and repairing personhood cycle are discussed in detail. These phases include reconciling loss, self-determining normalcy, and striving for normalcy.

AUTHENTICATING & REPAIRING PERSONHOOD CYCLE

The Data

Aspects of authenticating and repairing personhood, the core process, emerged early in the data. During the analysis this process was developed from **'loss of self', legitimising pain, LTOT and self'** and **'struggling for a valued life'**. Authenticating and repairing personhood fitted and permeated the emerging data and functioned to show, how data could be consolidated into conceptual categories, and their relationships. Participants responded to fragility, the core problem, by asking questions such as: What are we here for? What happens if the pump doesn't work? What happens if I can't stand the pain? Why do I feel guilty for something that isn't my fault? Why do

people question my pain and need for morphine? Why do nurses treat us like addicts? Based on the data, authenticating and repairing personhood is a process that individuals use to address their sense of fragility and how to facilitate managing being discredited and regain a sense of worth and control. Authenticating signifies action that is validating, repairing denotes healing and personhood reflects every aspect of what it is to be human. The development of this process is provided in Appendix 31.

Figure 1 provides a diagrammatic view of authenticating and repairing personhood and how it relates to the core problem of fragility.

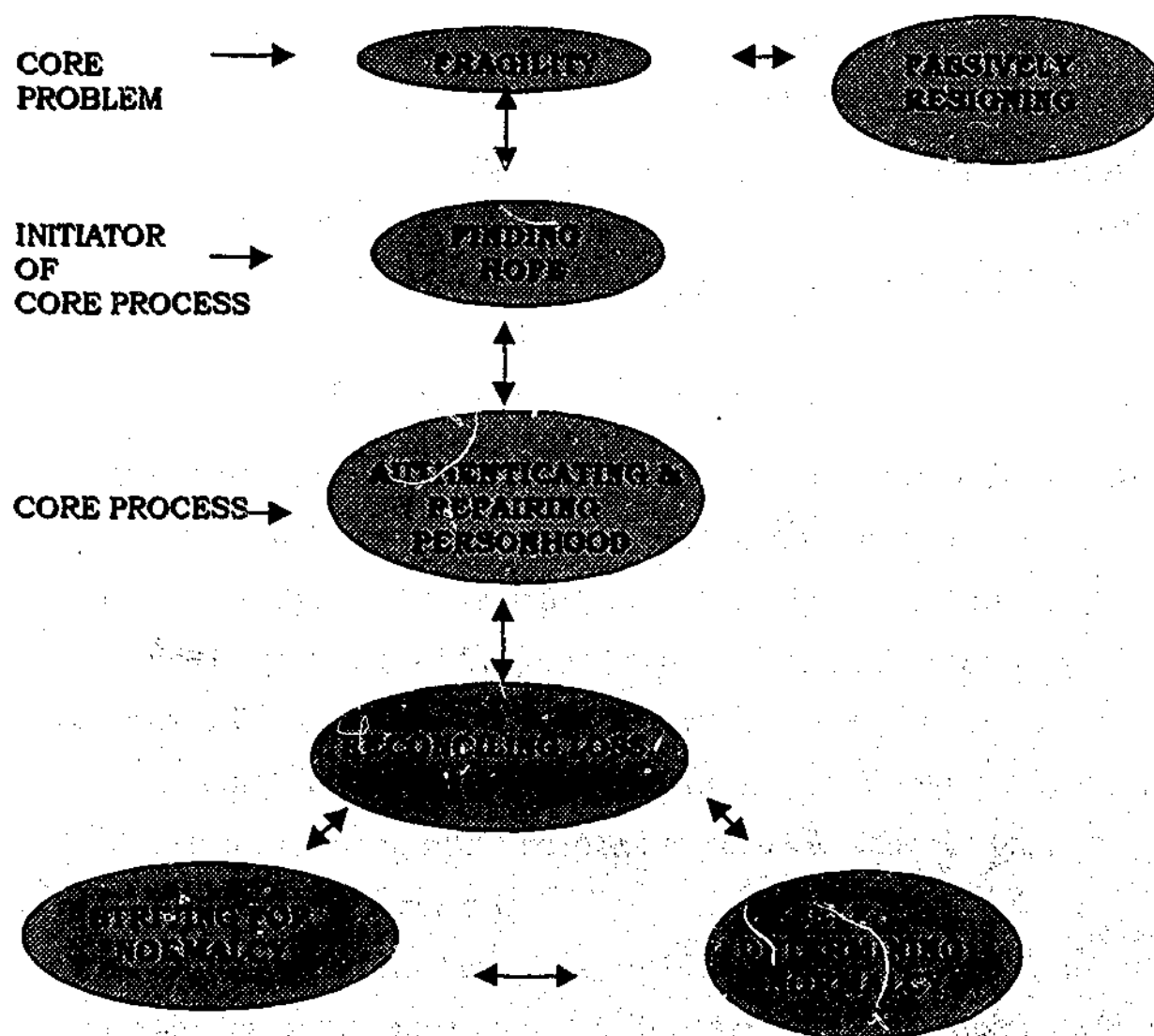


Figure 1: The Theory of Authenticating & Repairing Personhood

This core process – authenticating and repairing personhood – links other categories and their properties and accounts for the variation in patterns of behaviour. Authenticating and repairing personhood is a core process (Glasser 1978) because it explains the processes involved in addressing fragility and *“being a higher level of abstraction than the other categories accounts for the variation in behaviour and for the change over time from one phase to another”* (Fiveash 2000:173).

Authenticating and repairing means being motivated and engaged in the healing process of transcending the consequences of CNMBP treated with LTOT and living within one's capacity, circumstance and treatment regime; regaining control over the pain and one's life and reconstructing a valued self and life. Repairing and authenticating personhood is the key process that explains how persons embark on a personal journey to address the causes of their fragility with the aim of reconciling and reconstructing an authentic self and life.

The authenticating and repairing personhood process refers to cognitive and behavioural changes that occur in the individual to minimise fragility. Authenticating and repairing personhood process addresses the problem of fragility because it is both explanatory and informative. The core process is composed of three phases:

- A) Reconciling losses (a personal journey of acknowledging, re-evaluating, grieving and receptivity towards CNMBP treated with LTOT in order to move on)
- B) Self-determining normalcy (a self-initiated exploration of what constitutes their normalcy. A process of taking responsibility, setting goals and seeking resources to support their choices and

decisions with respect to achieving goals and constructing an honoured personhood and meaningful life).

- C) Striving for normalcy (attempting to construct and maintain a new meaningful life as close to their pre-morbid life as possible in order to reduce the stigma and negative stereotyping and thus their fragility).

Whilst it is presented in linear phases, in reality it is cyclical, dynamic and convoluted with sufferers moving around, backwards and forwards, in and out, depending on their individual circumstance. Given the chronicity of their condition, it represents a life long journey with no final destination.

The degree of engagement is determined by sustained hope, the level of pain control, sense of fragility and by the individual's will and capacity to do so. Authenticating and repairing behaviours are identifiable and contextual.

Authenticating and repairing personhood refers to the purposeful, productive behaviours that persons take to address their fragility. Sufferers may decide to address fragility and work through the phases of authenticating and repairing personhood or prefer to passively resign themselves to their current situation. They may passively resign themselves to their fragility because they do not possess hope, personal and/or social resources and the need to terminate the sick or victim role, which may have become entrenched, and a normal part of their family functioning.

There are a number of intervening conditions that facilitate or deter authenticating and repairing personhood. An individual's capacity to engage in this process varies according to a number of contextual

determinants. Intervening conditions that may expedite authenticating and repairing personhood include:

- pain control,
- compassionate and educated health care practitioners,
- motivation,
- social support,
- connectedness,
- courage to be,
- healthy pre-morbid personhood,
- willingness to change,
- ability to cope with uncertainty and ambiguity, and
- willingness to take risks.

Intervening conditions that may impede authenticating and repair personhood include:

- poorly controlled pain
- lack of understanding of CNMBP treated with LTO by health care practitioners, family and friends
- lethargy
- poor social support network
- flawed pre-morbid personhood
- reluctance to change
- inability to cope with uncertainty and ambiguity
- unwilling to take risks
- dependency
- addiction

An outcome of authenticating and repairing personhood is a robust self, a sense of credibility and an authentic and meaningful life.

Although the process is not linear, engagement at any phase always follows a period of fragility and the experience of finding hope.

Finding hope is a critical component and a precondition for the initiation of the authenticating and repairing personhood process. The categories for authenticating and repairing personhood will be discussed in detail in the next chapter. During the first phase the sufferer attempts to address fragility through attempting to reconcile themselves to the losses incurred through experiencing CNMBP treated with LTOT. Reconciling losses ensues finding hope. If the sufferer is unable to proceed along this journey of authenticating and repairing personhood they may passively resign themselves to their circumstance at that point in time. During this first phase the sufferer not only takes account of the losses that have, are or will occur as a result of their CNMBP treated with LTOT but incorporates constructs and accepts a new reality. In the second phase the patient regains control over their pain and life and determines what is a normal life to them, thereby nurturing and sustaining hope. In the third phase, striving for their normalcy, the sufferer reconciles and validates their pre and post morbid selves and lives. Struggling to live with their normalcy reflects as close as possible community norms and their pre-morbid lives. The outcomes of this process include a more robust self, higher self-esteem and a stronger sense of hope. Authenticating and repairing personhood involves self-discovery and is a healing experience. As sufferers learn more about themselves, their pain and treatment thus they develop knowledge and life skills that they will need to live with their chronic condition and cope with pain exacerbation, being discredited and future encounters with the health care system.

The journey starts when the sufferer experiences fragility, and follows the three phases of the process of authenticating and repairing personhood. Following fragility the sufferer may passively resign themselves to their circumstance and remain fragile, vulnerable and despairing or they may find hope to move through the phases of

authenticating and repairing personhood process. Through the latter action the sufferer is trying to regain control of their pain and life and overcome fragility particularly when nurses, doctors and family members do not validate their personhood, pain and treatment. When sufferers experience an acute exacerbation of their pain or a social crisis eg, partner leaves, initially they may temporarily passively resign themselves to their present circumstance and rely on health care practitioners to control their pain and lives, and family and friends for support and advocacy. When this is perceived as the only way to overcome their pain whether it be physical, emotional and/or spiritual, sufferers are prepared to do this even though their sense of fragility may increase.

Authenticating and repairing personhood also involves the actions/interactions of nurses, doctors and family. Different fragility contexts call for different actions on the part of sufferers, health care practitioners and family members to help the sufferer adapt. When their pain is out of control sufferers experience difficulty trying to cope and dealing with issues of living with CNMBP treated with LTOT. Thus, it is at these times that they need compassionate support from family members and health care practitioners. The individual whose pain is well controlled, and is living a valued life, experiences less fragility and thus may be seen as coping and having sustained hope and reconciled him/herself to their situation without the need of initiating the authenticating and repairing personhood cycle at that point in time. Those in moderate degree of fragility context require varying levels of authenticating and repairing personhood strategies.

Individuals vary in their willingness to take responsibility for their pain and lives as do health care practitioners in their preparedness to listen and validate the sufferer's pain and need for opioids. The context facing the sufferer is different for each individual. Whether

an individual is at home or in hospital may or may not make a difference to their willingness, capacity and opportunity to authenticate and repair personhood. The supportive nature of hospitals and homes varies enormously. The experience of CNMBP treated with LTOT is different for each individual and may depend on the character of the individual, their previous experiences and socio-cultural heritage. In addition to a sufferer's medical biography including how long they have had CNMBP, the cause of their CNMBP, whether or not they have had surgery and its' success, how long they have been on opioids, how they are administered, and if there is a third party involved (insurance company). Such biographies can render both sufferers and nurses suspicious, angry, confused and cynical that can negatively impact on developing therapeutic relationships. Some relatives can be coercive rather than supportive with respect to the patient's pain and disability. Thus, whether at home or in hospital, in some situations the individual may be self-determining and active in their pain management or they may passively resign and give control to somebody else.

Location and financial status may preclude access to appropriate health care practitioners (eg. psychologists, pain specialists) whose assistance may be crucial in assisting sufferers through the authenticating and repairing personhood process. These same barriers may also prove issues for accessing opioid therapy and other expensive pain medications and treatments necessary to achieve optimum pain control. Given the opioiphobia that exists within the current Australian health care system (Gourlay & Cherry 1991; Bell 1997), it doesn't provide a conducive environment for sufferers to take control and be responsible for their pain and it's management. A major issue is that many CNMBP patients treated with LTOT are cared for in either an acute care or rehabilitation facility even though their condition is considered no longer amenable to acute medical

and rehabilitation treatments. Many practitioners and administrators have not thought through the profound differences in philosophies and goals between acute, restorative care and that of long term maintenance treatment. Treating CNMBP within an acute care framework can result in fragmented care, inadequate information, overburdened staff and isolated sufferers left to manage the spiralling problems caused by their CNMBP treated with LTOT as best they can (Charmaz 1983). Furthermore, in acute care facilities CNMBP sufferers treated with LTOT can often experience client/practitioner relationships which could be characterised as being dominant/submissive that can lead to learned helplessness (Slimmer 1987). In such environments CNMBP patients treated with LTOT can become apathetic and 'give-up', and experience feelings of hopelessness and fragility (Slimmer 1987). Thus, it is important that CNMBP sufferers treated with LTOT need to be articulate, informed and persistent to achieve and maintain a sense of control over their personhood, pain, pain management and lives.

Strategies to support authenticating and repairing personhood include having optimum pain control that permits reflecting, re-evaluating, reconciling, self-determining, receptivity, setting goals and seeking appropriate support. These actions are undertaken to limit fragility and to regain a valued, robust personhood, reduce dependency, and to have a meaningful and credible life with hope for the future.

Consequences of authenticating and repairing personhood include decreasing fragility and vulnerability, and a better understanding of one's personhood, CNMBP and LTOT, reconciled to what constitutes normalcy for them and sustained hope. Sufferers who succeed along this journey are more likely to cope with the inevitable episodes of

exacerbation of their pain and stigmatisation in the future with minimal disruption to their life in general.

The Literature

The concept of 'personhood' is rooted in the concept of 'person' found in the literature of moral and meta-physical philosophy, ethics, theology and gerontology (Frankfurt 1971; Feinberg; Engelhardt 1982; Thomas 1986; Harrison 1990; Buzzell & Gibbon 1991). The ethical ideal of personhood as deduced from philosophy and psychology is that patients constructs a world of meaning distinct from the meanings held by others (Olsen 1997). From this proposition one can deduce that the patient's humanity is to be found in the creation of meaning. According to Olsen (1997:79) *"the creation of meaning is the basis on which the patient is morally synonymous to the nurse and others"*. When this concept of personhood is applied in clinical practice mutuality with the patient is founded upon the acknowledgment that whilst both patient and nurse are creators of meaning, there is no similarity of content of the meaning (Olsen 1997). Our understanding of others is derived from the *"the lived experience of selfhood"* (Buie 1978). From this proposition mutuality is the overwhelming moral basis for empathy and according to Kohut (1959, 1982) all human interactions necessitates a degree of empathy. Perry (1995) in her dissertation found that an essential element of the healing process is the recognition of each patient as a person. Taylor (1993a, 1993b), an Australian nursing scholar, in a phenomenological study exploring 'ordinariness' in nursing affirmed the notion of mutuality with respect to both the client's and nurse's humanity as a foundation for nurse/client therapeutic relationships. The concept of personhood in healing necessitates conceptualising the person as composite of interrelationships between physiology, psychology and socio-cultural factors. The premise that personhood

is comprehended as an irreducible totality underpins the notion of holistic nursing care.

In recent years there has been a departure from the patient occupying the passive sick role (Parsons 1951) to a self-care, consumer models of care (McLeod Clark 1993; Parse 1981; Parsons & Parsons 1997). Within the acute 'curative/sick' care model care tends to be generalised, prescriptive and directive which is less than therapeutic in terms of supporting CNMBP patients treated with LTOT becoming responsible for their pain, life and care to maximise their health potential (McLeod Clark 1993). Alternatively, in the care of individuals suffering chronic conditions the focus should shift from disease, task and cure to the person, care and living (Buzzell 1989). Again the latter is not the reality in many of Victorian long-term health care facilities. The move away from the dominant/submissive relationships to partnerships has been espoused in the literature (Buzzell, 1989; Gullino 1982). Partnerships require a certain level of involvement, as well as a sense of mutuality and equality from both parties (Gardner & Sandhu 1997). The concept of partnership acknowledges the rights of both the patient and the health care practitioner. It implies that the health care practitioner is committed to working with the person as that individual *"explores his/her possibilities, chooses his/her action and creates his/her reality"* (Gullino 1982:355).

Partnership is about communicating to CNMBP patients treated with LTOT that their pain, treatment and personhood are respected. *"Striving for partnership is not easy, whether in clinical practice, marriage or friendship"* (Buzzell 1989:14). Such an approach to practice calls for both professional competence and personal maturity and often challenges what nurses and doctors have been taught in

their undergraduate programs (Gardner & Sandhu 1997). However, as McLeod Clark notes,

"a social and cultural revolution may also be required to shift the goals and expectations of the other side of the health care coin - the consumer" (McLeod Clark 1993:269).

Health care services, such as pain management services, are not immune from the 'consumerism' that is permeating all public services. The increasing number of complaints and litigations within the Australian health care system is further proof of patients becoming more critical and discerning consumers.

Consumerism implies engagement in their own health care, the buying of goods to suit own requirements (Beisecker 1988; Waterworth & Luker 1990; Fiveash 2000). The public, as consumers, pay for the cost of health care through voluntary and involuntary taxes and insurance. Normally it is the person who pays for the service who assesses its quality and satisfaction.

Ferguson (1992) describes three types of clients, the passive, the concerned and the health-active/responsible person. The passive client holds the view that he/she cannot make a difference to their health and allow others to make the decisions. The concerned client seeks questions but always takes the doctor's advice. The health-active/responsible client are prepared to oppose the doctor, they actively seek information and help from within and outside the traditional health care system and make informed decisions.

In response to the increasing use of LTOs for chronic non-malignant pain in Australia (Bramley-Moore, Wodak, Day et al 1998; Bell 1997), the Australian Pain Society have published guidelines for the use of opioids in patients with chronic benign pain (Graziotti & Goucke 1997/2003). The guidelines advocate written contracts between the

patient and the prescribing physician, whereby the patient agrees not to sell their opioids and to only use one chemist for the dispensing of their opioids. Rather than promoting an equal partnership these contracts tend to be paternalistic and aimed at meeting the needs of the physician, whose main concern could be interpreted as being drug abuse and not the patient's quality of life. A better arrangement would be for an individualised, negotiated written health care agreement, which acknowledges and reflects the rights and expectations of both the consumer and health care provider and as such could provide the basis for all health service delivery between two consenting adults.

Many investigators have used models of stress and coping to help explain differences in adjustment that is to be found among CNMBP sufferers (Turner 1991; Jensen & Karoly 1991; Gross 1986). A consistent finding has been that patients, who believe that they can control their pain and do not feel disabled, function better than those who did not. However, the apparent relationship between coping strategies and adjustment to chronic pain is subject to question due to some methodological problems (Jensen & Karoly 1991).

Large and Strong (1997) undertook a qualitative study that focused on how people with CNMBP construed 'coping'. Half the cohort perceived the 'coper' to have lesser pain than the non-copers, whilst the other half felt that coping leads to less pain. Thompson (1981) raises the question as to whether if CNMBP sufferers are taught to cope will they feel less pain? A number of constructs focused on the notion of authenticity. Copers were perceived as to have genuine pathology. Coping, unlike dependency, was viewed as obligatory and not wilfully chosen. Coping was also equated with pacing as well as stoicism. The latter related to being positive and having 'pride'

related to gaining acceptance by others. Coping was also found to be related to hope and not being in constant pain (Large & Strong 1997).

THE CAUSE OF AUTHENTICATING & REPAIRING PERSONHOOD: FINDING HOPE

The data

To authenticate and repair personhood, an individual needs to have a certain level of pain control and a sense of hope for the future. When the individual's pain is overwhelming to the extent that they cannot articulate their needs they are not able to confront the changes and losses that they have incurred as a result of their CNMBP. Contemplating and grieving losses is the first phase of the authenticating and repairing cycle. To confront and reconcile losses the individual needs to have attained a certain level of pain control. If the individual has a sense of hope they are able to enter the authenticating and repairing personhood-cycle. Appendix 31 lists the development of '**finding hope**', an in vivo code.

Finding hope according to the data is an expectation that the pain can be controlled to a level sustaining meaningful existence. When an individual's pain is not well controlled their sense of hope diminishes. Participants describe hope as self-motivation, self-determination a sense of wanting to go on living. Finding hope refers to participant's need for hope to authenticate and repair self. Individuals need hope and some find it in themselves, others find it in consultation with friends and family members, health care practitioners and from various spiritual areas. Hope is a key factor in an individual's preparedness and ability to deal with fragility and to authenticate and repair personhood. Where there is no hope there is no authenticating and repairing of personhood.

Hope is a key issue for participants whose pain is difficult to control. It is a central issue when grieving and trying to find meaning to the suffering caused by the pain. Hope may blossom from some inner strength, and/or because of tangible support given by family and friends, health care practitioners and spiritual guidance, and/or the offer of trialing new analgesics or treatment to alleviate the pain. Hope is generated from a range or mixture of categories. It fluctuates depending on the perceived degree of pain control experienced. Hope is a vital element in authenticating and repairing personhood and thus dealing with fragility. Some participants never lost hope showing a profound inner strength regardless of their pain situation. They maintained an optimistic view of the future whilst others lost hope altogether and with it the meaning to go on living.

Being positive in the face of adversity eventuates due to some inner confidence, a successful pain management regime and/or an effective support network. Strategies that enhance being positive include seeking a meaningful existence from family, friends, health care practitioners and spiritual guidance. The consequences of being positive is a preparedness to engage in pain provoking activities, to take responsibility for managing the pain because of a belief in being able to have a sense of future.

The social support offered by family and friends can mediate hope. Strategies to engage family member's and friend's support include communicating with others about one's pain experience and needs. The consequences of having good social support networks is a sense of understanding and support, preparedness to be an active participant in pain management regime and have hope for the future.

Participants engage with health care practitioners when they are accessible, compassionate and demonstrate hope for the future. Strategies used to engage health care practitioners include

communicating, relating and seeking support and being a 'good' patient. Engaging with health care practitioners produce a range of consequences depending on the practitioner and his/her views relating to CNMBP and its' treatment with LTO therapy. The sufferer can experience a sense of hope for the future or complete despair.

Finding hope may accompany an improvement in pain control. Having experienced previous episodes of acute exacerbation of pain that have abated is also conducive to the sufferer finding hope. Having access to the technological advances in pain management ie, computerised pumps, spinal cord stimulators may instil hope especially if the sufferer has observed positive outcomes associated with these technologies in other patients.

Nurses and doctors consolidate the sufferer's position and preserve hope when they validate the patient's pain and suffering, explore the individual's needs and provide compassionate care.

Hope is essential to progress through the authenticating and repairing personhood cycle. The absence or erosion of hope in the presence of fragility and increased fear is always problematic for the sufferer. Hope is diminished by poor pain control, abandonment by family and friends and negative hospital experiences. Sufferers who experience uncertainty and erosion of hope find it difficult to be self-determining, whereas others who are hopeful attempt to be self-determining. The consequence of hope is preparedness to be self-determining and to confront their fragility through engaging in the authenticating and repairing personhood process.

The following transcript excerpts illustrate how participants experienced hope.

The initial quote illustrates hope and how it fluctuates according to the level of pain control achieved.

S21. My hopes for the future are that my new job continues to meet my needs. I continue to be well and hope to travel overseas next year. In the beginning I was in agony. Had terrible tests that hurt +++. Finally there was hope when I was offered an implanted drug pump. Unfortunately after it was inserted I was ill for six months until my body accepted it. I was an extreme case but the doctor learnt a lot by me and now I go and do counselling for people similar to my case.

The following quote illustrates that despite a lengthy medical biography the sufferer still has hope in relation to a miracle cure so that she can put something meaningful back in her life.

S23 I hope that I can put something meaningful back in my life. Get more independence. Get away from pain (that miracle cure) and narcotics and any medication. You try not to let it, but chronic pain runs your life. It is not only that life style has to change and it is hard to do basic things (such as shower, walk, and cooking) but that you succumb and frustrate yourself ie cannot push vacuum cleaner, even a rug a horse or go to the pub or stage show. After injury pain instantaneous. I tried to stay away from all narcotics at first. Tried physio, chiropractics, massage just to stay on my feet and work. I tried epidurals, acupuncture, relaxation, psychiatrists, psychologists, reflexologists plus many more, just got worse. I only went down the surgical path after 3 opinions. Surgery ended up being an emergency when bladder and bowel symptoms on top of loss of power and feeling and searing sciatica down legs and radiating to upper back. Took fusion to stabilise and ended up with permanent nerve damage. I think I went to the wrong surgeon. In hindsight I know whom I would have gone to, as well as

where to go to (ie. Rehab, where exercises can improve or decline symptoms). Before this I was never sick, never injured, lived a full life, had a mortgage. I am in a few support groups to help others. I don't want others to have to go through what I have had to. I live in hope life will get easier, or there will be a cure one-day.

The following quote reveals how access to pain management treatment instils a ray of hope for a sufferer to engage in meaningful pursuits.

S33 My hopes for the future are that I will be able to control my pain and create more with pen and clay. My life is very restricted because of pain. I wish to be able to control my pain so that I can create. I have damage from T9 to my hips. It took two and half-hours to do radiofrequency nerve blocks to my damage nerves. It is only since having that treatment that I have had any life. Before that I only left the house for doctors and shopping. I am now doing a writing and computer course. I am also creating with clay. I have set my garage up as a workshop. I have been told that the nerve blocks will eventually lose their effectiveness and I thus I would like to talk to you regarding what you think of the pain pump.

The importance of family relationships in instilling hope in some sufferers are recounted in the following survey and interview quotes:

S18 Q. How has chronic pain changed the way you think about yourself as a person?

P I no longer contribute, it doesn't matter whether I am here or not.

Q. What is the best thing about your life in general at present?

P Grandsons. They are my greatest joy and reason to live. I could never do anything that would hurt them in any way

Q. What is the worst thing in your life at present?

P Being useless, and no energy to change it.

Q. What are your hopes for the future?

P To return to work. The last 9 years of my life have been some of the happiest and also saddest of my life. Life is what you make of it. I hate sympathy but would like a bit more understanding.

IntD. My family gives me hope, and all I hope for is that my relationships with my family and my wife stays as it is now.

The following quotes represent the importance of positive thinking, taking responsibility for your pain management and the role that supportive health care practitioners can play in instilling positive outlook.

S6. Thanks to the wonderful help and understanding I have always received since my unfortunate mishap. The doctors involved with my medication are totally supportive and do all they can to help control the chronic pain. But in the long run it is entirely up to the sufferer to demand that the help is always forthcoming. With the daily use of Kapanol (slow release morphine) I now have quality of life that I deserve to have. And with the power of positive thinking and making the morphine work I know this will

be okay. You have to want things to work and you owe it yourself to have some quality of life; also take the pressure off those around you. If you want to achieve you can.

S54. When you do nothing to cause your back problem it is devastating. However, I was already in the care of a neurosurgeon, so my treatment was available immediately. I was also under the care of a pain specialist and had been for some time. So I find I have always been treated by caring, respectful human professionals. I hope in the future that I will no longer need my pump and stimulator and that I will be able to clean my own house, garden and look positively to a future.

Int.D. Dr.X. he's the main hub, he's the axle of my wheels. He gives me hope and I pray that nothing happens to him.

Some sufferer's, although despairing, find hope and solace in their spiritual roots. The following transcript is from a conversation I had with a woman during an observation period in one of the paint units.

FN. This young woman had injured herself at work and had soldiered on at work until the pain became incapacitating. She took holidays in the hope that rest would relieve her symptoms. She talked of nearly having a nervous breakdown due to the callous treatment she received from both doctors and employer. When asked what prevented her from having the 'nervous breakdown' she replied God. She found she could not share her pain and despair with her family because they could not cope with her pain and disability. So the only one she could

turn to with her worries was God. She stated she prayed a lot and thanked God she was alive.

During one of many Email discussions with the following man who was quite despondent regarding his current position we talked of how his chronic pain has brought him closer to God.

Int.DC

I. How is life for you at present?

P. I don't enjoy life as much. I don't go out. I virtually stay at home. I don't have sex any more.

I. What prevents you from doing all these things?

P. Pain is the whole problem. It is too painful to perform sex and it is demoralising when you can't perform properly.

I. What is the best thing in your life at present?

P. My cat and God. I am trying to get well and rebuild my life. Since 1994 my life got turned from being very very happy to feeling 'if I don't wake up tomorrow I wouldn't care'. I live alone and don't get a lot of support from my family due to living a fairway from them. I get my shopping done for me by a lady who gives me support. People who don't suffer chronic pain have no idea what it does to you physically and psychologically.

I. What role does God play in helping you cope with your chronic pain?

P. He helps counteract the loneliness and gives me a reason for keeping on living. I believe a lot more in God now than I did before I got chronic pain.

In the following survey quote the participant talks about hope and hopelessness simultaneously.

Q. What is the best thing about your life in general at present?

P. I must state it has taken me quite some time to come up with an answer to this question as I don't think there is much good in my life at present. However, I do have friends who care and support me and who continue to regard me as a special valuable person and friend.

Q. What is the worst thing in your life at present?

P. The feelings of uselessness, hopelessness, worthlessness and the inability to do what I would like to do (the normal everyday things in life).

Q. What are your hopes for the future?

P. That someone will come up with some drug or mechanism than can heal/control this pain. That I will be able to live with this on-going pain or rather want to go on living.

I know I really do not like me as a chronic pain sufferer, and feel useless and hopeless knowing that there is no outlook for recovery. I have retrained 4 times to stay employable but since 1995 even that has run out. Being single and unattached in a long-term relationship life is often more an ordeal than pleasant. Death can't come

soon enough for me. If I had cancer at least I can expect a shorter life span and it would be acceptable to speak of death and wanting to die. Why should euthanasia not be an acceptable option for someone with chronic pain? But no, this is a taboo topic.

The following quote is taken from field notes written during a period of participatory observation. A young mother of five recounted the impact of CNMBP and her sense of hopelessness regarding the future.

FN. This woman tells me the impact of her injury has been devastating. She described the devastation to every aspect of her existence. Her abilities of motherhood, spouse, homemaker, friend, lover, and conversationalist. Whilst her family remained a positive feature in her life, she continued to suffer from low self esteem from feelings of uselessness and worthlessness. For her life itself was the worst thing in her life and that she held no hope for the future. She was currently being treated for depression as well as pain management.

An interesting observation that whilst participants regularly referred to feelings of hopelessness, sometimes using adjectives and phrases such as "black periods", "darkness", "when death would be welcomed as a friend", the majority still retained a sense of hope for the future.

The literature

Within this study finding hope refers to psychological and physiological processes such as having an optimistic view of the future, enhancing relationships with family and friends and seeking spiritual guidance. The object of hope is to maintain a sense of self-

worth in spite of their losses, as well as engage in behaviours conducive to optimal psychological and physiological adaptation. A vast amount has been written about the concept of hope. Due to the limitations of this study only a small portion shall be critiqued.

Hope is a complex concept with no agreed global definition cited in the literature. Historically hope has occupied a prominent place within Western culture where it has often been treated as a fundamental emotion (Averill, Catlin & Chon 1990). Hope comes from the Latin root *sperare* meaning 'to hope'. The development of hope as human virtue according to the psychosocial theorist Erikson occurs during the formative life stages (Erikson 1964). The first as a result of the infant having experienced a favourable ratio of basic trust over distrust in the first life stage. Secondly, as one outcome of the integrity-versus-despair that characterises Erickson's final life stage (Erikson 1964; Pruyser 1986; Stephenson 1991).

Spirituality, faith and theology have long been a source of hope and promise (Farran, Herth & Popovich 1995). Hope is of itself an act of faith. One's faith alone can facilitate positive thinking and hope (Widerquist & Davidhizar 1994; Narayansamy 1999). Dufault & Martocchio view spirituality as incorporating the behavioural and affiliative dimensions of hope. Actions in the religious realm are those related to a belief in a higher power and prayer, fasting, meditating represent examples of the behavioural dimensions of hope.

Various disciplines including nursing, psychology, philosophy, have attempted to define of hope. Nurses, Miller & Powers (1988), defined hope as:

A state of being characterised by an anticipation for a continued good state, an improved state, or a release from

a perceived entrapment. The anticipation may or may not be founded on concrete, real world evidence. Hope is an anticipation of a future which is good, based on mutuality (relationships with others), a sense of personal competence, coping ability, psychological well-being, purpose and meaning in life, and a sense of 'the possible'. (p.6)

Stotland (1969) proposed a theory of hope that encompasses the active process of hope and defines hope as an expectation greater than zero of achieving a goal. "Hopefulness referred to high expectancies and hopelessness to low expectancies of success" (Erickson et al 1975:324)

Whilst Stotland (1969) identified the level of perceived probability of achieving one's goal as the core variable he also acknowledged the perceived importance of the goal itself. In relation to psychiatry Stotland associated mental illness with hopelessness with the therapeutic goal being to restore hope. He viewed hopefulness as a mediating process that amalgamates antecedent and consequent events (Stotland 1969). Whilst his theory was generally thought to show promise, some perceived it vulnerable being that it had been developed on retrospective data and not on original research (Erikson, Post & Paige 1975).

Nowotny (1989) an American nursing scholar studied 306 cancer patients and identified six characteristics of hope. These included confidence in a positive outcome, kinship with others belief in the possibility of a future, spiritual beliefs, active involvement and willingness. Gibson (1999) a Canadian psychologist used the Herth Hope Scale on a cohort of 305 adults identified spirituality, growth through illness, fatigue, social support and health service orientation

as major contributors to hope. Another American nursing study (Herth 1990) explored the meaning of hope with terminally ill adult patients identified strategies that either fostered or hindered hope. Hope fostering strategies included relationships with others, positive memories, spirituality, positive self esteem. Antecedents to hope included adversities in relation to an uncertain future. A major obstacle to hope was found to be loss of control over critical issues that jeopardise the future in a phenomenological study undertaken by Flemming (1997).

An important phenomenological study of hope was undertaken by the French existentialist Gabriel Marcel in a series of essays (1962). Marcel favoured the use of the verb hoping rather than the noun hope in an endeavour to emphasise it as a process thus opening it up to examination. He emphasised the difference between the two forms of expectation ie. Wishing and hoping by noting that the inherent role of the ego is less resolutely cathected in hoping than in wishing (Marcel 1962; Pruyser 1986). Unlike the strong state of desire and activity associated with wishing, hoping according to Marcel (1962) was more perceptual involving a degree of humility. Hoping is said to occur when one feels trapped, having encountered a crisis and is devoid of meaning (Pruyser 1986). Pruyser (1986) looks at maintaining hope in the face of adversity from a phenomenological perspective. He postulates that the individual is confronted with adversity, at that point in time, *"ones reality, is an overwhelmingly complex composite of forces that is differently edited and interpreted by different persons"* (Pruyser 1986:125). Thus, the basis for hoping are not to be found in the facts of reality but in the methods through which reality has revealed itself to the sufferer and the in meanings they have assigned to these revelations (Pruyser 1986). Adversity, such as CNMBP can result in the person gaining new knowledge and revising their acquired view of reality.

The existence of hope has been equated with meaning and value in life in a number of studies (Marcel 1962; Frankl 1969; Travelbee 1971; Watson 1979; Stephenson 1991). Following World War 2 Victor Frankl reflected on his experiences in a concentration camp and concluded that persons who had hope were able to survive the horrendous physical and psychological circumstances. Whereas people that lost hope did not live long. Thus he equated hope with having found meaning in life (Frankl 1959). Travelbee (1971) also discussed this assertion in her theory of nursing where she defined hope as a future orientation in which one looks ahead to a time which will be more meaningful. Asserting that, without hope, an individual cannot be psychologically or spiritually healthy.

Intrinsic to these various statements is the notion that hope involves an active process (Stephenson 1991). Conceptually, hope entails an active engagement of an individual's thoughts, feelings, behaviours and relationships (Dufault & Martocchio 1985; Miller 1983; Stephenson 1991). Stephenson (1991:1459) from nursing identified four attributes, which can be used when addressing the question, what is hope? They are:

1. The object of hope is meaningful to the person.
2. Hope is a process involving thoughts, feelings, behaviours and relationships.
3. There is an element of anticipation.
4. There is a positive future orientation, which is grounded in the present and linked with the past.

From psychology Farran et al (1995:5) stated hope *"propels persons forward when the odds seem to be against them...(it is) a creative process....(and) an active process"*. Perakyla (1971) from sociological

perspective undertook an ethnographic study with hospice patients that argued that both instilling and dismantling hope serve the same purpose ie. shaping their medical identities of dying patients. The intensive interactions between patient and staff during the dying process are referred to as 'hope work'. Thus 'hope work' refers to the communication between staff and seriously ill patients that either fosters or dismantles hope. Perakyla (1991) identified three different types of hope work being conducted in different health care agencies. These were 'curative', 'palliative', 'dismantling' hope' (Perakyla 1991:407). Hope work was critical to the terminally ill patient and an integral part of hospice nursing. However, conflicts were shown to have arisen when different practitioners engaged in different 'hope work'. These findings supported the work of Strauss, Fagerhaugh, Suczek and Wiener (1985) on interpersonal communications or psychological modalities eg hope in medical practice.

Hope is usually discussed in relation to suffering (Frankl 1959; Miller 1985; Nowotny 1991; Perakyla 1991; Snyder et al 1991; Daly et al 1999; Bland & Darlington 2002). Hope has also been discussed in relation to adaptation to chronic illness (Wright & Shontz 1968; Craig & Edwards 1983; Miller 1983; Gottschalk 1985; O'Mally & Menke 1988; Raleigh 1992; Young 1994; Kylma et al 1996). Raleigh (1992) investigated the sources of hope in the chronically ill. Sources of hope included family and friends, spiritual guidance, self, health care practitioners, nothing and work. Keeping busy, prayer, communicating, reading and expressing emotions were all found to be strategies to raise hope (Raleigh 1992). Kylma et al (1996) conducted a study in Finland with the aim of describing the meaning of hope and ways of fostering hope experienced by the chronically ill. They found hope meant life, health and the possibility to recover,

intrinsic mental balance, confidence in people, God and in care. Results confirmed similar findings in other international studies eg nursing studies that have connected hope and life (Hall 1990). As with later studies (Herth 1990; Stephenson 1991) hope was defined as a multi-dimensional phenomenon by Dufault & Martocchio (1985) who identified six dimensions of the hoping process: affective, cognitive, behavioural, contextual, temporal and affiliative. The results of the Finnish study Kylma et al (1996) partly corresponded to these dimensions. For example, trust in people, God and in care can be seen to reflect the affiliative dimension. Studies from the consumer social support literature have highlighted the importance of hope in their long journey to recovery (Hatfield & Lefley 1993; Poster 2000). Likewise with chronic mental illness as schizophrenia hope has been found to be essential to recovery (Kirkpatrick et al 2001). Hope in this cohort emerged from a sense of connectedness to others, such as family, friends and health professionals (Kirkpatrick et al). Darlington and Bland (1999) identified family members and health workers as "*hope carriers*" during times when the patient has lost hope. The affiliative component of hopefulness is critical in sustaining hope in the chronically ill and their families (Benzein & Saveman 1998; Bland & Darlington 2002). There is minimal discussion in the literature in respect to cross-cultural perspectives of hope (Farran et al 1995).

In the past decade there have been a number of qualitative studies including the works of Averill et al (1990); Herth (1990); Perakyla (1991); Ersek (1992); Klenow (1992), Raleigh (1992); Morse & Dobernek (1995); Kylma et al (1996); Flemming (1997); Daly et al (1999) and Bland & Darlington 2002). Quantitative studies on hope include Herth (1990); Farran, Salloway & Clark (1990); Farran & Popovich (1990); Foote et al (1990); Rabkin et al (1990); Abraham (1991); Udelmen & Idelmen (1991); Bonner & Rich (1991); Herth

(1991); Piazza et al (1991); Elliot et al (1991); Holdcraft & Williamson (1991); Staats (1991); Herth (1992); Scioli et al (1997); and Gibson (1999).

Many studies (Block 1970; Dubree & Vogelpohl 1980; Vaux 1981; Synder et al 1991; Bonner & Rich 1991; Kylma et al 1996) have cited hope as an important concept in fostering healing. However, Angell (1985) dissents from this point of view, believing that there is no relationship between health outcomes and the psychosocial status of the patients. Several hope scales have been constructed to determine a patient's level of hope. These tools include Gottschalk (1977); Erikson et al (1975); Stoner & Keampfer (1985); Miller & Powers (1988); Herth (1989); and Nowotny (1989). However, to date the tools are more likely to be used in the research setting than in clinical practice.

Hopelessness is the opposite end of the hope continuum (Farran et al 1995) and thus has very different outcomes to hope. Both have been described as having emotional, cognitive and behavioural components (Farran et al 1995). Hopelessness has been studied in the psychological literature related to giving up, dependence, despair and learned helplessness (Seligman 1975; Taylor 1991). The hopeless individual is devoid of motivation, goal setting, and is lethargic. In contrast to hope that is a motivational process characterised by goal setting, activity, independence, confidence and expansive thinking (Farran et al 1995). Hopelessness like depression can be transient or permanent and is characterised by an inability to problem-solve and think laterally due to feelings of despair. Instruments have been developed to assess hopelessness (Beck & Weissman 1974; Zung 1964) which like the hope scales are used predominantly in the research rather than clinical setting.

Hope has also been studied in relation to optimism and health recovery (Scioli et al 1997). Optimism has been described as a rational, cognitive calculation that there is high probability of achieving the desired result (Fiveash 2000). From a rational perspective, it has been suggested that optimism is developed during childhood when they achieve and get adult feedback, interacting with both optimistic and pessimistic significant adults, and/or experience trauma and disappointments (Peterson & Bossio 1991; Farran et al 1995). Scioli et al (1997) demonstrated that there was a stronger relationship between hope and health than optimism. Scioli et al (1997) also proposed that personal control accounts for the connection between hope, optimism and illness.

From this limited review it is apparent that hope is a multi-dimensional phenomenon and generally viewed as a positive attribute to a sorrowful circumstance. Hope is a catalyst and motivator for action. Hope can be elicited from within and has emotional, cognitive, behavioural and spiritual attributes. Spiritual faith, health status, supportive relationships and optimism can influence hope. It is fundamental to life and has the capacity to heal making it highly relevant during times of fragility and uncertainty.

In this study hope needs to be present for the authenticating and repairing process to be initiated.

SUMMARY

This chapter has described the beginning pathway that CNMBP sufferers treated with LTOT tread in order to address fragility. The core process- authenticating and repairing personhood- was used to deal with the core problem of fragility associated with CNMBP treated with LTOT. The core process involves three phases reconciling losses,

self-determining normalcy, and striving for normalcy. The process is initiated by finding hope. Finding hope is inherent to the sufferer's ability and willingness to deal with the core problem of fragility. The literature suggests that hope can be found from within, measured and strategies found to help find, sustain sufferers finding hope. In the next chapter the phases of the authenticating and repairing cycle are described and discussed.

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CHAPTER 7: THE CORE PROCESS - AUTHENTICATING REPAIRING PERSONHOOD CYCLE

INTRODUCTION

This chapter presents data that illustrates the categories of the authenticating and repairing personhood cycle. To contextualize the findings the data are discussed in relation to the literature. Authenticating and repairing personhood is the key process that explains how participants addressed the major consequence of their CNMBP treated with LTOT, fragility, with the aim of reconciling and reconstructing an authentic personhood and life. The process consists of three phases, reconciling losses, self-determining normalcy and striving for normalcy. The process refers to cognitive and behavioural changes that occur within the individual to minimise fragility by:

- A) Reconciling losses (a personal journey of acknowledging, re-evaluating, grieving, and receptivity towards CNMBP treated with LTOT in order to move on).
- B) Self-determining normalcy (a self-initiated exploration of what constitutes their normalcy. A process of taking responsibility, setting goals and seeking resources to support their choices and decisions with respect to achieving goals and constructing an honoured personhood and meaningful life).
- C) Striving for normalcy (attempting to maintain a new meaningful life as close to their pre-morbid life as possible in order to reduce the stigma and negative stereotyping and thus their fragility).

Whilst such processes may not always change the way the individual feels in the face of adversity it can help them understand their fragility and what resources and strategies they need to access and utilise in order to transcend future problematic situations thereby

diminishing their fragility. The authenticating and repairing personhood cycle is a continuous journey, which can have many detours and no final destination. Whilst it is presented in ordered phases, in reality it is dynamic with sufferers moving around, backwards, forwards and engaging phases sequentially or simultaneously depending on their individual circumstances over time.

Others who cannot find hope appear to continue to worry about their pain and circumstances and passively resign themselves to an impaired existence with CNMBP and LTOT controlling their lives.

PHASE ONE: RECONCILING LOSSES

The data

The first phase of authenticating and repairing process is reconciling losses. The development of reconciling losses is listed in Appendix 32. This challenging process is an essential component of addressing fragility. Reconciling losses is characterised by receptivity towards post-morbid personhood and life. Reconciling loss also involves one acknowledging and evaluating the consequences of the numerous losses associated with CNMBP treated with LTOT and selectively grieving various losses. Reconciling loss frees energy to take control and move on, which can lead to broader perspectives, activities and purpose.

Reconciling occurs when the sufferer finds some hope that motivates them to attempt to salvage what is important to them to reconstruct a robust and honoured personhood in order to help them manage his/her fragility. Reconciling losses requires the sufferer to have an optimum state of well being, including validation of their CNMBP,

LTOT, suffering and disabilities by family, friends, doctors and nurses. This challenging process occurs in response to fragility with the fear of becoming a victim of their pain and opioid therapy resulting in the risk of them being seen as a burden to their family and society. Reconciling losses is a process that occurs when the sufferer is able to consider their current situation in relation to their past and future. Sufferers attempt to reconcile their losses in order to strive for 'normalcy' in order to reduce the stereotyping and stigma, thus decreasing their sense of fragility. Reconciling losses associated with CNMBP treated with LTOT influenced how sufferers addressed their sense of fragility.

It is a complex process that can manifest itself through sufferer's verbal and non-verbal communication and behaviour. During the reconciling process it is sometimes difficult to differentiate grieving and pain behaviours. This is due to grieving 'behaviours' such as temporary loss of concentration and memory, difficulty in problem solving, mood swings, fatigue are also behaviours associated with chronic pain and the use of opioids (Large & Schug 1995; Clark & Cox 2002).

Given that many sufferers of CNMBP treated with LTOT appear to experience ongoing losses, in addition to the normal aging process, they can be in a constant state of reviewing and/or grieving and/or reconciliation. There are times when some are overwhelmed by a particular loss, or the accumulation of losses, that they become victims of their worry and grief and unable to reconcile themselves either in the short term or long term, which has a negative impact on their post-morbid personhood and life.

Reconciling losses is characterised by:

- Reviewing their losses related to CNMBP treated with LTOT, and what they mean to them personally as well as family members and/or friends.
- Grieving.
- Re-evaluating their priorities in life.
- Receptivity.
- Honouring

Reconciling losses can occur at any time during the authenticating and repairing personhood process as circumstances and health status changes, impacting on their personhood, life and fragility.

Many participants reported certain losses more problematic to reconcile than others. For example loss of 'me', work, sexuality, relationships, credibility relating to the negative ways some family members, employers and health care practitioners, especially nurses, perceived and related to them were for some problematic to reconcile. Whilst losses are a hallmark of fragility associated with CNMBP treated with LTOT, and family members are familiar with many of these, their ability to cope and offer support, in some cases, appear to be reliant on the sufferer's ability to cope. Many participants stated that their family's ability to cope was reliant on their ability to cope, placing an added burden on them during an already difficult period resulting in a reluctance on their part to share their grief with family members. Furthermore, whilst they may have reconciled themselves to a particular loss, their family member(s) may continue to have difficulty coming to terms with that loss which in turn can become a source of tension within the marriage/family.

The conditions, which facilitate sufferers successfully reconciling losses, include:

- Acceptable level of pain.
- Validation of pain, LTOT, losses and changes by health care practitioners, family and friends.
- Balanced pre-morbid personhood.
- Ability to cope with ambiguity and uncertainty.
- The level of disruption and the repertoire coping resources.
- Energy.
- Positive thinking.
- Ability to concentrate and problem solve.
- Ability to think laterally.
- Connectedness/mutuality (significant, shared and meaningful relationship with other persons, inner self, and/or spiritual beings involving both giving and receiving support (Haase et al 1992; Taylor 1993a 1993b).
- The readiness of self and family/friends to change.
- Previous experience of overcoming adversity.
- Time.

Reconciling losses can be problematic when incidents occur that confront the sufferer with issues for which they may not be ready or unable to address, which can result in worrying, sorrow, grief and depression. Under these conditions their chronic worrying and sorrow can turn into clinical depression, increasing their fragility, and in extreme cases lead to suicide ideation requiring professional intervention. The process can also be problematic due to:

- Unacceptable level of pain.
- Pain, loss and changes not validated by family members, friends and health care practitioners.
- Flawed pre-morbid personhood.

- Pessimism.
- Fatigue.
- Poor problem solving skills.
- Coercive family and friends.
- Lack of empathy from family, friends and health care practitioners, especially nurses.
- Lack of connectedness.
- Hopelessness.

Strategies to facilitate reconciling losses include getting pain under control through accessing and/or implementing appropriate pain management strategies. Reviewing losses includes acknowledging both positive and negative aspects of pre and post morbid personhood and lives, and having these acknowledged by family members, general practitioners, pain specialists, nurses and friends. Assessing past choices and actions in relation to broken attachments and changes, differentiating between those that were helpful and those that were not. Working on developing connectedness/mutuality both within and outside the family unit. Not worrying about the pain and LTOT. Creative thinking in relation to how one can engage in pre-morbid interests and new meaningful pursuits. Giving one's self time.

Reconciling losses is by no means a simple process but a multi-dimensional, multi-layered and dynamic process that takes time. It is a unique endeavour for each individual sufferer based on differing experiences of CNMBP treated with LTOT and the individual's pain, LTOT and disability trajectories, basic beliefs and values, personal aspirations, financial status and spirituality and differing pre morbid personhoods and lives. Sufferers may grieve some losses and not

others just as they may be able to reconcile the consequences of some losses and not others.

Reconciling losses associated with CNMBP treated with LTOT assists the sufferer to embark on a personal journey that offers many opportunities. These include bringing closure to ongoing emotional wounds, putting meaning and worth back into his/her life by being able to choose different routes to arrive at pre-morbid goals or replacing old goals with new ones that are both attainable and meaningful. It can also facilitate the reconstruction of a more robust personhood enabling them to deal with the inevitable adversities related to CNMBP treated with LTOT thus reducing their fragility.

Each context involves different experiences of reconciling losses, including grieving and the level of receptivity, which reflects to what extent the sufferer 'worries' about their pain, treatment and losses. However, all grieving is a sign of distress, indicating difficulty adapting to the reality of loss. Ethnicity can influence how one grieves, as can gender (Stroebe et al 1995).

Intervening conditions that may inhibit reconciliation include values and beliefs, poor pain control, medications, lack of insight, poor communication skills, inability to self advocate, disinterest, fatigue, financial status, inability to access appropriate personnel, lack of family, social and professional support and/or diminishing sense of hope.

The consequences of reconciling losses is an opportunity to accept and/or heal physical, emotional and spiritual pain and reorientate one's self towards a hopeful participation in life with diminished fragility.

The following quote illustrates how one participant is continually covertly grieving for the life that her and her new husband are living for which she feels responsible. It highlights the grieving process as a very private experience as well as the often precarious nature of reconciliation of particular losses resulting from their CNMBP treated with LTOT. H. had previously shared the impact of CNMBP treated with LTOT on a new marriage (refer Chapter 4, p.157)

Int.H I don't openly grieve, I don't inflict that on J (husband) but I am in a state of grief all the time for the things that I want and can't do, and for the life we are living because of what has happened to me.

I. Would you feel comfortable to share some of the things that you grieve for?

H. Yes. I grieve my job, I was a social worker, I miss the clients, the challenge, comradeship and, of course, the money. I grieve the loss of true intimacy and the fact that I can't have and raise children. Adoption is not even an option because I couldn't pick a child up and we certainly can't afford nannies.

I. You appear to be dealing with many levels of pain in your life at the moment. You said you don't share your grief with J, are you able to share your grief at all?

H. Yes, I see a psychologist who is very understanding and also my specialist is a very caring, compassionate man who I find I can confide in.

I. Have they been able to help you come to terms with any aspects of your 'past life' that you said you still grieve?

H. Yes. I believe I have learnt to overcome a lot, but there are some losses that are harder to accept.

I. How do you deal with those losses that are harder to accept?

H. I find writing poetry helpful. It is hard to describe, but I find it very therapeutic, it's like a sort of self-counselling. Poetry helps to put things into perspective and it also allows you to escape to anywhere you want to be. Sometimes it also helps to give others insight into not only your pain and its' consequences and perhaps why you are behaving in certain way, but also insight into the real you. It is often too difficult to verbally explain what is going on in your life, inside your head and inside your body, and poetry allows you to convey complex feelings. I also try and accomplish something physical that I can do and enjoy like decoupage. These kinds of things help me reconcile my life.

The following is one of her poems entitled "Patchwork of Pain" which tells of her personal journey with CNMBP. It was written after she had met her husband J.

Peace, utter peace.

I feel a warmth within that has touched my soul.

My breaths are like whispers they sing me a song.

*The warmth of the refrain breaks over my skin.
Peace rolls around and settles within.
My universe has opened and love has crept in.
My heart has expanded and joy has leapt within.*

*My lessons have been long, the pain has been great.
Who I am has been my fate.
Lessons unlearnt return to torment.
My soul cries out push past the hate.
My being reverberates to the lament,
What have you done what have you learnt?
My pain was tangible wearing me down.
I did not listen to the haunting refrain.
Have courage, be brave, be open to change.
Push back the darkness turn on the lights.*

*Yet, out of the darkness the meaning unfolds.
The burdens of past enriches the whole.
One's searches for meanings are often unstated.
The quiet desperation the promise unfulfilled.
The barren wasteland, the patchwork of life.*

*Fields of visions, swirling reflections of the past.
Faces, places, a kaleidoscope of things I have left behind.
Spider-like webs of sorrow reaching through the shadows.
Looking through the hollowness of hurt, the loneliness of loss.
Did I survive the horror, or was it pushed into the recesses of my
brain.
Silence, silent screams on the outer, screams on the inner,
contorting my mind.
Mindless, hopeless unforgiving pain that racks my body rendering
me helpless.*

Night and day, day and night.

The wounds of the body wound the mind, the soul, the being.

The blackness of this world invades the light that surrounds us all.

I used to have fields of dreams, visions of hope.

There is no end to this reality, this endless unforgiving road well travelled.

I met up with H. by chance nine months later whilst she was having her pump refilled and on inquiring how J was, she said that the marriage had failed and that they were permanently separated. She stated that J hadn't realised the level of disability her CNMBP caused and he was unable to come to terms with this. She said they parted amicably and she was now settled in her new house and very much involved with decoupage again and was getting ready for an exhibition of her work. Thus, despite yet another loss and grief she had still been able to reconcile her damaged personhood to the point that she had the energy and freedom, indicative of reconciliation, to be fully engaged in her creative pursuit of decoupage.

The above scenario also highlights the problem for family members, particularly spouses, who may not be able to reconcile their partner's losses, which impact on their lives too. A number of participants reported that their marriages had failed, in part, because of their CNMBP and/or its management with opioids, associated losses changing their personhood.

A series of losses that had had an enormous impact on a significant number of participants included the loss of sexual desire, loss of sexual satisfaction, and loss of penetrative sex. These losses had had a profound effect on how they perceived themselves as persons, to the extent that it contributed to the experience of losing 'me'. It also had

similar impact on the non-injured partner. Adequate sexual expression was perceived as an essential part of personhood and enhanced wellbeing. A survey of some participants' spouses revealed that 52.2% of partners of CNMBP treated with LTOT said that it had had a negative effect on their satisfaction and frequency of sexual intercourse. Only 4.3% assessed their pre morbid sex as unsatisfactory compared to 40% assessing their current sex as unsatisfactory. For a number of participants they and their partners had reconciled themselves to a sex starved marriage, this appeared to occur more often when the male partner was the one experiencing CNMBP treated with opioids. The male survey respondents indicated that they just couldn't *"perform"* due to either the pain and/or the effects of the medications. Some participants explored other ways of experiencing true intimacy with or without penetrative sex. During a focus group of family members of which 3 were male spouses they raised the negative impact of their partner's CNMBP treated with LTOT on their sexual relationships. I contacted them after the group to see if any of them would be comfortable talking about this very personal problem on a one to one basis so that I could try and understand their perspective. Two agreed to be interviewed regarding the impact of their partner's CNMBP treated with LTOT on their sexual relationships and how they had reconciled themselves to this aspect of their wives' condition.

The following are excerpts from the transcripts of these interviews relating to this very personal, intimate experience. The first was from an interview with T. aged 57 whose wife had suffered CNMBP for 10 years. It raises a number of important issues with this respect of personhood including the sexual needs of the 'pain free' partner generally not being acknowledged and addressed in clinical practice and the damaging effects on their personhood. It emphasises the importance of communication between partners and willingness to

experiment different approaches to intimacy that both are comfortable with when attempting to reconcile losses related to sexual functioning.

Int.T. It's very hard to 'get turned on' so to speak when you know that you are causing your wife pain. It wasn't as bad when she was getting some enjoyment and satisfaction but when she got to the stage when she no longer could achieve orgasm and was only experiencing pain, then I felt a right bastard. Then I experienced difficulty getting aroused. That then worried my wife because she felt that I no longer found her physically attractive because of the pump and all the scars. Despite her pain, she said she still had the desire but could not tolerate the pain of sexual intercourse, especially when it would take me awhile to 'come'. Of course, we are both getting older and I have had surgery on my prostate for prosta:itis which means that it takes me longer to reach orgasm and that I no longer ejaculate. The important thing is that we talk about it and more important we both still love each other. We have tried a few things, some have worked out. For example, if we want to have sexual intercourse, then we usually watch an erotic movie, nothing distasteful, to help our arousal and we have a lengthy foreplay that we can both enjoy and I only enter her when we are both highly aroused and ready 'to come'. She says this causes her less pain and we both get some fulfilment from it. The times when her pain is such that she has no desire for sex, which can be for weeks on end, she sometimes offers to masturbate me. On rare occasions she puts on some special music and lights the bedroom

or the living room wherever with candles and she wears my favourite lingerie and we enjoy just masturbating each other. But that doesn't happen very often.

I. Have you ever been offered help with this aspect of your wife's condition?

T. Way back I think my wife was given a piece of paper with drawings of stick men in different positions for having sex. But that's about it. The trouble is no one wants to talk about it, I mean your GP and the specialists they just 'sweep it under the carpet'. But it is a basic human need and when you lose the ability to fulfil it, it causes problems. Also I don't think you get compensated enough for the loss of having a normal sex life. The effects on the spouse rarely gets taken into account, it's like you don't exist. It becomes a source of tension within the marriage, which is not good for either of us, especially for my wife's pain.

The following excerpt from the discussion I had with G. a 62 year old extremely fit man, whose wife has had CNMBP for 14 years as a result of a nursing injury and been on opioids for 9 years. He said his wife's recent inability to have normal sexual intercourse posed a real problem for him personally and one that he wasn't sure could be reconciled.

G. I am currently working through the problem of not being able to have normal sexual intercourse with my wife. I found it hard to accept that my wife could do things like getting her hair done, or go swimming, both of which caused her pain, but she couldn't have sex with me. When I talked to her about how I felt she was mortified and I felt really guilty for raising it. She was

so distressed and ended up getting quite depressed, and became very withdrawn and tearful, which certainly did help matters. The problem is that since my wife's last operation last year she not only has back pain and leg pain but her clitoris is numb. She describes intercourse now as like having a "red hot poker" shoved up her vagina. Now not only is normal sexual intercourse extremely painful, she now can't even get any pleasure from masturbating. She said there was no comparison between having her hair done and having sex and felt that I was treating her like Workcare. I love my wife, and I felt a real prat. But I have always had a high libido, and sex to me is a very basic need, which needs to be met in order for you to feel good about yourself as a man. I get very frustrated.

I have to be honest and say that my wife has several times said that I should leave her and find someone that could meet my sexual and recreational needs. We have always been very active, my wife I used to do a lot of backpacking and skiing as well as having a very active and fulfilling sex life. I still backpack and ski and exercise regularly, running, cycling, weights etc. But I have always told her that I was here to stay. She has even suggested that maybe I should use a prostitute, because she said she thinks she could handle that better than me going and having an affair and caring about someone else. But I don't think I could do that.

It came to a head because my wife had stopped masturbating me and so we were have no intimacy at all. When we talked about that she said that she felt so

inadequate, unattractive and at the same time fearful that it would lead to sexual intercourse which she just couldn't bare. She also said she had noted that I was having difficulty climaxing when she was masturbating me that she felt that I no longer found her desirable despite her attempts to keep herself trim and attractive despite her pain and disabilities. I told her that knowing that your wife is in pain is not exactly a 'turn on'. Her specialist has pleaded with me to go and talk to him about our problems in this area. But I am reluctant, probably embarrassed but also I don't know what he can say that I don't already know. I am just going to have to learn to accept that I can no longer have normal sexual intercourse with my wife and that if we have to find other ways to be intimate that gives us both satisfaction to the level we can both feel good about ourselves. The important thing is we are talking about it and being honest with each other despite the hurt it is causing us both.

The loss of personal credibility associated with being negatively stereotyped stigmatised and not being believed was problematic for many participants to reconcile. Time and knowledge seemed to play major roles in overcoming this personal assault as indicated in the following two quotes:

Int.D. I used to be worry a lot about what the nurses thought about me. You know that I was a malingerer and a 'druggie'. But now I don't give a damn, I know my pain is real, Dr.X knows it's real and that I need morphine and that's all that matters. Because the reality is I know more about my pain and treatment than they do

and their attitudes and behaviour reflect their ignorance. Some nurses don't like that. But you get good at picking out those nurses who are genuinely interested in chronic pain. I will then take the time to talk to them about what my pain feels like, how it affects my life and how the pump works and the side effects of the medications that I take etc. I also tell them about myself, and what I used to do before my injury. Slowly they get to know you and they treat you differently.

IntC. I stopped taking their derogatory remarks and dismissive behaviour personally a long time ago now. I guess it coincided with a change in the way I viewed the world, and myself. The way some nurses, doctors and insurance company's claims officers treat us is unjust but the world is an unjust place and life is unjust. None of these people knew me personally so their insults were not aimed at C the person, but to C the 'chronic pain' patient who relies on narcotics to manage her pain. I also noticed over time that they treated me differently when I was having surgery and had legitimate acute pain as opposed to when I was admitted for exacerbation of my chronic pain. It was then that I realised that they were out of their depth when it came to looking after chronic pain patients being treated with narcotics. They didn't have a clue except what they learnt at the nurses station, which was that we were malingerers and addicts. Even though Dr.X tells me that some have attended in-service education on chronic pain and intrathecal pumps, which is encouraging, it certainly doesn't appear to have changed their attitudes and behaviour. So I make sure that every time I come into

hospital I bring in my folder with literature on chronic pain, intrathecal pumps and the use of narcotics in treating chronic pain and one typed page about myself. I always ask the nurse who is assigned to my care if she is familiar with the pumps and the literature on the use of narcotics in treating chronic pain and then offer to loan her the articles to read. If only one nurse picks them up then I feel I have achieved something. Of course I run the risk of striking one of those nurses who can't cope with the idea that the patient may know more about his/her condition than he/she does. When that happens I'm usually in for a 'rough ride' that shift. But their negative attitudes and beliefs are really a reflection of community attitudes based on ignorance. Ignorance about what it is really like to live with severe chronic back pain 24 hours a day and taking narcotics to control it and truth about Workcover and TAC. So we have to educate them ourselves if we want better, safe care and understanding.

The following quote illustrates strategies that one sufferer uses in order to deal with being discredited by nurses and family members and how reconciliation sometimes involves accepting people and their negativity and taking responsibility for the emotions they provoke.

IntCS. I have over time gained personal confidence and learned to stand up for myself and confront nurses about medications not given on time. In order to get treatment ie adequate analgesia, we have to be fairly adamant and straightforward with doctors and nurses. With the support of pain specialists this is now getting easier. But unfortunately there are times when it still hurts and I allow myself to get angry, upset and I often

withdraw. When family members make negative comments I tend not to say anything. I have learnt it's a battle I can't win and thus there is no point wasting energy on putting up a fight. If they ask something, I explain, but if they criticise I just keep quiet.

The middle-aged lady in the focus group who had talked about losing 'me' shared what grieving for the lost 'me' had meant to her.

Ffg5. I have grieved for the 'me' who worked, who cared for her children, was a friend and lover to her husband, who was spontaneous and lived life to the full. I enjoyed the outdoors with the caravan and water skiing. I have grieved for the 'me' who was surrounded by friends and colleagues who often filled my home. Grieving losing 'me' has been a roller-coaster ride of emotions. It has meant shedding a lot of tears and feeling angry, resentful, guilty. Guilty at what it has meant to my marriage and family.

This participant agreed to be interviewed to talk further about her grief and how she is trying to reconcile her losses and impact on her personhood and life. The following excerpt is from that interview. She shared that she had sought the help of a psychologist to help her reconcile the consequences of her CNMBP treated LTOT in order to "get a life". She said the process itself had been very confronting and often emotionally distressing. In addition, whilst she feels she has grown and reconciled a number of issues as a result of this process, her family, especially her husband, were having difficulty accepting the changes in her. It also illustrates how reconciling one's losses can be a multifaceted life long process.

Int.MD Working with the psychologist has helped me to re-evaluate my life and the things that have influenced the way I have dealt with my pain and its consequences in the past and how I have dealt with day to day family problems. I believe I have become more independent and confident. I used to feel responsible for everyone's happiness and problems and was full of guilt. I was brought up a Catholic and taught by the nuns, which I think that is why I have problem with guilt. As my psychologist and I often joke about me having a good dose of the Catholic guilt. I used worry about what other people, like nurses thought of me. But now I don't worry as much as I used to. During my last admission to hospital one of the regular nurses told me "I was alright, I wasn't like the others". Whilst it made me feel better, I felt sorry for the 'others' and it reaffirmed what I knew all along what they thought of us chronic pain patients. I know my pain is real and that petheidine helps relieve my pain to the point that I am able to live. However, it only takes one nurse to make a snide remark about your pain or your need for narcotics to make you feel like a second class citizen. They have no idea what you are going through and worst of all of they don't appear to want to know. Also if you do take the risk and confide in them about the difficulties you are having at home, they then jump to the conclusion that your pain is psychosomatic due to your social problems. I know that these problems do affect your ability to cope with your pain, but you wouldn't have them if you didn't have the pain in the first place. So I usually only share these problems with my psychologist, pain specialist, God and a couple of special friends who help me work through

these kind of problems. At the moment my husband is having difficulty accepting the fact that I have become more confident and less dependent emotionally on him. The big question I am facing at present is do I still love him? And at the moment I just don't have the answer.

Besides working through the impact that my pain has had on my marriage and family relationships, the other major hurdle has been coming to terms with not being able to work. I was only a state enrolled nurse but that was a big accomplishment for me. I left school early to help my mother cope with bringing up the triplets. The nursing course was a real struggle but I passed and had a terrific job working in a rehabilitation hospital. After my first operation I went back to work for a year before I re-injured myself. Not being able to work was the hardest thing to accept. I still grieve today, especially when I go into hospital and see others doing what I used to do, or when I meet up with your old work colleagues and friends. Most people don't understand that some people actually enjoy working. Also over time you lose contact and the friends you thought you had. Very few go the distance with you. It leaves a big whole in your life and you lose the reason to get up every morning. So you have to try and find something that you can do without exacerbating the pain to the point that you can bring in back under control that can also give your life some meaning. I am not at all creative, although this year I have done some knitting and long stitch. I took myself off to the craft show to see if there was anything that inspired me which I could do. I am now learning to make my own greeting cards using stamps and stickers. But

the satisfaction I get from doing a bit craft doesn't come close to the satisfaction that I used to get from my work. Very few people understand what it means not to be able to work.

The following excerpt is from an interview with a female participant who had three grown up children and it illustrates the difficulty of reconciling oneself to your post-morbid personhood.

Int.MN. I am still learning to accept and to like the person I have become and I don't know how long it is going to take, maybe a lifetime. It also involves others accepting whom you have become, or should I say becoming. Because it's ongoing, not only am I getting older but my pain appears too becoming harder to control. Your body gets used to the drugs and you need to take more to get the same result. It is hard to change, but I am gradually learning to put myself first and that I can't be responsible for everyone's happiness. I don't have a choice of getting away from my pain, whilst others do. I want to you use my 'good' pain times to be doing things, and being with people, that are important to me. I see myself as learning to be selfish by thinking about myself first, which up to now is totally not me.

The next few quotes are excerpts from the male focus group discussion that highlights how the process of reconciliation cannot proceed until the pain is 'under control'. In addition, in the end it is up to the individual to decide as to whether he can or wants to reconstruct a personhood that he can honour and that is meaningful.

Mfg2. I think that while you are under the really chronic severe pain before it's under control, it's the only thing you care about. You don't see anything, you don't feel too much apart from complaining, but once things become controlled you start to see the damage it has done to your relationships. How it's changed your family relationships, your inability to drive, your inability to take pride in the things you used to do beforehand. So you've got this period of "blackness" I suppose, then you come out of it, and at that time you've got to decide whether you're going to rehabilitate yourself or are you going to die. At that point I decided I was going to rehabilitate myself and aim myself in the direction of making the best of what I have left, and that's the way I'm going.

Like the previous participant the following male focus group member takes responsibility for 'rehabilitating' himself. However, he describes the process of reconciling losses as a 'fight' and like boxing fights you can win some and lose some. Implied in his words is that he is fighting to regain his pre-morbid personhood and life and whilst he has met with some success he has also experienced failure, increasing his fragility to the point where suicide is considered an option. The latter highlighting the importance of monitoring CNMBP sufferers treated with LTOT for depression, especially when they get to point when nothing further can be done to reduce their pain and they are left to reconcile themselves to the consequences of their CNMBP treated with LTOT.

Mfg1. You lose part of yourself when you fail to rehabilitate yourself. We have been very strong workers. I have been a very strong worker and really want to fight

this. We've all been through this for a long time. You are confronted with a number of changes and incidents that you fight back from, and succeed to a certain level, and you push yourself and push yourself because you want to have good relationships and your life back, but then you fail. You see yourself failing and you go back into something else and that's where I think a lot of your spirit is taken out of you and as T was saying, it gets to the point when you consider suicide.

The following participant also talks about successful pain management and rehabilitation as pre-requisites for successfully reconciling losses in order to construct a meaningful life.

Mfg4. I was days off it (suicide) when I first saw my Specialist. Since my pain has been controlled and with rehabilitation I've been getting some form of my life back. I don't mean working or anything like that. When I talk about getting some meaning back, I can only refer to it as getting out of the "black period" where there was nothing in my life except pain, to the point where I am able to accept my pain, myself and limitations and live a meaningful life within them.

Another excerpt from this male focus group discussion again highlights the reflecting on, and the re-evaluating of, one's pre-morbid personhood that occurs when attempting to reconcile the losses associated with CNMBP treated with LTOT that makes one so fragile. It also raises the issue of being reconciled to the personhood and life that one is able to construct with one's remaining abilities.

Mfg1. That's the reassessment process isn't it? Where you reassess, you challenge your whole life from what you were and find out what's important to you and trying to find some form of quality of life. Some life that you can cope with and that is acceptable.

The final quote from a member of the male focus group discussion illustrates his personal journey of taking stock of the losses that resulted have resulted in a high degree of fragility, which involve re-evaluating his whole life.

Mfg3. I think it's like once you go through the original 'why has this happened to me?' you really start to internalise the impacts on your social life, every relationship you have, particularly with your family, your work mates, how people treat you. I think we all play significant roles ie. Of father, husband or worker, and that's how people like to view us, but those things have been taken away. Your self-esteem is basically destroyed and you have to re-evaluate your whole life in terms of what is important to you.

The following is an excerpt from a transcript from an interview I had with a young mother of two young daughters who had suffered CNMBP since the age of 10 due to scoliosis. She shares how she and her husband reconciled and transcended the losses resulting from her CNMBP treated with LTOT especially when they decided to have a family. It highlights the importance of grieving in order to be able to move on, and that it is something that you "revisit" from time to time. It also highlights the importance of acceptance, connectedness and ability to live with uncertainty and ambiguity in order to transcend fragility and achieve goals. The participant also differentiates

between physical and emotional pain. The latter she appears to relate it to being discredited for taking opioids to manage her CNMBP and acknowledges that it is something she can't change and therefore has had to learn to accept and live with a certain level of fragility.

Int.T. Your life gets smaller and more insignificant and you grieve for your former life. But you move on because you have to. When my second husband and I decided to have family it was based on the full knowledge that we would need to work as a team and accept outside help. So when my children were younger I had to have a nanny to help me with things like bathing, lifting onto change tables and into highchairs. Now they go to school and some days I can't drive them to school either because of the pain and/or, exhaustion because you haven't slept and/or because of the effects of the narcotics. On these days one of the other mothers take them or my husband will go into work late and take them himself. It's on these occasions that you revisit old grief. Even though you get on with your life and learn to live within your limitations and the emotional pain of being stigmatised as a 'drug addict', from time to time something or somebody will remind you of your vulnerability. That's when I feel lucky that I have a very supportive husband and caring doctor who helps me manage my pain.

In the previous quote T. refers to the acceptance of help. A number of female participants talked of the difficulties they had in relation to first reconciling their inability to take care of their home and secondly accepting 'home help'.

Int.A. I injured myself playing netball. Having always been a housewife who stayed home to look after the kids, housekeeping was my job. I wouldn't say I was a fanatical house-proud woman but I enjoyed housework and took pride in my home. So it was extremely difficult to come to terms with the fact that I could no longer do certain household tasks and that someone, who was a complete stranger, would come into my house and do it for me. I remember at first feeling so uncomfortable, it was like having a maid and I was the mistress of the house. To overcome this situation I used to make excuses to get out of the house whilst she was cleaning, like going to hydrotherapy and the library. Also I had to accept her standard of cleaning which whilst she did a good job, wasn't the same as me doing it myself. Overtime we have become friends and I was able to talk to her about what needed to be done and what I used to do.

The Literature

During the past several decades, a dominant paradigm of loss and grieving has emerged in the psychosocial sciences. This paradigm emanated from psychoanalytic theory and behavioural psychology. It interprets loss as an objectively real, undesired, permanent non-existence to which one must adapt, and it further explains grieving as the process of recognising, processing and adapting to the loss (Cody 2000). For many scholars grieving is seen to include 'bereavement' and 'mourning' that may be related to a plethora of losses other than death. There is a large amount of nursing literature in which the application of grief theories, from other disciplines, using the

dominant paradigm, have been used to analyse the human experience related to losses not involving death. (Werner-Beland 1980; DiAngi, 1982; Miller, 1983; Stanton, 1983; Freidman-Campbell & Hart 1984; Haylor, 1987; Ignatavicius, 1987; Lamber & Lambert, 1985; Smith 1990; Cowles & Rodgers 1991). The psychodynamists such as Woden (1991) and subscribers of attachment theory of Bowlby (1961) described and promoted the understanding of the internal process of grieving as it was experienced by the individual (Murray 2001). Whereby social learning theorists (Averill & Nunley 1993; Rosenblatt 1993; Moss 1995) connect loss to a social environment that influences the meaning of loss to the individual, the resulting social adjustments and rituals that will impact on the course of recovery and adjustment (George 1993). Neimeyer & Mahoney (1995), constructivist psychologists stress the uniqueness of the individual interpretation of both the external and internal worlds of the sufferer confronting loss. Earlier Cowles and Rodgers (1991:121) on reviewing 74 of then current articles, had defined grieving as *"a dynamic, pervasive, highly individualised process"*, being the human response to a generic loss rather than death alone. Words as 'resolution' and 'acceptance', have been frequently used to describe the final phase and a definitive ending to grief, however, Stroebe et al (1994) interpret the term to represent an abatement of grief. Thus, acknowledging that people continue to hold memories of the loss and re-visit the implications of the loss over time. Other terms are now used to describe the endpoint of grieving such as reconciliation (Wolfert 1987), and assimilation (Rando 1993). According to Zisook & DeVaul (1985:377) most people *"never totally resolve their grief; significant aspects of the bereavement process go on for years after the loss, even in otherwise normal patients"*.

There are few studies that address the acceptance of pain, in particular CNMBP. Jacob et al (1993) defined chronic pain

accommodation as the perceived ability to live a meaningful life despite pain. Pain sufferers who were able to accommodate their pain had a higher level of confidence in their coping ability, were less likely to be depressed and demonstrate pain behaviours (Jacob et al., 1993). There have been some studies that have demonstrated that in some cases, acceptance of pain may have greater utility than struggling to control it (Geiser 1992; McCracken 1998). A study undertaken by McCracken (1998) to examine the concept of acceptance and to see whether there was a correlation between pain acceptance and pain intensity. The study involved 160 patients attended a pain clinic that relied on self report measures using Chronic Pain Acceptance Questionnaire, Beck Depression Inventory, Pain Anxiety Symptoms Scale and Sickness Impact Profile. The study showed a relatively low correlation between acceptance and pain intensity ($r = -0.28$, $r^2 = 0.078$) revealing that low pain intensity does not simply equate with acceptance of pain (McCracken 1998). The study did report that greater acceptance of pain was associated with not only less psychological parameters (pain related anxiety and depression) but also less physical and psychosocial disabilities (McCracken 1998). However, McCracken (1988:25) emphasised that these findings *"do not indicate that all patients with pain should give up trying to reduce it"*. A later study undertaken by McCracken (1999) that used the Chronic Pain Acceptance Questionnaire showed that acceptance of chronic pain involved three components. These included *"engaging in normal life activities", "recognising that pain may not change" and "needing to avoid or control pain"* (McCracken 1999:98). This concept of 'acceptance of pain' has emerged from a contemporary radical behavioural approach and not a cognitive behavioural approach. However, acceptance is not incompatible with current cognitive behavioural therapy for chronic pain, especially Rational Emotive Behavioural Therapy (Ellis & Harper 1997). According to McCracken (1999) studies of acceptance of chronic pain

have demonstrated that it may be a vital behavioural construct with the opportunity of improving clinicians' understanding of the suffering and impaired function of persons with refractory pain. Thus, acceptance of CNMBP, according to the cited literature, involves acknowledging that pain is a continuing reality, giving up fighting with the pain, believing that a meaningful life is still possible, and endeavouring to improve one's life.

However, as Thorne & Paterson (2000:9) caution, *"commonalities and variations within chronic illness experience make it apparent that neither disease-specific nor a generic approach to research alone creates an understanding of the phenomenon of what it is like to live with a chronic condition"*. In particular to producing research sufficient to guide clinical decision making or health service delivery policies (Thorne & Paterson 2000). Chronic pain and suffering having commonalities with respect to their ability to deeply shape the lived experience regardless of the origin of the pain (Bowman, 1991; Henriksson, 1995). In addition to chronic pain some chronic diseases such as HIV (Tewksbury (1995) and Spinal Cord Injury (Carpenter 1994), enforce changes with respect to roles and responsibilities that generally alter self concept. However, whilst not all chronic illnesses result in these experiences, Thorne & Paterson (2000:8) expound the credibility of research into a particular disease to expand our insight of common *"physical symptomatology, adjustment patterns, and social constructs"*. In so doing, such utility knowledge can then broaden the understanding that has been deduced from studies into particular chronic conditions resulting in more individualised and appropriate health care initiatives.

In the nursing literature there are various studies that address issues relating to impediments to forming partnerships with sufferers of chronic illnesses (Thorne et al 1999; Brown & Piper 1995; Paterson &

Sloan 1994). In particular to the attitudes of nurses when patient knowledge and understanding of their own chronic condition is greater and more sophisticated than the nurse. A number of studies (Benner et al 1994; Johansson et al 1996; Thorne et al 1999) report that patients attempting to convince a disbelieving professional of the seriousness of symptoms or their requests for medications results in them being labelled as over-anxious or obsessed with his or her condition.

A recent study using Q-methodology focused more specifically on understanding what can be established when sense has to be made of what it would mean to accept chronic pain (Stainton 1995; Risdon et al 2003;). Q-methodology generates diverse accounts that are not easily characterised as pre-defined attitudes or beliefs and frequently unexpected notions or themes emerge through a cultural rather than an individual focus (Stainton 1995). The participants are viewed as collaborators in an analysis of a common culture rather than subjects under investigation (Mulkay 1985). Accounts of acceptance emerge from within a culture of everyday pain in which understandings of pain are continuously reviewed, evaluated, negotiated, rejected, honed and used to explain experience (Scarry 1985, Morris 1991). Accepting loss of self was exemplified in this study as acknowledging a loss of the pre-morbid pain-free self (Risdon et al 2003). In addition, to accept chronic pain means to accept failure as well as acknowledging the loss of the former pain free self. However, this failure is not a reflection on character, but may be acknowledgment that *"personal attempts to control pain are not successful and an acceptance of this will incur some loss"* (Risdon et al 2003:381). Chronic pain is basically threatening, this threat goes beyond the threat of disability but to the *"core sense of a coherent and valuable self"* (Risdon et al 2003:384; Eccleston & Crombez 1999). Thus in order to learn to live with the pain one must

first confront the loss of self (Risdon et al 2003). Chronic pain sufferers are the only ones who can answer the questions like, am I the same person with chronic pain as without? In order to successfully accept chronic pain does it require one to accept a changed 'me'?

There are number of studies on the impact of chronic pain and chronic illness and sexual difficulties (Duquesnoy B et al 1998; Monga et al 1998; Ambler et al 2001; Nusbaum et al 2003). A survey of 1072 chronic low back pain suffers, mean age 44 years, looking at the psychosocial impact of CNMBP reported 46% of respondents experiencing significant sexual dysfunction (Duquesnoy 1968). In a quantitative, self report survey of 70 chronic pain patients, mean age 49.9 years (range 29-74), 66% of respondents remained interested in sex, 50% were satisfied with current sexual partner and only 20% were satisfied with their current sexual life (Monga et al 1998). Only 44% of respondents experienced normal arousal during intercourse; 33% practiced masturbation and 47% were involved in sexual intercourse or oral sex at least once a month. The majority of respondents were dissatisfied with orgasmic activities. No relationship was found between pain severity, duration, frequency and sexual functioning. However, a relationship was found between disability status, age and several psychological variables, especially depression, and various domains of sexual functioning (Monga et al 1998). Another quantitative survey of 237 chronic pain patients, with a 72% response rate was undertaken in the U.K. by Ambler et al (2001) to determine the specific physical and psychological problems associated with sexual activity in patients with chronic pain. The only difference between respondents and non-respondents was age, respondents being younger and experiencing lower levels of depressive mood. Seventy-three percent of respondents reported

pain-related difficulty with sexual activity; most had several, in various combinations of problems with arousal, position, exacerbation of pain, low confidence, performance worries, and relationship problems. All except position difficulties were associated with less frequent sexual activity. There were few gender differences, and only weak relations emerged between specific problems and mood and disability. They concluded that the high prevalence of sexual difficulties in patients with chronic pain was considered nearly double that of the general U.K. survey. In addition, the difficulties experienced by chronic pain patients were not simply related to mood and disability. They also found that sufferers indicated that they wanted help and concluded because of the range of problems experienced, a multidisciplinary approach would be required. Nusbaum et al (2003) reviewed chronic illness and sexual dysfunctioning. They contend that knowledge of the sexual response cycle is important to understanding the impact that chronic conditions, such as chronic pain, can have on sexual functioning (Nusbaum et al 2003). Desire being influenced by neurotransmitters, androgens, the sensory system and psychosocial factors such as self-esteem, body image can be negatively affect a CNMBP treated with LTOT interest in initiating or being receptive to sexual activity (Nusbaum et al 2003). Medications used in the treatment of chronic pain can also disrupt the sexual response cycle (Nusbaum et al 2003). General strategies for optimising sexual functioning include varying the sexual position, timing sexual activity, timing medication administration, reducing or eliminating if possible offending medications and expanding their sexual repertoire (Nusbaum et al 2003).

The literature also reports the association between both depression and antidepressant medication and sexual dysfunction (Woodrum &

Brown 1998; Kennedy et al 1999; Phillips & Slaughter 2000; Zieba et al 2000; Baldwin 2001; Coyne et al 2002; Nurnberg & Hensley 2003). Depression is a common comorbidity with CNMBP, occurring in approximately 50% of chronic pain patients (Weickgenant et al 1992; Ruoff 1996). Evidence exists to suggest that depression and chronic pain share common biologic pathways, namely, the serotonergic (5-HT) and noradrenergic systems, hence the frequent use of antidepressant medications such as serotonin-reuptake inhibitors (SSRIs) in pain management (Ruoff 1996, Woodrum & Brown 1998, Nurnberg & Hensley 2003). Thus, their pain management medications rather than their CNMNP treated with LTOT may be contributing factors to their sexual dysfunction.

PHASE TWO - SELF-DETERMINING NORMALCY

The data

Starting with fragility and finding hope the sufferer moves through reconciling towards self-determining normalcy. This self-initiated exploration of what constitutes normalcy for them involves searching for the treatment, resources and support to reassemble an honoured personhood that enables them to transcend the adversities resulting from their CNMBP treated with LTOT. The development of self-determining normalcy is detailed in Appendix 32.

Causes of self-determining normalcy.

Self-determining normalcy is a category that is related to the need to find ways of taking responsibility for one's health and care, improving, supporting and honouring one's personhood and life to help diminish the sense of fragility. Self-determining normalcy is a process of

taking responsibility, setting goals and trying to find resources to support their choices and decisions with respect to achieving goals. Self-determining normalcy is initiated by reconciliation and need to find ways to live with the consequences of CNMBP treated with LTOT. The reconciling phase of authenticating and repairing results in an opportunity to accept and/or heal physical, emotional and spiritual pain and reorientate one's personhood towards a hopeful participation in life with diminished fragility.

Characteristics of Self-determining normalcy

Self-determining is characterised by three sub-categories, **taking control, setting goals** and **'time out'** (in vivo code). Through self-determining normalcy sufferers discover ways to a) honouring their personhood, b) by self-determining their normalcy and taking responsibility for their lives and pain, and c) maintaining hope. Each context involves different experiences of being self-determined and 'normal'. Sufferers move in and out of different contexts during their CNMBP treated with LTOT career. Individuals who want some semblance of normalcy in their lives are willing to take risks and responsibility for their pain. Self-determining normalcy is problematic when the sufferer is unable to reconcile their pain and damaged personhood and lives. Strategies for self-determining normalcy includes, taking control, identifying meaningful pursuits, setting new goals, accessing information, services and support. The consequences of self-determining normalcy include support for a reassembled, honoured personhood that allows them to strive for normalcy and diminish the adversities resulting from their CNMBP treated with LTOT.

Self-determining normalcy behaviours were described by participants as you, and not your pain, trying to dictate who you are, trying to live an ordinary life, making choices and decisions, taking responsibility, negotiating and being your own advocate. Initiated by reconciling it is a major characteristic of authenticating and repairing personhood. Self-determining normalcy happens by, a) being self-motivated; and b) wanting to live normal lives in order that they may diminish their fragility. Characteristics of self-determining normalcy include taking control, setting goals and 'time out' (in vivo code).

Self-determining normalcy requires the capacity to understand their CNMBP and its long-term management, including LTOT and the ability, opportunity and willingness to be self-empowered. Self-determining normalcy is encouraged by:

- being reconciled to living with a certain level of pain;
- taking responsibility for pain and health status;
- being reconciled to post morbid personhood;
- believing that it is still possible to live a meaningful life;
- knowing what resources are available to support their 'normalcy';
- continuously developing and refining personal, life and health goals;
- having a working partnership with those involved health care practitioners involved in their pain management; and
- having supportive family members and/or friends.

Self-determining normalcy becomes problematic when the sufferer:

- is unreconciled to living with pain;
- remains focused on seeking a cure to their pain;

- believe they no longer have choices with respect to the way they live their life;
- lacks knowledge and insight into their CNMBP treated with LTOT;
- has paternalistic health care practitioners involved in the management of their pain;
- has coercive family members, significant others or friends.

Strategies for self-determining normalcy include seeking ways to improve quality of life, involving family members, significant others and friends, being positive, being realistic, being responsible and involving those health care practitioners involved in pain management. Self-determining normalcy contributes to an honoured personhood and better pain management. The consequence of self-determining normalcy is an opportunity to achieve some semblance of normalcy that not only sustains a meaningful life but also offers hope of reducing the negative stereotyping and stigma and thus help diminish their fragility.

The second phase self-determining normalcy either follows or occurs simultaneously with reconciling, and sometimes it will be revisited after 'striving for normalcy'. Self-determining normalcy includes honouring personhood, setting priority and seeking resources. At this stage the sufferer may resign or continue and move into the next phase and strive for normalcy. Factors that influence resigning in this second phase include: overwhelming pain and disability, fatigue, lack of support, inability or unwillingness to invest time and energy, loss of hope and inability or unwillingness to accept their normalcy. Factors that facilitate a sufferer moving into the next phase, 'striving for normalcy', include:

- accepting what constitutes normalcy for them;
- knowing what support and resources they need to assist them achieve their semblance of normalcy;
- maintaining acceptable levels of pain with minimal side effects; and
- the desire to try to be fully engaged in life.

The following transcript excerpts provide illustrations of self-determining normalcy behaviours.

This is an example of what self-determining normalcy has involved for a woman who has been able to remain in the workforce despite her CNMBP requiring LTOT.

S21. I nearly ended out of the workforce, which was an enormous crisis in my life in relation to being seen as 'normal' as apposed to an invalid. My old boss was a bastard. So I stood up to her and reported her for harassment and I won. I now have a new job, which is meeting my needs. Most folk are changed in their attitude to disabled folk and thank goodness I know a lot of them and I can go to work and be treated as an equal. I work differently than before, changing ways I do things. I do more on 'good' days and less on 'bad' days. Luckily I have a great family, friends and employer who I can relate to and be understood. One has to be open to ideas and start planning how to approach new ideas. Given 4 years ago I wouldn't have been so positive but when the pain is controlled you learn to cope much better.

Self-determining normalcy is expressed in the following quote highlighting the drastic choices and decisions that one sufferer of CNMBP treated with LTOT took to address her fragility from the negative attitudes towards her LTOT. It also illustrates the 'normal' activities that emerge as priorities in their lives which sufferers decide to pursue in their 'good' pain times.

S19. The negative attitudes. I never wanted anything to do with morphine ever again. I admitted myself to a drug rehabilitation unit with the illegal drug users. However, there was a pain specialist at the unit and he was the first professional who really understood and helped me. He said I was in the state I was in because I was under medicated and if I had adequate pain relief I'd just get on with my life like ordinary people do. Then people would relate to you as they do to any one else. I was so grateful to find I have reasonable pain relief with Kapanol that is allowing me to enjoy my new dog and spending time with my 12 year old niece. I have even begun to slowly work in my garden again.

The following quote demonstrates the importance of the ability to do both some of the mundane things of daily living and important activities independently with respect of her self-determining normalcy.

Int.S. Since having to have my intrathecal pump removed and now having to rely on injections I am no longer able to drive. Also the level of my pain became intolerable after only walking short distances, and even with my husband pushing the shopping trolley, walking around the supermarket became impossible. My husband suggested that I write a shopping list and he would do

the shopping. But I enjoy cooking and I like to see what is new as well it's like an outing to me. I also go down the local pool for hydrotherapy but by the time I got myself there I was in too much pain to get the most out of it. In addition, I read a lot and going to the library became un-pleasurable because I couldn't stand and browse through the books without my pain ending up going through the roof. In addition, I hated having to wait until my husband could take me and I certainly couldn't keep using taxis, even at half price, because it all mounts up. So I decided to investigate the electrical scooters. I hired one for a month to see whether I could manage it. Although sitting aggravates my pain, I was able to tolerate sitting on the scooter for the time it took me to get to, and go around the supermarket, and get home. I have my groceries home delivered. I also found that I was able to take the scooter right down to the poolside where there were changing rooms for disabled people, so it worked out well for my hydrotherapy. In addition, going to the library has become an enjoyment again. Based on the experience and my husband making the necessary changes to the house and shed (building ramps etc.) I applied to Workcover for an electric scooter, which they agreed to supply. It has had a very positive effect on my life by giving me the opportunity to engage in some normal pursuits, especially the things that are important to me.

The following field-note incorporating a discussion with a female participant who lives alone gives insight into how she has engaged in self-determining normalcy.

FN. I go through periods of complete withdrawal when I only get out of bed to go to the toilet and feed the cats and then periods which I call hyper-manic when I am doing a hundred things at once! I do my shopping over the Internet and have them delivered and my chemist delivers all my medications. I have home help once a week. These are especially helpful when my pain is so overwhelming that I just have to lay down all the time. When I am well I have a weekly massage, and try to go to hydrotherapy twice a week. I still drive my car occasionally, but when I can't drive I either get a taxi, or if it is a long journey to see my specialist my Dad takes me, he's retired. I am trying to complete a Masters Degree in nursing through the Catholic University, which is just around the corner. I have had to defer a number of times, but my supervisor and the disability unit at the University are very supportive. At least while I am studying, I'm not vegetating and engaged in something 'normal'.

The following succinct excerpt from a survey respondent demonstrates that the respondent has the insight necessary for self-determining normalcy but which needs to be communicated to her general practitioner, pain specialist and nurses.

S44 I have awareness of who I am and what elements I need in my life to go on.

In the next excerpt from a survey respondent she makes the observation how experiencing several set backs has made her more determined to overcome them as well as identifying her priorities in her new normalcy.

S33 I have developed more determination to beat set backs. I am determined to make a life for myself, keep involved with people, friends and family and remaining relatively independent. I continually try and over stretch my limits, which not only teaches me more about my pain but also about my ability to live with it.

The Literature

The literature in respect to self-determining mainly centres on patient rights that have become enforceable by law in some countries and states. In this context self-determining behaviours may be defined as rejection of another's authority and promotion of own (Hokanson 1991). Self-determining encompasses the individuals' right to accept, question and refuse treatment (Hall 1994). In the U.S.A. law through the Patient Self-Determination Act and advance directives in part protects these rights. The purpose of this legislation is to register the individual's preferences relating to treatment for implementation when they have physically and mentally lost the capacity to verbalise these wishes (Hall 1994). Australia has followed down the same legal road but for legally competent patients having the legal right to refuse treatment (Victorian Medical Treatment Act 1988) and in South Australian the Consent to Medical Treatment and Palliative Care addresses the issues of consent but is restricted to the terminally ill. Patient activity and self-determining and participation are closely related. A study on patient control found that participation in decision making, obtaining appropriate information and being self directed augmented patients' sense over control over their health situation (Dennis 1990). Self-determining and patient autonomy have been studied in relation to quality of care (McCormack 1993). He advocated client centred nursing practice, which incorporated including them in decision-making and keeping them informed in order that they may self-govern.

A U.K. nurse who broadly defined involvement as patient activity and participation in care (Iskander (1997) has studied the efficacy of consumer involvement in health care. Iskander (1997) identified the benefits to the client of consumer participation as being more likely to have their needs met, feel valued, empowered and respected. In addition to being autonomous, developing effective coping strategies and have a higher probability of finding their own solutions.

Nurse patient interactions offer opportunities for patient involvement in their care according to Saunders (1995). He believes that they can achieve this by participating in decision making, goal setting, partnership contracts, completing initial assessment documentation, self-care and self-medicating. In order to facilitate such involvement Saunders (1995) acknowledges that nursing documents would need to be made user friendly and accessible (at the bedside), provide facilities and freedom to make own refreshments and have bedside hand-overs with patient participation.

There have also been studies (Biley 1992; McCloud Clark 1993; Avis 1994) that have found reluctance among patients to be involved in their care. Findings indicated that patients were not interested in participating in their care and would prefer to be told what to do and leave the doctors and nurses to look after their health problems (Avis 1994).

An Australian report on service delivery of public hospitals in Victoria studied the way health consumers could be involved to improve hospital care (Draper 1997). Communication between patient and health care practitioner was seen as the nexus in patient involvement in care. Thus, according to Draper (1997) patient involvement in health care is about the interpersonal relationships that exist

between health care providers and patients. Amongst the range of reasons why patients should be involved in their care including "a democratic right to exercise a voice about their health treatment" (Draper 1997:ix).

The context, which self-determining has been discussed in this chapter, relates to how CNMBP sufferers treated with LTOT determine what constitutes normalcy for them. Thus self-determining based on the data includes taking control; being responsible for pain; being positive; being realistic; being responsible; being informed; setting goals; involving family members, significant others and friends and involving those health care practitioners involved in their pain management. Self-determining normalcy reflects the process by which individuals decide what constitutes normalcy for them after accommodating their CNMBP and LTOT into their post-morbid personhood.

Taking control

The data

The first of three subcategories of self-determining normalcy to be presented is taking control. Taking control is concerned with CNMBP sufferers treated with LTOT taking control with respect to what not only constitutes normalcy with respect to treatment and life, but also evaluation of treatment and quality of life. Taking control happens in order that they, their family members, general practitioners, pain specialists and nurses know what they are striving for in the final phase of the authenticating and repairing personhood cycle. Taking control is encouraged by being self-determined, self-motivated, reconciled to living with a level of pain, reconciled to post-morbid personhood, self-advocacy, supportive family, significant others, general practitioners, pain specialists and nurses. The development of taking control is listed in Appendix 32.

Taking control is problematic when the pain is overwhelming, LTOT is having a negative impact on cognition, there is a lack of desire, they possess poor communication skills, resources are unavailable, finances are inadequate, there is limited or no support and fear.

Strategies for taking control include making decisions, taking responsibility and communicating health, life and personal goals. These strategies include becoming informed, understanding medical and nursing roles and advice, and questioning medical and nursing roles and advice.

The following quotes provide examples of taking control.

The following quote also illustrates how self-determining normalcy involves taking control, taking risks and having knowledge of what resources are available in order to get appropriate treatment in order to have a chance of living any semblance of a 'normal' life.

Int.C. When I decided to leave Dr.X and before I approached Dr.Y I went to great lengths of finding out as much as I could about him and his philosophy of pain management, including his attitudes to narcotics for chronic back pain. He had a reputation of being a straight talker and liked people to be responsible for their own pain management. After my first consultation with Dr.Y I left him with a number of documents to peruse. These included a copy of my medical diary, relevant medical reports and a piece of paper outlining in point form what my needs and expectations were with respect of a doctor taking over my pain management. The main issues were being listened to, being believed in, trust and accessibility if I needed to contact him. At

that time my pain management included an intrathecal pump administering pethedine continuously. I had done this in order that it would give him time to evaluate what I had discussed with him during the initial consultation and that we were both clear about the terms and conditions of any future doctor/patient relationship. On my second visit to DY he said that he thought that what I was asking for was reasonable and that he was willing to take over my pain management.

I experienced a 'honeymoon' period with Dr.Y when he took my concerns seriously and we worked through problems together thus upholding his end our negotiations. However, I began to experience difficulties with the pump which I found very worrying, especially because I live on my own and have no one there to monitor what is happening to me and also because of previous experiences when I have ended up being overdosed with frightening consequences. A couple of times I had been so concerned that I had presented myself at the emergency department only to be dismissed and once over hearing Dr.Y referring to me in a derogatory tone as "over anxious and precious". I contacted the clinical support person for the pump company to get advice about the problems I was having and what suggestions, if any, did she have. She suggested that it may be related to the catheter and that it may be worth asking Dr.Y to puts some dye through the catheter to make sure its not kinked or displaced. Dr.Y disagreed and dismissed my concerns once again. So I told him that if he were no longer able or willing to implement our original negotiated 'contract' of care then I would

arrange to have the pump removed. He said that if I was not satisfied with his care and then he would leave it to me to make whatever decision I thought fit with regards to the pump. After discussing the issues with my very supportive GP I arranged with the doctor who had inserted the pump to remove it. The problem with computerised drug pumps is that you are totally reliant on the person who has the computer. There is little point in going to your GP or presenting at a public emergency department if you have a problem because they know nothing about them. After its removal my GP took over my pain management using oral Tramadol which has been working well.

I also found writing letters as a good way to get things 'off my chest', educating people about what is going on and bringing closure so that I can move on. On occasion I have made a formal complaint to the Health Commission and really it is the process of telling your story that really helps and the rare apology you get is just the 'icing on the cake'. I still keep a diary, but now it's about what I do each day and how it affects my pain and what was the level of enjoyment. It has been helpful in determining what normal activities I can still enjoy and which ones I enjoy most. This helps me decide what I am going to spend my 'good' pain time on.

The following quote illustrates taking control with respect to health care, which had surprising results leading her to engage in what to her are normal pursuits.

S4. Two years ago after getting really sick and ending up in hospital being treated for depression I sacked the company doctor and rehab people. I found a doctor who cared and who put me in touch with my current pain specialist. Although I still experience the occasional flare-up and bouts of depression, I am now able to function relatively normally, like meeting friends, doing some gardening and the shopping, with some help.

The following excerpt is from middle aged woman who had been admitted to have a new pump inserted, having had to have the previous one removed due to infection. It tells about how she and her husband took control with respect to her post-operative pain management.

Int.R. Unfortunately my pain specialist did not have visiting rights at the hospital that the procedure was being performed. I had brought in my medications together with a list, name of my treating pain specialist with his contact telephone number. I was admitted by the surgeon's senior registrar who immediately communicated that he would need to talk to the pain specialist before I could be administered by regular analgesia. Unfortunately, the specialist had left for the day and it took an hour to track him down. I had made a point of discussing my pain management with the surgeon when we discussed putting in the new pump. Especially, my concerns regarding managing chronic pain whilst managing my acute post-operative pain. He said I had nothing to worry about that his anaesthetist was very skilled in these areas and would make sure I was comfortable. I also discussed my concerns with the

anaesthetist when he did his pre-operative visit and again I was re-assured that my chronic pain management would not change and that he would make sure I was comfortable post operatively. Thus, it was to my horror to discover post-operatively that I was only ordered the same analgesia that I had come in on for my chronic pain. Nothing extra had been ordered to cover the post-operative pain, which was extremely intense due to having had a double laminectomy to get the intrathecal catheter into position. I explained the situation to the nurse who was assigned to my care and she contacted the anaesthetist who told her to put up an intravenous PCA (patient controlled analgesia). However, he had not prescribed a continuous fusion with bolus doses and the rate he had set, it would have taken 24 hours of me pushing the button to receive the equal to one normal injection dose. The nurse was not able to comprehend my situation that I had two different types of pain to manage my chronic pain and my acute pain. In the end I gave up trying to explain and refused to have the PCA. I asked if I could speak to the surgeon on the telephone to discuss my analgesia but the nurse said he was a busy man and unlikely to have time to speak to me. I then demanded that she contact him and ask him to contact me at his convenience. In the meantime I was struggling on my pre-operative pain regime which my husband found very distressing and became angry. He went straight home and brought in medication from home and in front of the nurse he drew up an injection and gave it to me. He said to the nurse, if you won't relieve her pain then I will. My wife suffers enough every day and to do this to her is cruel

and more than I can stand to watch. All hell broke loose then. The surgeon immediately came on the phone and doubled my fentanyl dose. I felt isolated by the nurses, I was in the observation ward and felt that they were monitoring my behaviour all the time. I convinced myself that they thought me an addict and got myself in a real emotional state until I found the courage to talk about what happened to one of the nurses. Her reply was that she just couldn't imagine the amount of pain I must have been in which had driven me to do such a thing. It was evident by the Unit Manager's behaviour that she wanted me to be transferred back to Hospital A where my pain specialist worked. However, there weren't any beds, so I decided that I would be better off at home and after speaking to the surgeon on the telephone he agreed, so I was discharged home. I never saw the surgeon once post operatively, nor the anaesthetist.

The following excerpt from a Field Note illustrates how a group of CNMBP sufferers treated with LTOT had set up their own support group to get them out of their homes and participating in some normal recreational activities.

FN. Over coffee one morning I asked a group of participants if they belonged to any support group for chronic pain sufferers? Two responded and said that they had attended a support group run by a psychologist and occupational therapist for a couple of years. However, in the end they felt it just became a bitch session that went over the same old things like nurses not caring about you, and the hard time you were getting from TAC/Workcover. One said she acknowledged that

it helped to have an arena where you could safely express your feelings but if nothing changes you wonder what the point of it all. After the session a few of us would go and have coffee and we got talking that we had out grown that support group and what we wanted was something that got us out and doing things. Something to get away from just talking about pain. And that we could be support for each other, feeling free to call and talk to someone if you were having a bad day. We felt we had to make a commitment to meet once a month for recreational purposes, and despite our pain we had to go the extra mile to get there, otherwise it becomes too easy to say I can't make it today because of my pain. Of course there are those days when it is completely overwhelming but we really wanted to try and get this off the ground. One month 4 of us went to the Gold Class at Crown to see Titanic. We ordered a glass of Chardonnay as we went in, then we had them bring us a choc-ice half way through the movie and then a cappuccino ten minutes before the end. We had a wonderful afternoon. We felt 'normal' and we didn't speak of pain once. M. and J. have kept it going they used to go to the Dandenong Market once a month as an outing. We sometimes go to the club and have lunch and spend \$10 on the pokies. The first time J. went she won \$250! It just a bit of fun and bit of normality in your life.

The Literature

In the literature the concept of control is often associated with the concepts of taking charge (Burke et al 1991; Lindberg & Nolan 2001) and empowerment (Gibson, 1995; Rodwell 1996; Mattsson et al 2000).

Despite the plethora of psychological literature relating to control we appear no nearer to understanding the diversity of consequences relation to the presence or absence of control (Peterson et al 1993). Despite our limited understanding of control, Mark (1998: 251) stated *"individuals' beliefs about controllability of what happens to them is a core element of their understanding of how they live in the world"*.

There is also a substantial body of literature on control relating to specific illness conditions (Wassen 1991; Hall & Carty 1993; Raja 1994; McNaughton 1995; VanderVoort 1995; VanderVoort 1997; Lindberg & Nolan 2001). A qualitative Canadian study (Hall & Carty 1993) explored the concept of taking control in relation to managing early discharge following childbirth. They found that taking control was influenced by the women's beliefs about family and home; their personalities including their ability to accept help; their available support and their perception of a successful experience. Another Canadian study (Lindsey 1997) which focused on the concept of covert caring for self amongst the chronically ill identified taking control as one of the themes that underpins covert caring practices. Johnson (1991) in her study of people learning to live again after a myocardial infarction found that regaining control was a complex process which was characterised by regaining a sense of predicability, self-determination and independence. Gibson (1995) refers to taking charge as part of the process of empowerment. Taking charge involved advocacy, learning the ropes, learning to persist, negotiation

and establishing partnerships (Gibson 1995). Lindberg & Nolan (2001) in a study examining women's decision making regarding hysterectomy discovered that 'taking charge' behaviours were displayed in the form of actions directed at arranging and preparing for surgery. A qualitative study along the lines of the constructivist paradigm focused on a synergy towards health in relation to nursing care for women living with the chronic pain condition fibromyalgia (Sylvain & Talbot 2002). In their study empowerment and partnership were embedded in their nursing intervention model (Sylvain & Talbot 2002). The only other study cited that focused on empowerment and chronic pain was one conducted by Swedish physiotherapists who related empowerment to active participation of a responsible patient (Mattsson et al 2000). The results revealed that the ability of the patient to cast distinct desired goals was closely related to improvement in psychomotoric function, pain and working capacity (Mattsson et al 2000).

Literature relating the concept of control to pain management is heavily weighted towards controlling acute post operative pain with the implementation of patient controlled analgesia (PCA) technology (Knapp-Spooner et al 1995; Van Boerum 2000; Rawal et al 2002). Most studies focus on efficacy either in relation to comparing PCA with what was routine post operative pain management, the types of PCA modalities and analgesics used in PCA. Knapp-Spooner (1995) undertook a comparative study to examine the differences in pain intensity, sleep disturbance and effectiveness, fatigue and vigour between patients undergoing cholecystectomy who received either intramuscular (IM) injections or intravenous PCA for post operative pain. Their findings were that patients receiving PCA had less pain and fatigue than those receiving IM injections. Van Boerum et al (2000) also did a comparative study but compared the efficacy of

epidural analgesia with PCA on 50 patients undergoing spinal fusion for idiopathic scoliosis. In this study epidural analgesia was found to be superior to PCA in relation to pain control, ability to tolerate a full diet post operatively and earlier discharge. A randomised, double-blinded study which focused not only comparing the efficacy of two different medications, but also on the feasibility and safety of patient-controlled regional analgesia (PCRA) in the home was conducted on sixty day surgical patients who had underwent hand surgery (Rawal et al 2002). They concluded that it was feasible, safe and acceptable to self-administer local anaesthetic to manage post-operative pain at home. They also concluded that a protocol including patient selection, follow-up telephone call, and 24-hour access to anaesthesiology services is a prerequisite for PCRA at home.

There were no studies cited that focused on patient controlled LTOT in relation to chronic non-malignant pain, nor in relation to taking control of their lives. The only article that talked of involvement of chronic pain patients in LTOT was a position paper from the Australian Pain Society that detailed guidelines for the administration of opioids for chronic non-malignant pain in which they advocate patient contracts (Graziotti & Goucke 2003). Thorne (1993:120) noted that the *"realisation that the health care professionals were incapable of taking on full responsibility for health care of chronic illness was an important step in helping patients and families accept that responsibility themselves"*. In this study taking control implies accepting responsibility for ones chronic pain, personhood and constructing a meaningful life as close too normal as is possible.

Setting Goals

The data

The second subcategory of self-determining normalcy to be presented is setting goals. Setting personal and health goals helps give some

structure and incentives to their post-morbid lives. By having health goals participants felt that it decreased the sense of hopelessness and that nothing can be done. Personal goals helped them put back some purpose in their lives. Sufferers' sometimes sought input from their pain management specialist, psychologist occupational therapist, family members, significant others, friends and/or support groups with respect to them developing realistic goals. Participants tended to approach their pain specialist or GP in relation to discussing their position in respect of their health goals and need for support to fulfil them. The development of setting goals is listed in Appendix 33.

Setting goals can be problematic if the sufferer's pain is overwhelming and/or they are depressed. If they not seen as equal members of the 'team' or 'therapeutic relationship. Strategies that sufferers use to set health and personal goals include only making a few goals. Beginning with a couple that are short-term with a high probability of achievement and including a long-term goal that carries a greater deal of difficulty and challenge. Also many participants assigned rewards to their goals for added incentive.

The following transcripts are examples of goal setting.

There were a number of participants, especially survey respondents who used succinct phrases to express their goals. These included *"to return to work"*, *"to be more useful"*, *"remain relatively independent"*, *"to have sex again"*, *"to be a grandmother"*, *"to see my children grow up and do well"*, *"to come off narcotics"* and *"travel overseas"*.

The following excerpt from an interview with middle aged male participant who was still able to play bowls, talked about his goals in relation to this very important part of his life.

I.D. I have a weekly goal of making it to the bowls club on a Wednesday and play game of bowls. Last year we made the championships and I had set myself the goal of going if we made it. So I discussed it with Dr.X and he gave me some extra analgesia to take with me. He told me to ring him when I got back in case it had turned out to be too much for me and I needed to come in to get the pain under control. Without his support I could never have contemplated going. A lot of doctors would just tell you that you are not accepting your pain and disabilities, and being unrealistic. Where Dr.X encourages you to live and then helps you pick up the pieces. Anyway I went, we didn't win but we had a good time and I managed reasonably well. I was bloody sore for a couple of weeks but I just took things easy and Dr.X turned my pump up for a couple of weeks. I don't know what I would do if anything happened to Dr.X.

I. You have obviously got a good working relationship with Dr.X.

D. I can talk to him about anything, and I do! There's Not much about family and me that he doesn't know. What's more amazing he is truly interested.

The field note from one of my observation period recounts how CNMNP treated with LTOT often talk to each other about their goals, whether they be related to their admission, treatment, pain or what they want to do when they have got their pump, or when their pain is manageable.

FN. Despite their level of pain and the lack of visible 'treatment' except medications there remains a level of optimism among a number of patients. A common goal

they would share with respect to their pain related to trying to reduce the number of injections that they would have that day. Another one would relate to the number of cigarettes they would smoke that day and setting the goal of getting off them when they got home. There was general consensus that it was hopeless trying to give them up in hospital. One young man said his wife would reward him with a baby if he gave up smoking. A goal that women often talked about was losing weight, but like the cigarettes it would be a goal that they couldn't achieve in hospital. So they would talk about joining Weight Watchers when they got home. They often consoled each other in respect to their weight saying that the medications had a large part to play in them gaining weight. The common reward for losing weight was to buy new clothes. Interestingly the men never spoke about their weight. Another goal that was often shared by a number of participants was "getting off" certain medications. Usually it related to undesired side effects, but a number wanted to reduce the amount of medications they were taking because "they can't be good for you". Non-health goals related to 'getting away' with one person seeing his goal of going round Australia with his wife as a 'dream'. However, some spoke of being determined travel. One lady said she was going to visit her friend who lived in Cairns in August when it was cold in Melbourne. Another participant's goal was to be able to afford to have a campervan fitted on the back of his 4WD. He said it would be fitted out to account for his disabilities in order that he and his wife could go and see the places in Australia that they hadn't seen. It was interesting to

listen to the response of other participants to each other's goals like "I could never do that", "you could never do that" and "you have to have dreams". Then usually a discussion would pursue in relation to the planning involved in trying to achieve such goals, especially the support of the pain specialist and/or GP, which was considered imperative. It was also interesting to note that they had usually set time limits on their goals. These were consistently related to their deteriorating condition, drug tolerance and age. They felt that they had a better chance of achieving these goals before their CNMBP deteriorated and their LTOT became less effective and before they got too old. However, setting goals related to 'getting away' were not always about visiting far and away places. One male participant's goal was to take his grandson fishing off the pier near his beachside home as soon as he was discharged from hospital.

The following quotes from a male and female participant relate to their goals that are aimed at improving their health.

Int.R. Because I have to lay down for periods to help relieve my pain I am aware that my muscles are getting weaker and that you haven't got the support of your muscles like you had beforehand so you have to try and strengthen your muscles the best you can. So I set myself the goal of taking the dog for a walk every day.

Int.H Since I have not been able to walk any great distance and now rely on a electric scooter to get around I am very concerned about my muscles getting weaker and the fact that by not walking I am making myself a

target for heart disease. So I set myself the goal of going swimming 3 times a week where I do as many laps as my pain allows. I have an injection prior to getting in the water to allow me to swim. Also in order to get some weight bearing exercise in order to help my bones, I try to get around the house with help one stick instead of the two sticks. It all depends how steady I am and how bad my weight bearing pain is on a particular day. I learnt to be flexible, because when I started on this regime I forced myself to do it when I was not capable and ended up not being able to do anything for a couple of weeks. I reward myself with a cappuccino at my favourite cafe the days I go swimming.

The following excerpt from an interview with young married woman with a family in which we talked about how she kept herself motivated given losses she had endured.

I.B My family keep me motivated. I try to be as normal mum as I can. I set myself goals like attending their parent/teacher interviews, and watching them play basketball each week. My goal for this year is to reduce the times I have to go into hospital. My husband said if I reduce it by one episode, he will take me away for a special weekend.

There was general consensus among participants that their LTOT goals were to 1) get adequate sleep, 2) be able to engage in meaningful relationships and 3) perform activities of daily living independently.

The Literature

Research addressing goal setting in health care is scarce and those studies that have been undertaken are usually restricted to the disciplines of nursing, the allied health professional disciplines of occupational therapy and physiotherapy, and health administration. The latter tend to focus on goal setting in relation to health promotion from local to global perspective's (Chomik & Frankish 1999).

There was a paucity of research cited in the literature that addressed goal setting in relation to pain (Snyder 1998; Slaughter et al 2002). Snyder (1998) puts forward a theory of hope and applies it to chronic pain. Snyder & Harris et al have defined hope as "*reciprocally derived sense of successful (a) agency (goal-directed determination) and (b) pathways (planning ways to meet goals*" (p.571). Goal is the desired endpoint of human actions, and according to Snyder & Harris (1996) high-hope people commonly identify their goals, whilst low-hope people are ambiguous about their goals. A goal related process relates to what Snyder (1998) call pathway thinking. Pathway thought enables one to produce a mental map to reach a goal. Another goal-related thought relates to the person's perceived ability to initiate and continue moving down the chosen pathway (Snyder 1998). According to this model it is agentic thought that provides the motivation to go after goals (Snyder & Harris 1996). In terms of chronic pain, pre-morbid goals and 'no pain' goal act as pathway blocks that produces a sense of loss relative to previous functioning (Snyder 1998). The premise of this theory that impeded goal pursuit results in negative emotions and lowered well-being, has been supported by other independent researchers and theorists (Diener 1984; Emmons 1986; Omodei & Wearing 1990). The only other article that addressed setting goals in relation to pain focused on how nurses assessed comfort (pain intensity) and function (Slaughter et al

2002). The article discusses patient comfort-function goal, as the level of comfort as rated on 0 to 10 scale needed to achieve a specific function. It emphasises that it is unrealistic for the nurse to expect a chronic pain patient to achieve a pain rating intensity of 0. In addition cultural contexts need to be taken into account. In some cultures it's admirable to endure as much pain as possible and consequently identify a high pain level as 6, as the comfort function goal (Bates et al 1997). Slaughter et al (2002) encourage nurses to refer to the research undertaken by Twycross and colleagues (1996) who found pain ratings higher than 3 on a 0 to 10 scale interfered markedly with patient activities, and scores of over 6 had a profound effect on the person's quality of life.

Studies, which focused on self-identified goals, were generally related to the rehabilitation process of various physical and mental illnesses (Costello-Nickitas 1994; Theodorakis et al 1996; Melville et al 2002; Ng & Tsang 2002). Costello-Nickitas (1994) undertook a phenomenological study to discover the meaning of the lived experience of choosing life goals. Choosing life goals in this study was described as struggling to fulfil competing ambitions in the process of affirming strongly held beliefs while experiencing paradoxical feelings of "calmness-turmoil", success-failure and security-insecurity (Costello-Nickitas 1994). Personal goal setting has also been addressed in the literature in relation to self-efficacy and self-satisfaction on sports injury rehabilitation (Theodorakis et al 1996). They had two experimental groups and one control group. The experimental cohorts were asked to set personal goals and complete self-efficacy and self-satisfaction scales. They found there were *"significant performance improvements for the two experimental groups; correlation coefficients between self-efficacy, self-satisfaction, goal setting and performance were significant at the .001 level. Personal goal setting was affected by level of ability and thus has a*

direct effect on performance" (Theodorakis et al 1996:221). Based on their findings they suggested that personal goal setting might be a significant determinant for performance improvement in sports rehabilitation programs (Theodorakis et al 1996). Ng & Tsang (2002) developed of a protocol to assist people with severe mental illness to formulate realistic life goals. It adopted an individualised approach and consisted of 4 phases from affirming the person's self-worth, imaging the new ways of living, establishing a sense of control to setting goals for the future (Ng & Tsang 2000). A pilot study with 25 psychiatric in-patients was encouraging with increase in goal setting and self-esteem and 92% of participants expressing a willingness to leave the hospital, with 72% planning to be engaged in competitive employment.

'Time out' (in vivo code)

The data

The majority of participants affirmed that regular periods of hospitalisation were part of their normalcy. Eighty-eight percent of survey respondents (n=50) had been admitted to hospital in the last twelve months, approximately 74% being planned admissions. The number of hospital admissions in the last twelve months ranged from 1 - 7, mean 3.50 (SD 2.06). The majority (89%) were admissions to private hospitals, 52% of which were designated pain units and 31% to medical wards. Forty-two percent of admissions lasted between 8-14 days and 31% lasting 15 days or more. The major reasons for 'time out' (in vivo code) were exacerbation of pain, drug tolerance, adverse drug effects, annual review, spouse/family respite and physical/mental exhaustion. The development of 'time out' (in vivo) is listed in Appendix 33.

The following excerpts from transcripts from focus groups participants and individual interviews illustrate the their perceptions

of 'time out' (in vivo code) in terms of need, environment, impact on families and positive and negative aspects in terms of addressing their fragility.

The first quote illustrates acceptance of these 'time out' (in vivo codes) periods in hospital as part of their pain management.

I.H Occasional periods of hospitalisation are part of my ongoing care. Dr. calls some of them receptor holidays, because on those occasions he usually turns down my pump to a negligible amount in order to give the receptors in the spine a break in the hope that when he turns the pump back on it works better on a lower dose. While it is turned down I am on 3 hourly injections of Morphine and 6 hourly injections of Medazolam. Other times I come in because being totally exhausted and I just rest and sleep as much as I can with the help of extra medications and analgesics. Once I have caught up on sleep and feel rested I then get bored. Even though the hospital advertises itself as offering pain management there is no area where we can go and do things during the day, or a physiotherapy department with hydrotherapy pool. It doesn't do us any good either physically or emotionally spending so much time in bed once our pain is under control. The reality is we are eventually having to go home still with pain and thus it wouldn't hurt to have an area where we can prepare our lunch and make a cup of coffee to test how much progress we have made and if we are ready to go home. But that's all in an ideal world.

The following excerpt from the female focus group discussion relating to their perceived need for ongoing 'time out' (in vivo code). Whilst they accept it on one level as part of their long term pain management they discussed the negative aspects and alternatives to the current set up.

Ffg3. I absolutely refuse to go hospital unless I am just so desperate, so I don't go in that often. It's a sad inditement on the nursing staff that I don't always come in when I need their help the most because I am afraid they will make things worse. Like I'm already under stress and if they start playing their games with respect to giving me my analgesia and showing no compassion or understanding towards me then they just make the whole thing worse.

Ffg4. I know what you mean, there is always one nurse who will have you in tears before you go home, but you come in because the Dr thinks you need to be in for whatever reason and that's what we have to focus on.

Ffg2. This is just a pipe dream I suppose but I envisage one day having access to like 'hospital in the home' in relation to pain management.

Ffg1. In some respects me coming into hospital I'm out of the house and not seeing what's going on because I only get more guilt if I'm laying on the bed, so I'm better away from it. However, because our condition is chronic and because we have to change positions or whatever to help the pain, like I have to pace to distract me from the pain. I think nighttime they need to set up some area where

you can go and make a cup of coffee like you do at home, pace up and down so you're not disturbing anyone else.

The following excerpts are from the male focus group discussion.

Mfg1. Even though Dr.X has talked with me to see it as part of my long-term pain management plan, like an insurance policy so that the drugs will last longer, I hate it. I don't want it, but I'm hating it more and more and more, but I don't think there's any option.

I "Why do you hate it so much?"

Mfg1. I hate leaving my family, because they get used to getting on without you. Also the nurse's attitudes can nearly tip you over the top. When your pain is completely out of control and you are climbing the walls, you don't need to be left waiting for an injection while they do their paper work. It tells you straight away that they couldn't give a damn.

Mfg3. No one likes coming into hospital but when you have constant, unrelieved pain and sleep deprivation you just can't cope any more. The last time I put up with it until it just run me down...worn me down and down and down, and everybody knows what I talking about, you're not sleeping, your pain is more and it scares you what you might do if you don't get help.

Mfg4. I wish the doctor would give me the drugs and allow me to look after myself at home.

Mfg1. I would prefer to have the nurse come to give me the injections at home.

Mfg3. When you have gone right overboard you have to spend some time getting yourself back to square one and then go home and rehabilitate yourself the rest of the way over the next couple of weeks, but three 'bloody' weeks in hospital it's a bit too much.

The following field note describes my observation of CNNBP patients treated with LTOT who have been admitted to a small private hospital that advertises itself as having a pain management unit.

FN. There are two pain specialists working here, both of whom are anaethetists. There is six CNMBP treated with LTOT in the hospital at present. There isn't a separate unit for pain patients they tend to be spaced around the hospital that has two wings. Some private patients are in single rooms whilst the majority who are either covered by TAC or Workcover are in two or four bedded wards with surgical and medical patients. Four of the patients came in because their current pain management regime was no longer covering their pain and they were physically and mentally exhausted. One patient who had come in because his oral morphine was no longer covering his pain was now being trialed for a spinal cord stimulator. The other patient who lives in rural Victoria had come down to have her pump refilled with concentrated morphine and she said she always stays for two weeks respite every six months when she has her pump filled. Those patients who are admitted for review of their pain management due to it no longer holding their pain resulting in them becoming completely exhausted often presented with a sad affect, grey colouring,

difficulty ambulating and sometimes vomiting. On the two occasions that I witnessed patients entering the hospital vomiting into empty ice-cream containers the routine response from the admitting nurses was to exchange the ice-cream container for a kidney dish and ask the patient what do you normally take for nausea? Then tell the patient that he/she will get an order for it if it doesn't settle. Then she would proceed to admit the patient. I even observed one nurse trying to weigh the patient whilst the patient was vomiting. This was followed up with a question to the patient, 'what do you think is causing you to vomit?' The patient said it was her pain. But the nurse still continued to complete the admission, which took from anywhere between 15 and 30 minutes once the patient's vital signs had been taken. Only then did the nurse address the issues of vomiting and pain, by stating that she would now contact Dr.X to get an order for something for the vomiting and pain. I observed other nurses immediately acknowledging the patient's need for analgesia and before doing the admission they contacted the admitting doctor and got a telephone order for analgesia that was given straight away. This appeared to occur when the admitting nurse was very familiar with the patient and there was an established level of trust and respect between them both.

There seemed to be a pattern of behaviour with respect to those who are admitted mentally and physically exhausted. They appear to hibernate in their bed and only get up to go to the toilet or if they smoked, to have a cigarette. Those in a two or four bed ward would often ask for the curtains to remain drawn. The only interaction they had with the nurses occurred when they had their injections, which they would try and have them strictly 3 hourly as ordered.

However, this rarely happened for a number of reasons, some avoidable and some unavoidable. Some patients were put on Ketamine drips that avoided any hassles about getting analgesia on time. The surgical patients' analgesia was often given a higher priority than the chronic pain patients'. By the beginning of the second week the curtains would start to be left open and they would begin taking short walks around the hospital before getting back to bed and resting. Occasionally at this time the television got turned on or a book or magazine taken out to read. The smokers would start staying outside longer with the other smokers. Then by the end of week 2 those who did handcrafts are often filling in the day doing them, and engaging with other patients. Also at this time they start to decrease their injections and those with the Ketamine drips would have them ceased. They certainly appeared better than when they were admitted. During their admission a psychologist and an occupational therapist saw some of the patients. However, there were no specific facilities for pain patients with respect to physiotherapy, occupational or group therapy.

The Literature

It is well documented in the literature that even when opioids have a good analgesic effect and the patient has developed good coping strategies and social support, they will experience exacerbation of their pain from time to time (Savage 1996). These exacerbations can be related to a variety of factors including deterioration of any underlying pathology, physical and emotional stress and drug tolerance (Foley 1991, Savage 1996). When the exacerbation of pain is not effectively treated by transient, small increases in opioid dose and other relevant pharmacological adjuncts to opioids and

supportive care, it is believed to be best managed in hospital (Portenoy 1994; Savage 1996; Goldstein 2002). In hospital opioid dose escalation, if appropriate, can be closely monitored in terms of efficacy and side effects and/or other pain management strategies can be employed as warranted, for example, nerve blocks, physical therapy, stress management and counselling (Portenoy 1994, Savage 1996, Turk 1996). Such intervention has been reported (Portenoy 1994) to result in a return to pre-admission opioid dose in a controlled environment in a relatively short time frame thus reducing the cost of LTOT.

Tolerance to the analgesic effects of opioids can be an issue for some (0.8 - 56%) chronic non-malignant pain patients receiving LTOT (Foley 1991; Dellemijn 1999). It has been reported that tolerance can be counteracted by a trial of an alternative opioid, or a taper of the opioid can be instituted with substitution of an alternative non-opioid medication (Savage 1996). The transition from one medication to another is better tolerated if the new medication is incrementally increased (Dellemijn 1999). Changes in drug regimes involving opioids requires hospitalisation so that the patient can be closely monitored and supported with respect to pain relief, symptoms of withdrawal from opioids and assessment of responsiveness to a new pharmacological regime (Portenoy 1996). Portenoy introduced the term 'responsiveness' to represent the level of analgesia achieved at a dose associated with tolerable side effects, ie-maximal efficacy (Portenoy 1994). Such intervention might be cost effective in the long term by reducing the risk of tolerance and the need for escalating doses of opioids.

According to Portenoy (1996) therapeutic efficacy of opioid therapy can be evaluated in terms of a) responsiveness of various patient cohorts; b) the durability of analgesic responses; and c) the effect of

opioid therapy on other therapeutic goals. For most CNMBP patients treated with LTOT the aim of treatment is to both improve comfort and physical and psychosocial functioning (Portenoy 1996). From the research the impact of opioids on these goals are not uniform (Chabal et al 1992; Fordyce 1992). The variability in outcomes reported in the literature is said to probably reflect the selection criteria (Portenoy 1996). For example, the unfavourable reports from multidisciplinary management teams may be associated with the high levels of psychosocial stress and functional impairment that characterise their patients (Crook et al 1989; Pilowsky et al 1977). The overall utility of LTOT cannot be generalised from this selected population. However, opioids could be a valuable adjunct treatment for some specifically selected patients attending a multidisciplinary management program (France et al 1984). Studies have shown that responsiveness can be influenced by the neuropathic pathophysiology underlying the pain, impaired cognitive function and moderate levels of psychological stress (Bruera et al 1989; Mercadante et al 1992). Genetic factors could also be involved in respect of responsiveness to some drugs (Sindrup et al 1990).

When side effects to opioids evolve to the point when they become intolerable and compromise the patient's general health and functioning, hospitalisation may be necessary to reduce or cease the opioids for a short period of time (Taylor et al 1980; Schofferman 1993). Patients need to be managed in hospital so they can be monitored for signs of opioid withdrawal and have their pain managed appropriately. Such respite from opioid therapy can improve the analgesic effect of the opioid when reintroduced, often at a lower dose (Savage 1996).

According to the Australian Pain Society patients on LTOT should undergo a detailed review on an annual basis (Graziotti & Goucke 1997). Such comprehensive reviews, which are usually undertaken

as an in-patient, can often detect physical, psychological and social problems that can then be addressed before they become major issues with long-term medical and financial consequences (Graziotti & Goucke 1997).

It is well known that the demands placed on chronic patients' families and spouses not only puts them at risk of emotional distress and depression but can lead to family and marriage breakdowns (Flor et al 1987; Snelling 1991; Schwartz et al 1991; Schwartz & Slater 1991). Thus admission to hospital may be necessary for spouse and carer respite and re-assessment of the patient's and family's coping strategies and functioning. Marital relationships are particularly vulnerable when the patient's pain is not well controlled and their coping skills are compromised (Ahern & Follick 1985; Snelling 1991). Respite periods, combined with family counselling and the reinforcing of positive coping strategies, can help maintain marital and family relationships (Flor 1987).

It is well recognised that severe chronic pain is associated with sleep disturbance and fatigue (Hitchcock et al 1994). Regardless of opioid efficacy and patient's coping abilities, there will be periods of pain exacerbation that will render them physically and emotionally exhausted which can not only compromise their immune system but increase their risk of depression and even suicide (Livengood & Parris 1989 Liebeskind 1992; Hitchcock et al 1994). Thus it is sometimes necessary to admit these patients to hospital for respite and reassessment of their pain management regime in order to prevent medical and/or psychological crisis which can be devastating in terms of human suffering.

PHASE 3 - STRIVING FOR NORMALCY

The data

During the last phase, the outcome of authenticating and repairing behaviours striving for normalcy, the sufferer is attempting to maintain a new meaningful life as close to their pre-morbid life as possible in order, in part, to reduce the stigma and negative stereotyping and thus their fragility. Striving for normalcy may occur at the same time as reconciling losses and/or self-determining normalcy. During striving for normalcy sufferers either meet their own goals or the goals of others such as family, doctors and nurses. When sufferers achieve their own goals they experience a greater sense of personal control. When they achieve other's goals they experience a loss of personal control because it entails fitting in with either the social or professional expectations of others. Sufferers who achieve their own goals have a greater sense of control over their life. Achieving own goals may necessitate either modifying their goals or modifying circumstances. For those who are unable to meet their goals they may lose hope and resign themselves to being control by pain or return to a previous phase to re-appraise their position and maybe set new goals.

Striving for normalcy is an outcome of authenticating and repairing behaviours. Based on the data this process is the sufferer's attempt to diminish his/her fragility by achieving goals and living a life as close as possible to their previous way of living. Achieving own goals results in a greater sense of honour and control over their pain, personhood and life. Achieving other peoples goals (family members, doctors, nurses) and fitting into some lifestyle perceived as socially acceptable by others rather than self is also part of striving for normalcy. Both address the core problem of fragility. The development of striving for normalcy is listed in Appendix 33.

Striving for normalcy happens and is encouraged by:

- being able to live with CNMBP treated with LTOT;
- reconciled to losses and changes;
- setting goals;
- communicating own goals;
- achieving goals;
- post-morbid personhood is accepted by others;
- treated as normal individual;
- participating in pre-morbid activities where possible;
- being able to reach out to others;
- being able to experience joy; and
- maintaining hope.

Striving for normality is made problematic by:

- refusing to set goals;
- unrealistic goals;
- coercive spouse/family;
- being treated as an invalid;
- fear;
- unwilling to take risks;
- not wanting to relate to others; and
- lack of support.

Strategies for striving for normalcy include:

- setting own goals;
- knowledge of available resources and help;
- communicating to family, friends, doctors, nurses how they can be helpful;
- accepting help;

- sharing own resources to help others; and
- viewing life as more than managing pain.

The consequences of striving for normalcy or outcome of authenticating and repairing personhood includes:

- achieving own goals;
- achieving goals of others;
- being psychologically reconciled to living with, and the consequences of, CNMBP treated with LTOT;
- self-determining own standards of normalcy;
- feeling better equipped to deal with the inevitable adversities of having CNMBP treated with LTOT especially when interfacing with the health care system, especially nurses;
- independence where possible;
- sense of control;
- fitting into society;
- regaining a meaningful lifestyle; and
- decreasing fragility.

The consequences of authenticating and repairing personhood include decreasing fragility and increasing a sense of control over their pain and lives. Being able to reconcile oneself to the negative impact that CNMBP treated with LTO has had on their personhood and lives and take control in determining what they want normalcy to be for them the suffer is more likely achieve both their personal and health goals. In so doing they are less likely to experience such fragility that could lead to thoughts of suicide.

The following quotes illustrate participants' desire for being normal and a belief that they could live a life where they were in control and not the pain and the opioids.

This woman strives for normalcy whilst acknowledging her chronic condition and that it is not only for her benefit but those around her. It also illustrates how she has brought enjoyment back into her life.

Int.N. You have to continually push yourself to do things and try to be as 'normal' as possible for everybody's sake. But first you have to accept you are not 'normal' that you have a chronic disability and that whilst you have special needs you are still a human being with the same needs, hopes and dreams like everyone else. I'm continually looking for ways of enjoying the things that most people, like me, used to take for granted. For example, I can now go to the movies again because I can lie down in the Gold Class Cinema armchairs. A group of us from the pain support group that we used to attend went and saw Titanic at Gold Class as there was no way any of us could sit through a three hour movie in an ordinary cinema. It is cheaper if you go on a Tuesday. My husband and I have been on a couple of cruises because I am able to lie down when I need to and walk around the deck. That way I get to visit places I would otherwise not be able to get to see because I couldn't sit in an aeroplane or coach for any length of time.

The following excerpt is from a participant who was having 'time out' during an observation period. She told me she does creative crochet

and that she was awarded a scholarship from the Cotton Board to attend a seminar in Sydney which was being given by someone who was world renowned for their creative crochet. The quote illustrates her courage and determination and how willing she is to share her skills with other sufferers.

Int.E. I was so chuffed at getting the scholarship that I was determined to get there. My husband thought I was mad but he said if I wanted to go he would take some time off work and take me. So off we drove to Sydney which nearly crippled me. But the two days at the seminar made it all worthwhile, I learnt so much, got so much encouragement and it was so good feel 'normal' despite being in a lot of pain and talking with people of similar interest who have nothing to do with pain. I found people coming up to me asking me how I had achieved this appearance and texture and it was good to be able to share my knowledge. I came home on such a high that it didn't matter how much pain I was in. We were asked to take a piece of our work with us and anyway the guy who took the seminar was most impressed, it's a dress I have been working on, anyway he gave me some more ideas. Anyway to cut a long story short, I entered it into the Royal Melbourne Show and won first prize. I know I have ended up in here again because of going to the seminar, but if that's the price I have to pay to be able to have some normalcy in my life then so be it. I always bring my work in and I have taught so many of the other patients how to crochet, it gives me a lot of pleasure and makes me feel useful again.

The following quote illustrates how attaining her goals gives her both a sense of achievement but a life that has some normalcy and meaning.

IntK. I am hopeless in the morning; I seem to get my best sleep between 5am and 9am. It also takes me awhile to find my land feet, because I am always a bit off balance in the mornings, which I put down to my night medications. I have an agreement with myself though that I am always out of bed by 9.00 am. I set myself the goal of going out at least once a day taking my dog for a walk with me on my electric scooter. It's wonderful ride along the creek around to the Yarra River. I aim to go to hydrotherapy twice a week. I also belong to a book club that meets once a month in the evening, that is where I meet other women and for a couple of hours I am just like everybody else. They are quite a diverse group of women, mostly my age and we have great discussions and debates about all sorts of things. Joining the book club was one of my New Year's resolutions. I seem to go for periods when I seem to achieve a lot then I fall in a heap. But that's how I am.

The following Field Note was written during a participant observation period. I had met B. who was a very quite gentleman who had been to the day procedure unit to have his intrathecal pump refilled. We had met several times whilst having our pumps refilled in the past and had got to know each other a little. This field note highlights how applying one's pre-morbid skills to another field of interest can facilitate reconstructing a meaningful personhood and life. It also demonstrates how one's willingness to engage in pain provoking activities it can result in opening up new opportunities for normalcy

and enjoyment. Also like the previous participant, he highlights the importance of engaging with 'normal' non-patient people.

FN. B. arrived on the ward today carrying a large parcel under his arm. I asked how he was doing and he said he had just had his pump refilled and was managing OK at present. He said he wanted to leave a painting for one the night nurses who had seen one of his paintings when he was last in and said she would love to have piece of his work. I asked if I could look at the painting, it was a Melbourne streetscape with trams. It was magnificent. I asked him if he had always painted and he said no, that he used to be a draughtsman and that when his back injury robbed him of his livelihood he thought he would try painting, as he had always been good at drawing at school. He said he had turned his garage into a studio and he said he looked on it like going to work every day when he goes out to his studio every morning. He said he has got everything set up so he doesn't have to bend or twist. He said he has to lay down for periods but that finding art has made a big difference in his life. He said he had plucked up the courage to enrol in an art class at the local neighbourhood living and learning centre, which goes for a couple of hours. He finds he has to lay down when he gets home but said he had enjoyed meeting new people with a common interest that had having nothing to do with pain. At the class I am just an ordinary bloke the same as everybody else.

The following quote is an excerpt from the female focus group discussion in which one mother shared how good it was to be the one giving care rather than receiving it.

Ffg.5 My daughter who lives in Queensland had to go into hospital for an operation and she has two school age children. So I decided to go up and look after the children and her when she got out of hospital. As far as I am concerned that is what mothers do, look after their children no matter what age they are. My son-in-law who I get on very well with was a bit concerned that it might be too much for me but I could tell that he wanted me to come. My husband knows me too well so didn't try to persuade me not to go. So off I went. The kids are 8 and 10 so they didn't need a lot of looking after as such, in fact the youngest liked taking care of Grandma. It was really a matter of making their lunches and getting them ready to go to school. My daughter had arranged with a friend to take and pick them up from school. My son-in-law did the things around the house that I couldn't do like vacuuming, hanging the washing out and bringing it in. But I did all the cooking and got to know my two grandchildren, which was wonderful. I would go by taxi and visit my daughter every afternoon and sit with her as long as I could. Sometimes I lay on the bed with her! It was much easier when she came home. She kept telling me to rest, as she was worried about my pain. So we rested together when the kids were at school, watched the 'soapies' together and of course talked a lot. I still got the evening meal, which she really appreciated as it had been sometime since she had had her Mum's cooking and it was nice to be able to do it for her. Even though I ended up in hospital for 3 weeks when I got back it was worth it. Because I really felt that I had been able to be a normal mum and grandmother and that I had been

able to help instead of being helped. It gave me so much satisfaction and enjoyment, I'm getting emotional just talking about it, but other people wouldn't understand how precious these moments of satisfaction and enjoyment are when you are like us. I didn't tell my daughter that I had had to be hospitalized when I got back. I didn't want her to feel responsible for me being in hospital.

Ffg.1 How did you manage that?

Ffg.5 I made sure I rang her every morning before she would ring, or else if she did ring home my husband would say I was out or in the shower depending on what time it was.

Ffg.3 Good on you!

Ffg.5 I would do it all again regardless of the 'pay back pain'.

The following is an excerpt from a field note in which I had described a discussion I had had with a group of participants over coffee when we discussed how important it was to seem to be living a normal life.

FN I talked to two females and one male about whether they thought they lived normal lives and whether that was important to them. They said that they had become good actors as they often concealed their pain while engaging in normal day to day things that normal people do. One of them said that in certain circumstances he would not use his elbow crutches or even his walking stick so that he didn't look different

and people would interact with him normally instead of focusing on why he needed the crutches etc. Another participant said that she had to conceal her pain and disabilities from her mother because she couldn't handle seeing her in pain and would worry her self sick about her. Another common comment was while you are appearing to be functioning normally then the family functions normally. It is seen as a case of, that if you cope then they cope. But there was a consensus that if you disciplined yourself and paced yourself in relation to activity/rest then it is possible with having narcotics, to live a fairly normal life. The male participant said that most peoples' lives have ups and downs and pain patients are no different, only that they probably prone to more downs than ups than the general population. One participant said that when she feels good then she makes sure she makes the most of it and does something that she gets enjoyment from. There was also consensus that striving for normalcy involved working on a 'pay back' system where if you knowing engage in a pain provoking activity you pay the price later with respect to an increase in your pain intensity. They also talked of 'time out' periods being part of their normal life and, in part, that some can be related to striving for normalcy.

Striving for normalcy includes assimilation, being treated as an equal, assuming roles and responsibilities and contributing to society within their limitations. Participants may conceal the visible signs of their pain and suffering in an attempt to live a life as close to normal and to be accepted by others. They are reconciled that they cannot return to their pre-morbid pain free personhood but a return to a meaningful life that is as close as possible to their pre-morbid life.

Participants may conceal their pain and suffering for selfless, altruistic reasons, because they do not want to burden others. This concealment is an attempt to try and maintain the status quo so that life carries on as close as possible to what used to be normal because if they are seen as coping then their families cope. This phase may occur at anytime during the authenticating and repairing personhood cycle. Even when they are having 'time out' (in vivo code) in hospital they may attempt to minimize the severity of their chronic pain or the pain related to surgery (insertion of spinal cord stimulator) or procedures (nerve blocks). In so doing they achieve a sense of control over what is happening in respect to themselves and their families. Striving for normalcy includes contributing to others as an important aspect of an honored personhood and evidence of utility.

The Literature

Normalcy is a prevalent concept in the nursing literature (Strauss et al 1984; Morse & Johnson 1991; Wilson 1991; Thorne 1993, Thorne & Paterson 1998, Haggman-Laitila 1999; Small & Lamb 1999; Pickens 1999; Raithel 2000). The studies tend to be qualitative. A North American nurse used grounded theory to explore husbands' experiences during their wives' chemotherapy (Wilson 1991). Wilson (1991) found that their experience involved passing through a process composed of four stages, identifying the threat, engaging in the fight, becoming a veteran and recurrence. It was also discovered that throughout this process husbands attempted to sustain a sense of normalcy. For these husbands it meant *"maintaining a life-style close to the way it was before the cancer experience"* (Wilson 1991:282). Morse & Johnson (1991) analytically reviewed five grounded theory studies on illness experiences in order to analyse the findings with respect to major characteristics and similarities. They put forward an Illness-Constellation Model comprising the four stages of uncertainty,

disruption, striving to regain self and regaining wellness (Morse & Johnson 1991). Salvaging normalcy was reliant on the individual regaining pre-morbid relationships, roles and responsibilities (Morse & Johnson 1991).

Two Canadian nurses (Thorne & Patterson 1998) undertook a major review of qualitative research on patient roles and chronic illness undertaken in the previous two decades. The studies were selected because they offered the perspective of those who suffer chronic illness. Thorne & Patterson (1998:173) discovered that more recent reports have a focus on *"health within illness, transformation and normality"* and a changed relationship between nurse and sufferer to one of partnership. In Thorne's (1993) text on negotiating health care includes a dialogue on the meaning of normal for the individual with chronic illness. She described normal as assimilating in with others and engaging in activities of every day living and thus not being perceived as 'sick'. Activities of daily living rather than pre-determined health measures were used to measure normalcy. Thus normalcy meant living life as close to pre-morbid normalcy as possible regardless of symptoms, which concurred with earlier work by Strauss et al (1984)(Thorne 1993). However, like CNMBP sufferers treated with LTOT, to attain normalcy may necessitate sufferers adjusting their perception of what is 'normal' and accommodate their pain and treatment into their daily living (Strauss et al 1984). Thus, *"normal is individualised and redefined to accommodate the illness"* (Fiveash 2000:265). According to Knafl & Deatrck (1986) this only reflects denial of the chronic illness. Whilst Stephenson & Murphy (1986) acknowledge the utility of denial in avoiding being stigmatised, treated differently and experience discrimination. Normalcy may require some adaptation to the nature of what is understood as normality. According to Strauss, et al (1984) such adaptation may involve a self-adjustment in terms of expectations about receptivity to lowering or a different level of normalisation. Striving for normalcy is

attempting to live as close as possible to their pre-morbid life as possible and to accomplish this may require individuals, such as CNMBP patients, adjusting their notions of what is normal and integrating their CNMBP and LTOT into their everyday living.

Pickens (1999) undertook a qualitative study exploring the desire for normalcy for people living with serious mental illness. They discovered the major categories of desire for normalcy are having normal things and experiences; doing meaningful activities; and being well, safe, free, and independent (Pickens 1999). In a PhD qualitative study focusing on maintaining normalcy when managing the chronic physical illness of asthma the informants reported that maintenance of health was the focus of the social process of normalcy (Raithel 2000). The following six actions emerged as contributing to maintaining health: struggling, experiencing, listening, affirming, changing and failing. When health was maintained, the consequences of taking control and caring for self were present (Raithel 2000). In her PhD dissertation Fiveash (2000) using grounded theory explored client managed care from the consumer's perspective. Normalising was found to be the end point of the activating process that some clients engage in to maintain a sense of control while recipients of health care. The client is normalising by living close to their pre-morbid lives as possible including *"decreasing vulnerability and uncertainty and increasing control over health and goal achievement"* (Fiveash 2000:257).

A collaborative and participatory research undertaken with 81 midlife women living with adult onset chronic illness used the terminology of ordinariness to describe incorporating chronic illness into their lives (Kralik 2002). Ordinariness, according Kralik (2002) incorporated two major constructs, 1) the illness experience as transforming and 2) reconstructing life with illness, which could also be said to underpin the process of striving for normalcy. Both striving for normalcy and

ordinariness when experiencing a chronic condition involve being transformed by loss and change, embracing the illness rather than being a victim, having a sense of future, regaining a sense of balance, empowerment and control and reconstructing personhood (Kralik 2002). Taylor (1993) advocates that it is ordinariness inherent in their humanity that can provide the basis for authentic patient/nurse relationships to develop. A participant in Taylor's (1993) phenomenological study described living an ordinary life in terms of simplicity, being uncomplicated *"by allowing yourself to experience the incredible wonder of the ordinary, you will create space that allows other people to also be who they are"*(p.40)

SUMMARY

The authenticating and repairing personhood cycle consists of three phases reconciling losses, self-determining normalcy and striving for normalcy. Phase one reconciling losses occurs when the sufferer finds some hope that motivates them to acknowledge, evaluate and grieve the losses that contribute to their sense of fragility. The consequences of reconciling losses is an opportunity to accept and/or heal physical, emotional and spiritual pain and reorientate one's personhood towards a meaningful participation in life with diminished fragility. Self-determining normalcy comprises of three subcategories, taking control, setting goals and 'time out' (in vivo code). Self-determining normalcy is a self-initiated exploration of what constitutes their normalcy. It is a process of taking responsibility, setting goals and seeking resources to support their choices and decisions with respect to achieving goals and constructing an honoured personhood and a meaningful life as close to their pre-morbid life as possible. Taking control is concerned with being responsible for not only what constitutes their normalcy with respect to treatment and life, but also evaluation of treatment and quality of life. Setting personal and health goals give some structure and incentives to their post-morbid lives. By having health goals

participants felt that it decreased the sense of hopelessness and that nothing can be done. Personal goals helped them put back some purpose in their lives. Sufferers' sought input from their pain management specialist, psychologist, occupational therapist, family members, significant others, friends, spiritual guidance and/or support groups with respect to them developing realistic goals and obtaining the needed support to fulfil them. The majority of participants affirmed that 'time out' (in vivo code) (regular periods of hospitalisation) were part of their long-term pain management plan and thus their normalcy. Factors that facilitate moving into the final phase, striving for normalcy, include: accepting their normalcy; knowing how to access identified support and resources needed to assist them to achieve their normalcy; tolerable pain and the desire to try to be fully engaged in life. During the last phase, striving for normalcy, the sufferer is attempting to maintain a new meaningful life as close to their pre-morbid life as possible in order to reduce the stigma and negative stereotyping associated with CNMBP treated with LTOT and thus their sense of fragility. The consequences of striving for normalcy and outcome of the authenticating and repairing personhood cycle include decreasing fragility and increasing a sense of control over their pain and lives. Being able to reconcile oneself to the negative impact that CNMBP treated with LTOT has had on their personhood and lives and taking control in determining their future normalcy the sufferer is more likely to achieve both their personal and health goals. In so doing they construct an honoured and robust personhood making them less likely to experience the levels of fragility that have in the past lead some sufferers to contemplate suicide. At any time during these phases sufferers may either actively or passively resign. Resigning carries with it some degree of vulnerability and fragility. Sufferers who actively resign maintain a sense of hope, but those located in passive resignation have yet to find hope and remain fragile.

The next chapter provides a discussion and conclusions of the findings, limitations of this study, and the implications and recommendations of study for sufferers, nurses, general practitioners, orthopaedic surgeons, neurosurgeons, pain specialists, psychologist, allied health practitioners, health care policy, education and research.

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CHAPTER 8: CONCLUSIONS & RECOMMENDATIONS.

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INTRODUCTION

In this chapter the major findings, conclusions, limitations and recommendations of this study are discussed. These recommendations cover issues related to CNMBP clients treated with LTOT, family members, nurses, general practitioners and other health care practitioners, health care policy, organization of health services, insurance companies underwriting worker's compensation and traffic accident commission, education and further research.

DISCUSSION OF MAJOR FINDINGS AND CONCLUSIONS

Findings from this study indicate that persons who suffer CNMBP that are treated with LTOT experience a sense of fragility characterized by vulnerability especially when interfacing with the health care system. Fragility is associated with (a) 'being discredited', (b) 'not being believed', (c) loss of self, (d) undergoing losses/changes, and e) experiencing compromised health. Fragility is related to permanent disruption to normalcy, negative stereotyping, stigmatization, and opioiphobia among some health care practitioners, especially nurses and the adverse effects of LTOT. These findings describe how participants proceed through a process of authenticating and repairing personhood from the position of fragility and vulnerability toward reconstructing a robust personhood and a self determined normalcy. Only those sufferers who find hope commence the authenticating and repairing personhood cycle. Hope is the nexus between fragility and striving for a self-determined normalcy. Some sufferers remain in their fragile state and passively resign themselves to a life, which is controlled by pain.

The phases of the authenticating and repairing personhood cycle consists of reconciling losses, self-determining normalcy and striving for normalcy. These activities support the sufferer to live a meaningful life, where they are in control and not their pain.

Through authenticating and repairing personhood sufferers take control of their lives, reconstruct an honored and robust self and legitimize their normalcy. Reconciling loss follows finding hope. A sense of hope is having an expectation that the pain can be controlled to a level sustaining meaningful existence with diminished fragility. Each phase of authenticating and repairing personhood process has its' own characteristic activities. Reconciling is a cognitive/emotional/behavioural process involving acknowledging, re-evaluating, grieving and receptivity towards one's new reality of having to live with CNMBP treated with LTOT and their consequences. Reconciling loss is liberating, freeing energy to take control and move on, which can lead to broader perspectives, activities and purpose. The combination of chronicity and aging leads to reconciling loss being a life time process. During this phase the sufferer may actively or passively resign or actively move into the next phase. Active and/or passive resigning is congruent with maintaining a sense of fragility. Resigning is consistent with the literature (Wallston, 1992; McCleod Clark, 1993; Fiveash 2000) that affirms that many patients do not seek control over their health care, opting for others to make decisions for them. In this study participants found 'losing me' (in vivo code), loss of sexual desire and pleasure and loss of employment as the most difficult of their many losses to reconcile and for which many received little or no help from their primary carers. A number of studies (Higgins 1987; Markus and Wurf 1987; McCracken 1998; Aldrich 2000) have postulated that adjustment to living with chronic pain may require changes in "fundamental aspects, such self-concept and identity" (Aldrich 2000: 465). The findings in this study support that postulation, indeed it is

the crux, however problematic for some, of the authenticating and repairing personhood cycle. Sexual dysfunction was a major problem for many sufferers and their spouses for which they believed was not adequately acknowledged (only 13% being offered sexual counselling), treated or compensated for. However, only 37% of survey respondents said they would accept sexual counselling if offered. These findings concur with studies addressing sexuality and sexual dysfunction of patients with chronic pain (Mnga et al 1998; Ambleret al 2001; Nausbuam et al 2003).

In relation to nurses, the majority of participants felt that *"they have no idea"* with respect to the aforementioned difficulties, chronic neuropathic pain, LTOT and what they are going through in terms of striving for normalcy. The nurses who participated in this study generally did have limited knowledge regarding CNMBP, opioids and the person for whom they were caring. Indeed participants' perceptions appear to be supported by a number of recent studies (Romyn 1992; Fothergill-Bourbannais & Wilson-Barrett 1992; Lebovitz, Florence, Bathina et al 1997; Warden, Carpenter & Brockopp 1998; Twycross 2002) that suggest existing nursing curricula may not adequately prepare them for managing pain in practice. In addition coercive family members, negotiating access to LTOT and the use of computerised, implantable drug delivery systems can also influence the sufferer's ability to take full control of their pain and life and movement into the next phase, self-determining normalcy.

The second phase, self-determining normalcy either occurs following or simultaneously with reconciling losses. The subcategories of self-determining normalcy are taking control, setting goals and 'time out' (in vivo code). It is a self-initiated exploration of what constitutes their post-morbid personhood and normalcy. It involves taking responsibility for pain management, setting goals and seeking

resources to support their choices and decisions with respect to achieving goals and reconstructing an honoured personhood and a meaningful life. The nexus of self-determining normalcy is an acceptance of one's own ascendancy and ability to bring about change at the intrapersonal, interpersonal, organisational and/or community levels or to have the support of others who can. This involves taking responsibility for one's own pain and health state and preparedness to make choices, decisions and action. Both CNMBP sufferers treated with LTOT and health care practitioners need to have a desire to work together and theoretical models and health care facilities, which facilitate efficacy in relation to client, directed pain management. Several studies have been undertaken about the efficacy of multi-disciplinary pain management units and practitioners willingness to work in partnership with clients, which do not necessarily go hand in hand (Saunders 1995; Schietinger & Daniels 1996; Draper 1997). However, further work is needed to develop strategies that health practitioners, in particular general practitioners, pain specialists and nurses, can use to facilitate opioid dependent clients having optimum control over their pain management regime and health care. Being ignored, excluded and negatively stereotyped by health care practitioners profoundly impacts on CNMBP sufferer's treated with LTOT sense of fragility.

During the authenticating and repairing personhood cycle sufferers require the support of health care practitioners, family and friends. Family and social networks are imperative in facilitating reconstructing an honoured personhood and meaningful life. Family member's knowledge of their pain, suffering and personhood can alert practitioners, in particularly nurses, to the unique, often subtle signs that the client exhibits when their pain is not controlled. They can also provide insight into the sufferer's pre morbid personhood and lifestyle assisting health practitioners to not only provide individualised care but also help sufferers to achieve their

goals. In addition, they can also acquire the necessary skills and knowledge to facilitate home care. For example, being taught to give injections, urinary catheterisation and changing Hickman's catheter dressings. Family members can play a crucial role in the sufferer's successful reconciliation and reconstruction of a robust personhood and meaningful life. However, if they are unable to accept the sufferer's new reality and personhood they may put at risk their relationship with the client that can ultimately result in the breakdown of the marriage and family unit.

Other CNMBP sufferers treated with LTOT can also play a role in assisting self-determining normalcy. They may be inspirational and supportive or act as a deterrent (*"I don't want to end up like X"*). Self-determining normalcy involves setting personal and health goals, which helps to give some structure and incentives to their post-morbid lives. In addition, achieving goals can restore confidence and self-esteem. The majority of participants affirmed that regular periods of hospitalisation ('time out' (in vivo code)) were part of their normalcy but that it was a two-edged sword in relation to addressing their fragility. This is related to having to give up control over their pain management, in particular, medications and also they have to interface with nursing staff who may be opioiphobic and whom they perceive to negatively stereotype them as malingerers and drug addicts. Thus, whilst these 'time outs' generally decrease their physical fragility they can also compound their emotional fragility through being alienated from family, responsibilities and negative interactions with nursing staff. The participants in this study were very forthright with respect to what they considered to be an appropriate environment for such periods of hospitalisation, in addition to what resources needed to be made available (physical therapy, hydrotherapy, occupational therapy, psychological counselling, massage). However, for the majority of the participants in this study they were generally admitted to a private facility for

'time out' with limited resources and ad hoc access to other allied health professionals even those who identified the facility as a pain unit. In addition, a number of participants indicated that they would like the choice of being treated at home instead of being hospitalised, especially male participants.

During the self-determining normalcy phase individuals may resign from the process and live with fragility or elect to go forward and enter the next phase where they attempt to meet their goals and live a 'normal' life as determined by them. This often constitutes living life as close to their previous way of living that is possible whilst fully acknowledging their abilities and disabilities. In self-determining normalcy the individual has renegotiated with self about expectations of normalcy and receptivity towards a different level of normalcy (Charmaz 1983; Strauss et al 1984; Morse & Johnson 1991)

In the last phase, being the outcome of reconciling and self-determining normalcy, the sufferer is experiencing optimum pain relief and striving to achieve their goals and living what constitutes normalcy for them. Striving for normalcy may occur at the same time as reconciling losses and/or self-determining normalcy. When CNMBP sufferers treated with LTOT strive for normalcy they attempt to resume some of their pre-morbid roles and responsibilities, be engaged in life demonstrating utility and being accepted and respected by others. In striving for normalcy they aim to reduce the stigma and negative stereotyping associated with CNMBP treated with LTOT thereby diminishing their fragility. Having achieved a certain level of reconciliation with respect to the losses incurred, re-evaluating their lives in terms of their beliefs and values, abilities and disabilities, they negotiate with self a new personhood that one can honour and a life that is worth living. By promoting a positive self-image, they are less likely to be stigmatised and are thus feel less fragile. By being true to oneself and in control of ones pain and life, the individual is better equipped to deal with the inevitable

experiences of having their pain and treatment discredited including not being believed. Whilst the authenticating and repairing personhood process diminishes fragility invariably the CNMBP sufferer treated with LTOT has to learn to live with a degree of fragility. Striving for normalcy inevitably involves engaging in pain provoking activities for which most sufferers take responsibility for but sometimes in special circumstances they may seek 'time out' to bring their pain back to a manageable level. In most instances striving for normalcy is a balancing act of maintaining an optimum level of pain control while achieving own goals and those of others with the minimum amount of opioid analgesia and adjunct pharmacological, psychological and physical therapy, dispersed with appropriate periods of rest. Individuals who get the balance right have a greater sense of control over their pain and life. However, for those individuals who struggle to achieve their own goals and those of others with no reward may resign themselves to a life governed by pain or return to the previous phase and renegotiate new goals and boundaries of their normalcy.

According to participants they evaluate the effectiveness of their LTOT by their ability to sleep, perform activities of daily living independently (with the use of aids) and being able to engage in meaningful relationships. Whilst addiction was an issue for both the nurses working with CNMBP patients on LTOT and some family members, it was not an issue for participants. None of them considered themselves addicted to their LTOT, although they believed their bodies to be dependent upon opioids, and that they would experience withdrawal symptoms if it were ceased abruptly. Whilst in this study LTOT appears beneficial to sufferers of CNMBP and allows them to reconstruct an honoured personhood and a meaningful life in very few cases does it permit return to paid employment. However, a large number of participants felt that their quality of life would be enhanced if they were free to undertake ad hoc voluntary community

services, for example, feeding a nursing home resident, when their pain permits. The participants who were receiving compensation were not prepared to undertake such voluntary work in fear that the insurer would deduce that they could return to part-time/full-time paid employment and cease their benefits. Indeed, in Victoria the claimant has to declare whether they have engaged in any voluntary work. This requirement acts as a deterrent for CNMBP sufferers being treated with LTOT who have been classified as totally incapacitated to become a useful member of society and thus reduce rather than increase their fragility.

It appears that a theory of authenticating and repairing personhood could be useful to those sufferers who desire to have control over their pain management and who have the capacity, motivation and opportunity to do so. It is imperative to remember that some sufferers may prefer to relinquish control of their pain and health (Dennis 1987/1990; Fiveash 2000). In deed, for some having full control over their pain management and health may be detrimental, especially those with a prior history of substance abuse (Seeman 1991; Aldrich 2000; Eccleston et al 2001). Therefore it is imperative that CNMBP sufferers treated with LTOT have access to individualised care in which they be given choices with respect to preferences relating to levels of control over pain management and health without fear or favour. For the majority of ordinary people control over health is salutary (Wallston 1992) and thus there is a case for CNMBP sufferers treated with LTOT being afforded the same opportunity. There are a number of inherent factors that may impact on CNMBP clients treated with LTOT having control over their pain management and health. They comprise a range of both internal and external factors. These include the sufferer's willingness and capacity to own their pain, self advocate, process and understand new information in order to acquire the necessary level of knowledge relating to CNMBP, LTOT and how the health care system

functions. External factors include legal requirements related to Schedule 8 drugs, family, professional and insurer supports, organisational policies, lack of consumer information relating to CNMBP and LTOT and other pain management strategies, access to resources and financial constraints. Thus, sufferer's desire and capacity to take control over their pain management and health may not be sufficient with respect to them being afforded the opportunity to do so.

Whilst the literature advocates a multidisciplinary approach to chronic pain management (Coughlin et al 2000; Karjalainen et al 2001; Thomsen et al 2001; McCracken et al 2002; Skouen et al 2002) and the growth in the number of multidisciplinary pain units in Australia, the majority of participants in this study were treated by sole specialist medical practitioners with ad hoc access to other allied health professionals. The professional background of these pain specialists ranged from anaesthesiology, psychiatry, rehabilitative medicine and neurosurgery with them working predominantly in the private health sector. A probable reason for these findings is that the majority of participants were from the state of Victoria and were covered by a third party (eg. workers compensation) which provides for them to be cared for in the private system. In addition, the public pain units, which were approached by the researcher to participate in the study, declined on the basis that they didn't generally subscribe to the use of opioids in chronic pain management, thus very few of their patients would be eligible to participate. Those who would have been eligible were thus not given the choice to participate in the study.

Although the majority of participants expressed the need to have access to a range of health care practitioners, they generally possessed a very sceptical opinion of multi-disciplinary pain units. The general perception was that they "just want to get you off all your

drugs and get you back to work regardless of the severity of your pain". These perceptions emanate from the publicity in the popular press surrounding the establishment of the first multidisciplinary pain units, which tended to be very emotive, typically telling the story of a chronic pain sufferer who prior to attending the unit was totally incapacitated and over-medicated. And how through cognitive-behavioural therapy and adjunct therapies was now drug free and leading a normal life. In addition, it is a policy of some multidisciplinary pain units that you have to come off your opioid therapy in order to be able to attend. However, in reality a number of multidisciplinary pain units do prescribe opioids for some patients either administered orally or intrathecally and access is only problematic due to lengthy waiting lists.

In this study general practitioners were rarely the primary carer with respect to the sufferer's pain management, with the Schedule 8 Authority being generally given to the pain specialist. This under utilisation of general practitioners in the care of CNMBP sufferers treated with LTOT could be detrimental for a number of reasons. Firstly, the general practitioner usually knows the client and the family not only in terms of their health status but their pre-morbid personhood, life style and family functioning. Such information being crucial for an authentic comprehensive assessment of the sufferer's pain, need for opioids and ability to take control of their pain management and health care. Most people have a close, trusting therapeutic relationship with their general practitioner, which usually has taken years to establish. In such a relationship the CNMBP sufferer treated with LTOT is less likely to feel intimidated and discredited and more able to negotiate control over their health care. In particular, general practitioners are in a prime position for monitoring the impact of the client's condition on spouses and family members, as well as monitoring the sufferer for signs of clinical depression and suicide ideation. In addition, general practitioners are

more accessible than pain specialists are and their services are considerably cheaper.

In Australia, as in many other western and European countries, there is continuing debate about whom should manage the client's health: the doctor, nurse or another allied health professional. One bold proposition is that of client-managed care (Fiveash 2000). Client-managed care is underpinned by the belief that individuals who want to have a sense of control over their health should be given the choice to do so, and be supported in that choice. The CNMBP sufferer treated with LTOT who engages in the authenticating and repairing personhood cycle is in an optimum position to manage their own care. They do this by assessing, evaluating, reconciling, self-determining what constitutes their normalcy through setting goals and seeking resources to meet those goals. People, who suffer CNMBP, like any other chronic condition, know their pain and condition better than anyone else does. Only they feel it, own it and have to live with it. Fiveash (2000: 285) argues that "subscribing to the premise that clients own their own body, their health state, and that they are self responsible and have authority over their health, it does not follow that health providers should collaborate, or participate in decisions about client health goals and their preferences in respect of their health care". Therefore, according to client-managed care it can be argued that CNMBP sufferers have the authority to make choices and decisions and take control relating to their long-term health care if they so wish. What is being enunciated is the re-establishment of personal responsibility and control over health in the health care setting as is the case when sufferers are at home (Fiveash 2000).

It would not be appropriate to make broad generalisations from this study - a number of recommendations are presented for

consideration. They are particularly relevant to contexts in which the findings of this study are seen to be transferable.

These recommendations concern CNMBP sufferers treated with LTOT, family members, nursing practice & education, medical practitioners, the organisation of pain management services, health care policy, third party insurance, legislators, professional and community education and research.

RECOMMENDATIONS

Consumers - CNMBP sufferers treated with LTOT.

- 1) Consumer support groups could augment public and professional awareness of :
 - CNMBP and its' sequelae;
 - the legitimate use of LTOT in the treatment of some forms of CNMBP and criteria used by clients to evaluate its' efficacy;
 - the experience of having LTOT administered through the various modalities;
 - the importance of the need to find and maintain hope and that it can be facilitated by family, friends, supportive relationships, spiritual guidance, having a positive attitude, connectedness and mutuality, setting goals, determination, honouring personhood and identifying positive future possibilities;
 - seeking access and input into the Australian Pain Society's newsletter, position papers and conferences and/or proceedings.
- 2) Consumers who wish to live a meaningful existence, where they are in control and not their pain, be given the opportunity of following the authenticating and repairing personhood pathway. This includes supporting ways to,

- Find hope.
- Reconcile losses.
- Re-evaluate values, beliefs and aspirations.
- Reconstructing an honoured personhood.
- Self-determining their normalcy.
- Self-determining pain management regimes.
- Setting health and life goals.
- Seeking resources to achieve goals, including health care practitioners, health care organisations and facilities, family, friends, community organisations.
- Communicating their choices, decisions, goals, pain management regime, normalcy and pre and post morbid personhoods.

Intrinsic to this route is a sufferer who:

- a) Takes responsibility for their pain, self-advocates, believes in self-autonomy, is consumer rather than patient orientated, communicates and is an active contributor to their health.
- b) Purposefully re-evaluates their pain, health care status and life, exploring ways to address their needs and identified goals.
- c) Seeks out pain management specialists and other allied health professionals who can provide the health care service their require.
- d) Seeks professional, family and/or spiritual support and guidance, self care where possible, remains hopeful and prepared to active rather inactive.
- e) Willing to take risks and engage in pain provoking behaviour for which they take responsibility for the outcome.
- f) Communicate their concerns to the health care practitioner. If these concerns are not adequately addressed then they should feel that it is their responsibility to bring their complaint to their attention of the health care facility and/or the relevant statutory authority (Health Commission in Victoria).

- 3) Utilise conciliation facilities to dispute decisions that have a negative impact on their ability to achieve their goals and with which they do not agree.
- 4) CNMBP patients treated with LTOT help explore the need and development of support groups for family members.
- 5) CNMBP sufferers treated with LTOT could seek individual contracts with health care practitioners including nurses.
- 6) CNMBP sufferer treated with LTOT may find information that will help understand their pain, treatment and fragility and what others can, or are doing to address or undermine these. This can be achieved by:
 - Acquiring information skills and equipment;
 - utilising practitioners and units which have been accredited by the Australian Council of Health Standards;
 - seeking answers from a range of sources;
 - clarifying complex information;
 - finding out what they can do for themselves;
 - confronting practitioners who offer conflicting information and/or advice;
 - confronting nurses who do not respect their pain and treatment;
 - providing health care practitioners with a short precis of their pre-morbid personhood, life and pain trajectory;
 - use the Freedom of Information Act obtain copies of reports requested by a third party (eg. insurance company).

Nursing Practice

There are many ways that nurses can support CNMBP sufferers who elect to use opioids as part of their pain management regime. These include:

- 1) provide evidence based practice;
- 2) adhering to the 'gold standard' that pain exists when the client says it does;
- 3) use tools (Neufeld, Degner & Dick 1993) to determine client's preparedness to be involved in their care;
- 4) configure their practice to support CNMBP sufferers treated with LTOT finding and maintaining hope. Nurses need to have the capacity and will to demonstrate a compassionate interest in sufferers and inspire confidence in the care that they provide. Hope scales (Miller & Powers 1988; Herth 1989) may be used to determine the client's level of hope;
- 5) using validated pain assessment tools like McGill Pain Questionnaire (Baillie 1993) to gain insight and understanding of the client's pain experience;
- 6) using validated tools to assess the impact of the client's CNMBP and its' treatment with LTOT (eg. Depression Scales (Beck & Beamsderfer 1974); personhood tools (Buzzell et al 1993; Olsen 1997); Vulnerability scales (Ellett & Young 1997; Rogers 1997);
- 7) giving client's the opportunity of having input into or writing their own nursing and discharge plans, including identifying needs, nursing strategies to address them and criteria to evaluate their efficacy;
- 8) giving client's the opportunity to self medicate whilst in hospital including Schedule 8 drugs;

9) determine client's views relating to control over health. Nurses could use a Control Preference Scale (Degner et al 1997) to assess the amount of control the client wants in terms of decision making. When CNMBP sufferers treated with LTOT wish to have control over their pain management and health, nurses could:

a) re-configure their practice to suit the client;

b) recognise, acknowledge and accept:

- the client's lived experience of CNMBP treated with LTOT;
- their personal knowing about their pain and treatment and that their personal knowing is as relevant as any other knowledge;
- client's view of their situation;
- their pre and post morbid personhood;
- client goals
- client's world view;

c) support client to reconcile their losses by:

- recognising, acknowledging and accepting their experiences of loss;
- listening;
- providing access to grief counselling;
- making available appropriate resources;
- monitoring for signs of clinical depression related to unresolved grief and pain;
- specifically identifying and including family and friends;
- focusing on, and reinforcing their unique attributes and abilities;
- providing relevant knowledge about CNMBP and its' treatment with LTOT.

d) Provide client with a written copy of the facility's mission statement and list of their rights.

- e) Provide knowledge how the health system and the health care facility functions.
- f) Offer clients an opportunity to communicate their goals and questions.
- g) Give clients the opportunity to make informed choices and decisions relating to their care.
- h) Explain the nature of their work so that client knows how nurses can facilitate them achieving their goals.
- i) Where the client is accompanied by technology the nurse give attention initially to the client rather than the technology.
- j) Do not provide nursing care that the client or carer is capable of undertaking.
- k) Include family and friends (where nominated) in client care with the knowledge that the client's CNMBP treated with LTOT can have a negative effect on loved ones. Nurses need to be aware of the burden and effects of client's chronic condition can have serious consequences for spouses, partners and children and when they occur bringing the situation to the attention of the relevant health care practitioner.
- l) Determine the nature of client goals and concerns and where possible addressing their concerns.

- m) Inform client of the internal and external pathways for addressing unresolved concerns.
- n) Make available to clients their own health records and give them input into their progress reports.
- o) Make available to client the results of investigations, for example CT scans and pathology.
- p) Conducting nursing hand-overs at bedside to allow input from client.
- q) Make available on public record their qualifications, experience and expertise in relation to their profession and pain management.
- r) Do not assign State enrolled nurses to the care of CNMBP sufferers being treated with LTOT, as they are unable to administer Schedule 8 drugs.
- s) Document health care arrangements and provide a copy of this arrangement to the client and other relevant health care practitioners. The document to set out clear expectations of clients, nurses, admitting doctor and other relevant health care practitioners involved in their care. Such a contract needs to be agreed on and signed by all parties. The contract may formalise the care that the client has requested and specify:
 - 1. the rights and responsibilities of the client and health care practitioners;
 - 2. the purpose of the admission;
 - 3. the right to feel free to withdraw from the contract at any time;

4. full disclosure of risks and benefits of care and treatment;
 5. a full description of the health care being offered;
 6. complaint procedures at a local, accessible level; and
 7. all service providers and the client sign the contract on agreement of the contents.
- t) CNMBP sufferers treated with LTOT should have access to a clinical nurse specialist in pain management both in hospital and in the community.

Nursing Education & Administration,

The following ^{insights} recommendations concern nursing education and administration.

^{? advisable}
It is recommended that:

1. Nursing undergraduate curricular contain a module on acute, chronic malignant and nonmalignant pain management, which includes the legitimate role of opioids in the management of non-malignant pain.
2. ~~That~~ a post graduate diploma course in pain management be developed and nurses working in pain management be encouraged and supported to undertake such a course.
3. Pain management be recognised as a legitimate specialist area of nursing practice.

4. That clinical nurse specialists in pain management be prepared at the Master's level by undertaking such courses offered by the University of New South Wales which is a multidisciplinary postgraduate degree program in pain management.
5. Graduates from such programs can either specialise in acute, cancer or chronic pain management.
6. Clinical Nurse Specialists in pain management be employed at the minimum of Level 5 and be afforded the same authority as the Unit Manager.
7. Clinical Nurse Specialists in pain management undertake a consultative role rather than direct pain care, thus being a resource to nurses and clients both within the hospital and in the community utilising Internet facilities where available.
8. Clinical Nurse Specialists in pain management should be accredited to undertake DAS pump refills in the community.
9. Nurses working in pain management be encouraged to be active members of the Australian Pain Society Nurses Special Interest Group.
10. Nursing working in pain management be encouraged and supported to attend and participate in the Australian

Pain Society's annual scientific meetings and the International Association for the Study of Pain conferences, which are held every four years.

11. Nurses working in pain management have access to the recent pain literature through health care facilities subscribing to prestigious journals that address CNMBP treated with LTOT (Pain, Journal of Pain Symptom Management).
12. Nursing Administration develop policies and procedures which facilitate the provision of care as outlined in the recommendations for nursing practice.

General Practitioners

The following recommendations concern the role of the general practitioner in the management of the CNMBP client treated with LTOT.

It is recommended that:

1. The curricula for general practitioner accredited programs contain a module relating to CNMBP covering all treatment options, including the use of opioids.
2. General practitioners be given the opportunity to become the primary carer in the community, being responsible for obtaining the Schedule 8 Authority and prescribing opioids. This could occur once the patient has been assessed, rehabilitated as far as possible and stabilised on an appropriate pain management regime by preferably a multi-disciplinary pain management team or by a pain

specialist who is a member of the Australian Pain Society and other appropriate health care practitioners.

3. That all general practitioners have access to the Australian Pain Society's directory of pain units and pain specialists, and their guidelines for the prescribing of opioids in the treatment of non-malignant pain.
4. That general practitioners enter into written contracts with CNMBP sufferers treated with LTOT along the lines of those previously discussed.

Health care policy

The following recommendations concern health care policy and the organisation of health services in relation to the care of CNMBP sufferers treated with LTOT.

It is recommended that:

1. CNMBP sufferers treated with LTOT who wish to have more control over their pain management and health lobby policy makers for the introduction of written contracts between health care practitioners and clients. Such contracts formalise care that the client has requested and the services that the health care practitioner has agreed to supply. These arrangements to provide a clear explanation of the services to be rendered.
2. Health care policy makers require that the skill, qualifications and experience of health care practitioners be available in the public domain. Quality assurance programs need to be in place to monitor and evaluate health care practitioners' performances.

3. A charter of consumer rights be established in law in all States and Territories. This would support CNMBP sufferers treated with LTOT having a sense of control and provide clear guidelines and action for them to take if the health care services are not satisfactory.
4. Mechanisms put in place for client's to personally lodge critical incident reports at the time of their concern when they are at most risk and extremely fragile, rather than at a later point.

Organisation of pain management services

In relation to pain management services it is recommended that:

1. Health care facilities and pain management services restructure to accommodate those CNMBP sufferers treated with LTOT who wish to have control over their pain management and health.
2. Health care facilities providing pain management services adopt a philosophy of client inclusion.
3. Health care facilities that report to be providing pain management services be required to be accredited by the Australian Council of Health Standards in order to do so.
4. Health care providers, be informed of client's rights, particularly those to be self-determining and their right to refuse treatment.
5. Pain management units be affiliated with Universities who conduct health science programs and in doing so set

up a client resource service where CNMBP sufferers treated with LTOT and their family members can access relevant information, learn self care skills and chat rooms where they can receive individual attention.

6. Pain management units provide CNMBP sufferers treated with LTOT:

- access to allied health professionals (physiotherapist, occupational therapist, masseurs, psychologists);
- an environment which is more conducive to self management (appropriate recliner chairs, cooking and laundry facilities, recreational area);
- provide user-friendly documentation, which also supports self-medicating of Schedule 8 drugs as they do at home;
- clients history be used to facilitate communication between health care practitioners and client, thus permitting client to read and write in their history;
- developing client health provider contracts;
- have procedures in place for clients to be able to evaluate services;
- inservice education for health care practitioners on client control over pain management and health.

Third party providers

In relation to third party providers (eg. insurance companies, Traffic Accident Commission) it is recommended that:

1. Management and claims officers undergo in-service education in respect to:

- Clients being able to control their pain management and health;
 - The long term health needs of CNMBP sufferers treated with LTOT;
 - The legitimate role that opioids can play in the management of some CNMBP;
 - The long-term effects of LTOT;
 - Adjunct therapy to LTOT;
 - Clients' criteria for evaluating the effectiveness of their LTOT.
2. They use accredited pain management specialists in conjunction with the CNMBP sufferer's general practitioner to review their CNMBP clients receiving LTOT.
3. The introduction of written negotiated contracts with claimant when insurer has accepted liability and the client is classified totally/permanently incapacitated. Such contracts should clearly state:
- the rights of both claimant and insurer;
 - the long term health needs of the claimant (eg. 'time outs', pain management procedures (eg. nerve blocks); medications including opioids; drug delivery systems; hydrotherapy; home help).
 - what health services and aids are compensatable;
 - process by which the claimant can evaluate the effectiveness of the contract;
 - mechanisms for lodging complaints with respect to non compliance;
 - the period of time for which the contract is effective;
 - the signatures of both claims officer of behalf of the insurer and the claimant.

4. Third party providers give consideration to permitting long term claimants who are permanently incapacitated engage in a number of hours of voluntary work without jeopardising their entitlements in order to reduce their fragility and give them a sense of belonging and utility.

Research

There are various areas of research that would help minimise CNMBP sufferers' treated with LTOT sense of fragility and support them to take control of their pain and lives and successfully transverse the authenticating and repairing personhood process. These include:

1. research studies to explore nurses' attitudes and behaviour towards this cohort of patients;
2. research into the impact on pain control and client satisfaction with nursing care of the nurse knowing the client's personhood;
3. research to explore strategies nurses use to learn the pre-morbid personhood of CNMBP sufferers treated with LTOT and what impact that knowledge has on their care.
4. research in how pain management services can mediate the process of client control over pain management, including Schedule 8 medications;
5. pilot studies (using action research) to find ways of introducing client control over pain management into health care facilities;

6. comparative studies of levels of client satisfaction, pain control and function between those who self-determine their pain management and those who do not;
7. research into the most appropriate and acceptable ways of helping CNMBP sufferers treated with LTOT and their spouses/partners address related sexual dysfunction;
8. research into the long-term needs of spouses/partners and family members of CNMBP sufferers treated with LTOT.
9. research is needed in relation to the concept of compassion in care of CNMBP sufferers treated with LTOT;
10. research the cost effectiveness of having the general practitioner act as the primary carer for those receiving LTOT for their CNMBP.

LIMITATIONS OF THIS STUDY

This study may be limited because:

- whilst data was collected from family members and nurses due to doctoral limitations this study primarily explores the client's perspective;
- participants predominantly resided in Victoria and thus may not be useful with respect to CNMBP sufferers treated with LTOT living in other states or territories;

- participants were predominantly cared for in the private sector and thus findings may not be useful or applicable with respect to those treated in the public sector;
- although doctors play a key role in the management of CNMBP clients treated with LTOT and were identified as a source of fragility by participants, their views were not sort due to doctoral limitations.

CONCLUDING COMMENTS

The consequences of experiencing CNMBP and having LTOT as part of their pain management regime are, like their condition, complex with both positive and negative outcomes. For many LTOT is literally a lifesaver with respect of reversing suicide ideations. Regardless of the adverse effects of LTOT it allows some sufferers of CNMBP to lead a meaningful life. Although CNMBP sufferers treated with LTOT are extremely comfortable with their decision to use opioids as part of their pain management regime, many health care practitioners, particularly nurses are not. Addiction was not an issue for clients but it remains an issue for many nurses. There remains a lack of clarity between what constitutes addiction and physical dependency. Consequently this cohort of clients are often discredited, stereotyped, stigmatised and not considered authentic when they interface with the health care system, especially with nurses. This causes them extreme emotional pain, damaging their personhood and making them extremely fragile. This theory of authenticating and repairing personhood is a beginning attempt to consider a route for CNMBP sufferers treated with LTOT to take which assists them to take control of their pain and life, to repair their personhood and construct a meaningful, authentic life. The result of which diminishes their fragility and makes them better equipped to deal with nurses, family members and health care practitioners who may

discredit their pain and/or treatment and/or personhood. This is occurring in a society with individual rights, where government policies are requiring individuals in so many ways to manage their own lives and which is becoming more litigious. It is only a matter of time before a CNMBP sufferer treated with LTOT takes legal proceedings against practitioners who discredit and harm them. Given the humanistic nature of nursing it is possible that many will be prepared to take action to address issues of client fragility. CNMBP sufferers treated with LTOT are more likely to achieve and maintain a sense of control over their pain and life if they reach out to the appropriate health care practitioners, family, friends (and others) to seek their support. In many cases they are only asking for what is their right under existing charters and mission statements of the health care facilities within which they are currently cared for. CNMBP sufferers treated with LTOT have the basic right if they so desire to have a sense of control over their pain management and health and to be treated with dignity and respect when they interface with the health care system.

Hopefully with improved imaging and interventions for CNMBP based on best evidence guidelines, the incidence of CNMBP will be reduced or the level of pain modified. Perhaps better analgesic regimes will be developed so that practitioners and sufferers will encounter less of the problems identified in this thesis. However, for those inevitable cases, like the participants in this study, it is hoped that the insights provided by studies, as presented in this thesis, will help provide a better understanding of the human issues involved, resulting in better outcomes.

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APPENDICES

APPENDIX: 1.

Gardner, J. (2001). "Nurses' perceptions and experiences of caring for opioid dependent chronic back pain sufferers". Presented and Published in the Proceedings of the Australian Pain Society's 22nd Annual Scientific Meeting.

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C.6 NURSES' PERCEPTIONS AND EXPERIENCES OF CARING FOR OPIOID-DEPENDENT CHRONIC BACK PAIN SUFFERERS

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Aim of Investigation

To determine how nurses view chronic non-malignant back pain (CNMBP) patients being treated with the long-term opioid therapy, including nursing's role in CNMBP management and perceived clinical issues. This study is part of a larger study that is exploring both consumer and nursing issues related to CNMBP treated with long term opioid therapy.

Methods

Two focus groups were conducted, with four and six participants respectively. All participants were experienced RNs (mean 19.6 years), 88% having had attended in-service education on chronic pain management. They all worked in the private sector with 77% having daily contact with chronic pain patients and had worked with chronic pain patients on average for 5.6 years.

Results

Participants generally associated CNMBP with failed surgery, compensation and stigma. Whilst it was generally acknowledged that many CNMBP patients are courageous there was also a prevailing view that a significant number of these patients tended to be depressed, egocentric, manipulative and defensive. From a nursing management perspective CNMBP patients were considered to be low dependency physically, but high dependency psychologically. Validating a CNMBP patients' levels of pain and need for

opioids was considered by all to be difficult and problematic. The majority relying on the patient's physical appearance and level of functioning. A number of participants expressed a lack of trust in relying on patient self-reporting of pain and 'pain tools'. Participants agreed that there was a role for opioids in the management of some CNMBP but they had major concerns regarding tolerance, dependence and addiction. All participants felt that CNMBP warranted a multidisciplinary approach but that this was poorly implemented in their facilities, which many perceived to be inappropriate for the care of CNMBP patients. Poor inter-professional communication was identified as another major issue that often resulted in nurses feeling alienated and frustrated. Their role in CNMBP management was often reduced to giving out medication. However, regardless of their current levels of frustration, most participants believed they had an important role to play in CNMBP management in terms of psychological support, education and coordinating care.

Discussion

Nursing CNMBP patients treated with long term opioid therapy poses challenges for both clinicians and managers. Accurately assessing the 'nursing dependence' of these patients for staffing purposes appears problematic. This may be related to some nurses being reluctant to use appropriate clinical assessment tools. Furthermore, given these patients often carry much 'baggage' from failed treatments, litigation, stigma and discrimination within the health care system, developing a trusting, therapeutic relationship poses a special challenge for nurses who often haven't been assigned the time for such vital care. The role of nursing in the management of chronic pain appears ambiguous for many working in private facilities that offer 'pain management'. When their role is reduced to administering narcotics their perceptions of the opioid dependent CNMBP sufferer can be limited and distorted. The majority of participants believed that the introduction of patient contracts and CNMBP nursing protocols would not only improve patient care but also help articulate nursing's unique role in chronic pain management.

Conclusion

Despite feeling that they had sufficient information, patients demonstrated a very poor knowledge of their proposed treatment. Some patients expressed very clearly that they did not wish to know anything about their procedure. This raises issues concerning the provision of information and the obtaining of informed consent.

It was demonstrated that patients would rather receive a leaflet describing their proposed procedure, than talk about it to the CNS. This finding suggests that the role of the CNS in the interventional pain clinic is limited to the design of a good information leaflet, rather than direct patient contact. Clinical nurse specialists in this field need to target appropriate education to those patients who have a need and a desire for more information, using an appropriate method. Those patients that would simply like to be guided by the medical team also need to be identified and their position acknowledged and respected.

There is clearly a need for further investigation and discussion of these issues in this patient group.

C.3 HOSPITAL ADMISSIONS OF OPIOID DEPENDENT CHRONIC NON-MALIGNANT BACK PAIN SUFFERERS (CNMBP): CONSUMERS PERSPECTIVE

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Aim of investigation

To determine the nature and frequency of hospital admissions of opioid dependent CNMBP sufferers for pain management, including consumer appraisal of services offered. This study is part of doctoral thesis that is exploring both consumer and nursing issues related to CNMBP treated with long term opioid therapy.

Methods

Focus groups were used to explicate major consumer issues relating to the use of opioids in CNMBP management

and to develop a questionnaire which was used in an analytical, postal survey with 50 respondents from around Australia.

Results

Hospital admission was perceived to be a regular part of long term CNMBP management with opioids. Eighty-eight percent of participants had been admitted to hospital in the last twelve months for pain management i.e. respite, drug manipulations and procedures (e.g. nerve blocks). Eighty-two percent of respondents had had multiple admissions (mean 3.5) with 68% of these admissions lasting between 7-14 days. The majority (89%) had been admitted to private hospitals with 52% of admissions being to a private facility which respondents perceived to be specializing in pain management. Respondents were otherwise more likely to be admitted to a medical ward within a private facility. Forty-three percent of respondents reported that the majorities (73%) of their admissions to hospital were planned and part of a long-term pain management strategy. The majority (60%) of respondents did not have access to a multidisciplinary pain management team and access to non-medical specialists was ad hoc. Eighty-four percent of respondents reported feeling stigmatized because they took opioids to manage their pain. Furthermore, 82% stated that nurses had questioned the legitimacy of their opioid therapy at some stage in their admission causing them deep emotional pain. Sixty-three percent of respondents said they did not believe the majority of nurses who cared for them during their last admission had the necessary knowledge and expertise regarding chronic pain and its treatment with opioids.

Discussion

The management of CNMBP with long term opioid therapy appears to involve regular and relatively long periods of hospitalization. Patients admitted to private designated 'pain units' appear not be guaranteed of receiving specialized nursing or multidisciplinary pain management. The perceived lack of knowledge and expertise of nurses regarding chronic pain and its treatment with opioids may account for the stigma and emotional wounding experienced by these patients. It appears many are being admitted to an acute care facility for an exacerbation of a chronic problem that requires a different philosophy of nursing care to that which is being provided.

APPENDIX: 2

Gardner, J. & Sandhu, G. (1997). The stigma & enigma of chronic non-malignant back pain (CNMBP) treated with long term opioids (LTO). Contemporary Nurse 6(2): 61-66

The stigma and enigma of chronic non-malignant back pain (CNMBP) treated with long term opioids (LTO)

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Abstract

Certain diseases and drugs, like chronic non-malignant back pain (CNMBP) and opioids, are maligned by society, resulting in sufferers and users experiencing discrimination within the health care system which has the effects of increasing, rather than alleviating their pain and suffering. Many patients with severe CNMBP suffer not because their pain is untreatable but because their pain and personhood have not been validated by doctors and nurses who are opioiphobic. Such ignorances, fears, beliefs and biases not only deny some CNMBP patients adequate pain relief but also puts their lives at risk as it has long been recognised that chronic pain can lead to immunosuppression, affecting morbidity and mortality. Beyond the effects on patients, CNMBP treated with long term opioids (LTO) has a profound impact on families, whose pain and suffering is rarely addressed in practice. There is an urgent need to change current practice if CNMBP patients treated with LTO are to maximise their health potential and become responsible consumers of health care.



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Key words: Back pain,
Chronic pain, Narcotics,
Stigma, Addiction

Introduction

Certain diseases and drugs are maligned by society and thus their sufferers and users can experience discrimination within the health care system which increases, rather than alleviates, their pain and suffering. Chronic non-malignant back pain (CNMBP) treated with long term opioids (LTO) is an interesting example of this phenomenon. The term 'opioid' is used to refer to a large number of chemically diverse substances that have in common the capacity to bind specifically and to produce actions at several distinct types of receptors (opioid receptors). Commonly used opioids in CNMBP

include morphine, pethidine, fentanyl. Opioids can be administered orally, subcutaneously, intramuscularly, intravenously or intrathecally. LTO therapy is usually administered either as a sustained release oral preparation or intrathecally via implantable pumps. This article raises a number of important practice issues which challenge current treatment philosophies and practices relating to the care of CNMBP patients receiving LTO.

The prevalence

Chronic, non-malignant back pain (CNMBP) is among the major health issues confronting Western societies. According to the 1990 National Health Survey, 12.6 per cent of the Australian population experience long term back related musculoskeletal problems with 9.1 per cent suffering back problems, 2.8 per cent intervertebral disc disorders and 0.7 per cent sciatica (A.B.S. 1991). The number of persons suffering from intervertebral disc disorders has doubled in ten years, having accounted for 1 per cent of the population in 1977-78 and 2.6 per cent in 1989-90 (A.B.S. 1991). Musculoskeletal back disorders tend to affect people in the prime of their life, with 15 per cent of persons aged between 45-59 years experiencing back problems (A.B.S. 1991). Forty-two percent of those suffering back pain seek help from health care practitioners, that is, medical practitioners, chiropractors and physiotherapists. Fifty-seven percent of people reporting back pain use medications to alleviate their pain (A.B.S. 1991). The management and treatment of CNMBP consumes an enormous amount of Australia's scarce health resources. Despite its prevalence, debilitating effects and demand on health, social and financial resources, CNMBP remains

an enigma to a majority of health care practitioners.

The enigma

CNMBP is a complex, multidimensional disorder with social and economic consequences for both the sufferer and society, and is poorly managed by health professionals. Chronic pain is generally defined as 'persistent pain that is not amenable, as a rule, to treatments based upon specific remedies, or to the routine methods of pain control such as non-narcotic analgesics' (Merskey & Bogduk 1994).

CNMBP includes spinal, radicular and referred pain that persists longer than three months and which is not related to the presence of malignant disease (Merskey & Bogduk 1994). Living with CNMBP means engaging in a constant struggle to remain in control of one's pain and life, and thus sufferers tend to define and evaluate their pain in terms of their whole-life situation (Pellino & Oberst 1992).

The causes of CNMBP, like its consequences, are varied and complex. In the past, chronic pain has tended to be viewed as a syndrome, masking psychological problems emanating from unresolved life crises such as childhood abuse (Little 1983, Gamsa 1994). However, modern advances in neurophysiology are giving more credence to the pathophysiological bases of CNMBP (Jayson 1994). Although CNMBP may be due to the persistence of the original injury/disease, in many cases new pathology develops resulting in chronicity. Such pathology may involve discs, nerve roots, facet joints, neuromuscular and vascular changes. Furthermore, the absence of detectable spinal pathology does not necessarily mean the

pain is imagined, as recent research suggests some chronic pain may be related to morphological cerebral changes (Derbyshire, Jones et al 1994).

CNMBP has many manifestations, ranging from a localised, low-grade discomfort to moderate and severe diffuse pain experiences. Severe CNMBP can devastate a person's life and even lead to suicide. Furthermore, it has long been recognised that unrelieved pain can be associated with immunosuppression effecting morbidity and mortality. Thus, no back pain can be considered benign (Leibeskind 1991).

Unlike acute pain, chronic pain rarely produces detectable physiological changes to prove its presence. Furthermore, many CNMBP sufferers have developed strategies for covering up their pain and often fail to demonstrate 'pain' behaviours which staff believe they need to observe in order to validate the patient's pain. However, the skilled clinician can often detect the subtle tell-tale signs unique to each patient. For while the CNMBP experience may be shared, each individual sufferer interprets the experience and gives meaning to it based on their 'personhood'. The reality is, in order to know and understand someone's CNMBP you need to know and understand the 'person' that is the patient. Personhood is not easy to explain. It encompasses our personal likes, dislikes, needs, wants, beliefs, culture, habits, strengths, weaknesses, past and future (Buzzell et al 1993). Getting to know the CNMBP patient as a person is somewhat difficult when in clinical practice our encounters are so brief as a result of today's health care system being 'diagnosis and dollar driven'. Patient histories with their emphasis on medical data, rarely provide 'a composite picture of the "whole person"' (Fagerhaugh & Strauss

1977:117). Furthermore, both CNMBP patients and staff can be rendered suspicious, angry, confused and cynical from previous 'failed' encounters with health care practitioners and CNMBP patients respectively, imposing further difficulties in establishing trusting relationships.

The stigma

There have been considerable advances in the management of pain, especially in relation to the treatment of acute cancer and arthritic pain. However, severe CNMBP has remained neglected and maligned by society, health care practitioners and policy makers. Sufferers can not only be ignored by health care practitioners but can suffer at their hands (Fagerhaugh & Strauss 1977). This suffering occurs either on a physical level as a consequence of treatment and/or on an emotional level when practitioners fail to validate their pain and personhood. Further, some patients with severe CNMBP suffer not because their pain is untreatable but because many health care practitioners are opioid-phobic (Turk 1996). Many research studies addressing the undertreatment of pain with opioids identify peer pressure, lack of knowledge about opioids, actual and perceived regulatory pressures as contributing to the problem (Cole 1995, Turk et al 1994, Coniam 1989, Turk & Brody 1991). Similar nursing studies, undertaken in both hospital and community settings, identify nurses' lack of knowledge and poor assessment and judgement as contributing to the under medication of patients with pain (Greipp 1992). A consistent finding is a significant tendency for nurses to under estimate the pain of chronic pain sufferers, in contrast to acute pain patients (Fagerhaugh & Strauss 1977,

Teske et al 1983). Furthermore, it is reported that a nurse's judgement regarding pain is predominantly influenced by the patient's medical diagnosis and underlying physical pathology (Taylor et al 1984, Halfens et al 1990). Given the enormous physical, psychological and financial load that CNMBP patients and their families already carry, they should not be further burdened with the prejudices and phobias of health care practitioners. Nurses' ignorance, fears, beliefs and biases can not only deny CNMBP patients safe and effective pain management but can result in care which contravenes the ethical principles of autonomy, beneficence, nonmaleficence and justice which underly nursing practice (Greipp 1992). Thus, nurses need to consciously seek to relieve the suffering of patients with chronic pain by providing safe and effective analgesia to be beneficent and nonmaleficent (Greipp 1992).

In the past, chronic pain research and services has tended to focus on cancer, arthritic and non-specific chronic back pain. For the latter, the focus has been on reducing the number of CNMBP patients that become permanently disabled and dependent on long term opioids. However, such programs ignore the plight of those sufferers for whom the current health care system has already failed, and LTO, combined with other pain management techniques, offer the only hope of a tolerable life. Unfortunately, CNMBP patients receiving LTO are likely to suffer further discrimination in the health care system because they are often considered weak and less deserving (Cole 1995).

LTO therapy

LTO therapy, while well accepted for the management of cancer pain,

remains controversial for those with chronic non-malignant pain (CNMP) (Savage 1996, Krames 1993, Portenoy & Foley 1986). Until recently, the prevailing view held by medical practitioners was that there was no role for LTO in the management of CNMBP because they were believed to actually contribute to the severity of pain felt by the patient and bring about behavioural dysfunction (Fishbain et al 1992, Halpern & Robinson 1985, Taylor et al 1980). However, it is now recognised that LTO can be beneficial in the treatment of some patients with severe refractory CNMBP caused by a primary lesion or dysfunction in the nervous system (Schofferman 1993, Turk & Brody 1992). In response to the increasing use of LTO for CNMP in Australia, the Australian Pain Society in 1996 developed draft guidelines for the management of opioid maintenance therapy for non-malignant pain, in an attempt to minimise the perceived adverse effects of such treatment, that is, addiction and drug abuse.

Efficacy is one of the major controversies surrounding the use of long term opioids for CNMBP. Many practitioners uphold the view that for an opioid to be considered effective it must result in both a reduction in pain and an improvement in patient's function and abilities (Portenoy 1990, Schofferman 1993). Thus, even though opioids may result in the patient with CNMBP feeling better as a result of pain reduction, they may be withheld if there isn't a corresponding, significant improvement in functioning. The practice of requiring that both criteria be met, notes Turk et al (1991), raises a number of difficult ethical and practical issues, including the ethics of withholding treatment that has the potential to decrease pain severity and the failure to prescribe opioids to relieve pain as

grounds for malpractice. Opioids, while causing constipation, respiratory depression and intoxication from overdose, are not known to cause end-organ pathology unlike the hepatic and renal pathology caused by non-narcotic analgesics such as non-steroidal anti-inflammatory drugs (NSAIDs) (Cole 1995).

Addiction remains another major controversy in the debate, despite evidence that the likelihood of patients taking opioids for legitimate pain becoming addicted is considered to be 1:1000 (Fishbain et al 1992, Cole 1995). However, while CNMBP patients treated with long term narcotics are unlikely to become addicted, they are likely to experience physical/chemical dependence and tolerance as a natural consequence of treatment (Savage 1993, Sees & Clark 1993). The issue being, that many nurses continue to confuse the two clinical entities of addiction and dependence. Physical dependence to opioids is an expected neuro-adaptation to continuous opioid use characterised by the patient experiencing withdrawal symptoms (for example, yawning, anxiety, abdominal cramps, diarrhoea, muscle and bone pain) when the opioid is ceased abruptly (Morgan 1986). Addiction is a psychological and behavioural syndrome characterised by a) a strong desire for the drug and obsession regarding accessing further supplies; b) compulsive drug use, for example, unauthorised self medication including escalating dose; and/or c) evidence of one or more aberrant behaviours, including manipulating physicians and prescriptions to obtain extra drugs, drug hoarding and selling (Portenoy 1990). Furthermore, practitioners fail to acknowledge that physical dependence to opioids is not unique to chronicity, but can occur even with their short term use after surgery, that is, > 48 hours (Savage

1993). The addiction debate is further complicated by the unsubstantiated claims that addictive diseases, for example, alcoholism, are more prevalent among chronic pain patients than the general population (Savage 1993).

The technology

The discovery of spinal cord opioid receptors led to the initial trials of administering opioid drugs intraspinally to patients with chronic pain in the late 1970s (Wang et al 1979, Beehar et al 1979). Research relating to intrathecal infusional therapies has mainly concentrated on the treatment of cancer pain (Penn & Paice 1987, Krames et al 1985, Coombs et al 1983). However, there is now growing evidence that patients with severe, chronic non-malignant pain can be managed satisfactorily with long term (> six months) intrathecal opioids delivered via implanted programmable and non-programmable drug pumps (Coombs et al 1983, Penn & Paice 1987, Lamb & Hosobuchi 1990). A major advantage of intrathecal drug pumps is they generally provide maximum pain relief from minimum amounts of opioids with minimal systemic effect, although incidences of amenorrhoea, polyarthralgia and spontaneous lactation associated with intrathecal morphine have been reported (Lamb & Hosobuchi 1990).

A major concern relating to the use of drug pumps in the management of CNMBP is the risk of the technology becoming the focus of care rather than the person suffering CNMBP. For the growing number of CNMBP sufferers who are being implanted with intrathecal programmable drug pumps for pain control, their pain and life becomes beholden to a computer and the people who operate them, requiring frequent visits

to the specialist for pump refills and reprogramming. In addition, they face an uncertain future in terms of tolerance, side effects, mechanical failure (rare) and inevitable surgery for the replacement of hardware every four to five years.

Patients become entrapped in such 'techno/medico marriages' only after all traditional, conservative therapies have failed; further surgical intervention is contraindicated; psychological clearance obtained; and a intrathecal trial has been successful (Krames 1993). These marriages, by their very nature, have the potential to foster passivity and an over reliance on medication as well as perpetuating the dominance of the medical 'sick/curative' model in CNMBP management. Therefore, while intrathecal drug therapy can play a very positive role in the treatment of some CNMBP, it is essential that nursing care is centred around the patient rather than the technology.

The family

Beyond the effects on the patient, CNMBP also has a profound impact on families, who traditionally undertake the primary responsibility for the care of the chronically ill and disabled in the community (Stuifbergen 1987). Recent studies have identified the patient's spouse as being particularly at risk for emotional distress and depression (Flor et al 1987, Ahern et al 1985). How well spouses adjust to the altered family functioning appears dependent upon how well the patient copes with his/her pain rather than their pain severity and level of disability (Flor et al 1987, Ahern et al 1985, Snelling 1994). Furthermore, research also highlights the role that family members can play in cultivating chronicity (Flor et al 1987). However, while ineffectual

family coping strategies, marital conflict and sexual dysfunction consistently emerge as major issues in CNMBP these issues are rarely addressed in clinical practice (Flor et al 1987, Ahern 1985, Snelling 1994). Furthermore, there is little research to date which investigates the impact on the family unit when a member suffering CNMBP is treated with LTO.

The suffering

A person's suffering is not confined to physical symptoms such as pain. Patients suffer not only from their diseases and injuries but also from their treatment. Suffering can occur in relation to any aspect of the person. 'Suffering is experienced by persons, not merely by bodies' (Cassel 1982:639).

CNMBP patients suffer when their pain is overwhelming and they feel loss of control. They also suffer when doctors and nurses fail to validate their pain. In addition, when CNMBP patients feel rejected and they can no longer talk to others about their pain, they become socially isolated adding to their suffering.

Both CNMBP patients and their families suffer. Suffering refers to the experience of severe distress resulting from events that threaten the integrity of the person (Cassel 1982). Suffering, like pain, is subjective and ultimately a personal matter and reflects the patient's personhood. As stated previously, personhood has many facets and it is ignorance of these that actively contributes to both the patient's suffering and frustration on the part of practitioners to provide a service. Personhood is at the root of individual vulnerability 'when it is honoured we feel comfortable, when

it is not taken into account by others we feel depersonalised' (Buzzell 1989:4).

It is possible that CNMBP patients being treated with LTO who are labelled difficult, manipulating, drug seeking etc., are suffering and demonstrating behaviours which reflect greater damage to their 'person' than their physical pain. In order to understand and relieve such suffering, nurses first need to know the person who is the patient.

A major problem is that many patients with severe CNMBP are often cared for in either acute care or rehabilitation facilities even though their condition is considered no longer amenable to acute medical and rehabilitation treatments. Many practitioners and administrators have not thought through the profound differences in philosophies and goals between acute, restorative care and that of long term maintenance treatment.

Acute care is often characterised by dominant/submissive relationships which can lead to learned helplessness, distinguished by motivational, cognitive and emotional deficits (Slimmer 1987). Therefore, in such environments the CNMBP patient treated with LTO can become apathetic and 'give up', and experience feelings of hopelessness. Within the acute 'curative/sick' care model care tends to be generalised, prescriptive and directive which is doomed to failure in terms of helping CNMBP patients treated with LTO become involved in their care and to maximise their health potential (McLeod Clark 1993).

Alternatively, in long term health care the focus shifts from disease, task and cure to the person, care and living (Buzzell 1989). It requires a different kind of nurse/patient

relationship, that is, partnership, which requires a certain level of involvement, as well as a sense of mutuality and equality from both parties. The concept of partnership acknowledges the rights of both the patient and the nurse. It implies that the nurse is committed to working with the person as that individual 'explores his possibilities, chooses his action and creates his reality' (Gulino 1982:355). Partnership is about communicating to CNMBP patients that both their pain and personhood are respected. 'Striving for partnership is not easy, whether in clinical practice, marriage or friendship' (Buzzell 1989:14). Such an approach to practice calls for both professional competence and personal maturity and often challenges what nurses were taught in their undergraduate nursing programs.

However, as McLeod Clark notes 'a social and cultural revolution may also be required to shift the goals and expectations of the other side of the health care coin—the consumer' (McLeod Clark 1993:269). Health care services are not immune from the 'consumerism' which is permeating all public services. No longer should CNMBP patients be passive recipients of care but rather active participants in all phases of health care delivery. The increasing numbers of complaints and litigations within the Australian health care system is further proof of patients becoming more critical and discerning consumers.

Conclusion

While there is a growing body of literature acknowledging the role of long term opioids in the treatment of some CNMBP, there are few cited studies which look at CNMBP treated with LTO from the consumer's perspective, that is, their per-

ceived rights, roles, responsibilities, outcome expectancies and quality of life. At present there is a lamentable shortage of outcome studies in relation to CNMBP treated with LTO. A collaborative, long term health care model could provide countless possibilities in terms of identifying consumer health-focused outcomes through which to evaluate effectiveness. It is imperative to demonstrate a relationship between health care practice and the outcome in terms of patient and family well being. Given the subjective and complex nature of CNMBP, the evaluation of patient services cannot be left to the professionals alone, but should be viewed in the light of consumer perceptions and personhoods. The extent to which CNMBP patients treated with LTO perceive that their personhood and pain are respected, and that they have some control over their pain and treatment, could affect their appraisal of pain severity, stress, disability, their ability to cope and perceived quality of life. Furthermore, if nurses are to fulfil their roles and responsibilities in the treatment of CNMBP with LTO, which not only requires them to be highly skilled clinicians but also humanitarian and moral agents, then it appears that there is an urgent need to re-examine current treatment philosophies and practices relating to CNMBP.

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APPENDIX: 3

The first guideline that they refer to indicates that "data collection and analysis are interrelated processes (Corbin & Strauss 1990:6). This refers to the need to analyze data as they are collected so that they can be utilized to inform the next interview or data collection. This process allows concepts to be explored and developed and grounded by constantly exploring a range of data (for conditions, consequences, covariance, contingencies, context and causes) and provides theory-observation congruence (Corbin & Strauss 1990:7). The second guideline identified by Corbin & Strauss (1990:7), "concepts are the basic units of analysis", explains the necessity to conceptualize the raw data into units of theory rather than mere descriptions of events and situations. The third criteria states, "categories must be developed and related" (Corbin & Strauss 1990:7), suggests that through the process of comparing similarities and differences some concepts are grouped into more abstract categories along with properties and dimensions, conditions and consequences and when related form the building blocks of theory. The fourth guideline described by Corbin & Strauss (1990: 8), "sampling in grounded theory proceeds on theoretical grounds", describes how issues of representativeness are addressed by sampling theoretically rather than selecting individuals and by the consistency of concepts, variation in incidents, events, conditions, consequences and interaction. The fifth guideline, "analysis makes use of constant comparisons", refers to constant comparisons being made between data and analyses. Data from one area are compared with data from another area in respect to their similarities and differences. Making comparisons provides an opportunity to question concepts using different data. The sixth guideline, "patterns and variations must be accounted for", relate how data is explored that provide variation including the full range of patterns that consider absent and present patterns. The seventh guideline, "process must be built on theory" (Corbin & Strauss 1990: 10), shows how theory must indicate a process, series of changes or events or a course of action. The eighth guideline addresses the issue of "writing theoretical memos is an integral part of doing grounded theory" Corbin & Strauss 1990: 10, describes how memos are a written record of the development of the theory and the process of analysis. The ninth evaluative criteria, "hypotheses about relationships among categories should be developed and verified as much as possible during the research process" (Corbin & Strauss 1990: 11) refers to the need to check hypotheses about relationships among categories and the need to constantly revise and verify with new data from a range of sources that reflects both supporting and negating evidence. The tenth guideline, "a grounded theorist need not work alone" (Corbin & Strauss 1990: 11), recommends that a useful strategy to balance researcher bias is to discuss the process of analysis with informed colleagues, for their examination. The last evaluative criteria, "broader structural conditions must be analyzed however microscopic the research" (Corbin & Strauss 1990: 11), requires the researcher to not only explore the issues directly concerned with the phenomena under study but also to integrate them into the emerging theory and specifically illustrate how the broader issues such as economics, power, medical dominance, gender, and politics are linked.

APPENDIX 4: The research process can be judged according to:

How the original sample was selected?
 On what grounds (selective sampling)?
 What major categories emerged?
 What were some of the events, incidences, actions, and so on that indicated some of these categories?
 On the basis of what categories did theoretical sampling proceed?
 That is, how did theoretical formulations guide some of the data collection?
 After the theoretical sampling was carried out, how representative did these categories prove to be?
 What were some of the hypotheses pertaining to relations among categories?
 On what grounds were they formulated and tested?
 Were there instances when hypotheses did not hold up against what was actually seen?
 How were the discrepancies accounted for?
 How did they effect the hypotheses?
 How and why was the core category selected?
 Was the selection sudden or gradual, difficult or easy?
 On what grounds were the final analytic decisions made?
 How did extensive "explanatory power" in relation to the phenomena under study and "relevance" figure in the decisions? (Corbin & Strauss 1990: 17).

Questions that are criteria for empirical grounding of findings include:

Are concepts generated?
 Are concepts systematically related?
 Are there many conceptual linkages and are the categories well developed?
 Is there much variation built into the theory?
 Are the broader conditions that effect the phenomena under study built into its explanation?
 Has process been taken care of?
 Do the theoretical findings seem significant and to what extent?
 (Corbin & Strauss 1990: 17/18).

APPENDIX: 5**Monash University****General Explanatory Statement****RE: RESEARCH INTO CHRONIC BACK PAIN TREATED WITH LONG TERM NARCOTICS**

My name is Janet Gardner and I am a nurse studying for my Doctorate degree. A research project is an important component of the course and I am undertaking my research project under the supervision of Dr. Gurpal Sandhu, Senior Lecturer, Department of Health Sciences and Professor J. Murtagh, Head, Department of Community Medicine, Monash University.

The specific aim of this research project is to learn patients' and their family members' views about the management of chronic back pain (not related to cancer) that is being treated with long term narcotic analgesics e.g. morphine, pethidine. I hope the findings of this research project will be useful in improving the care of chronic back pain sufferers and their families. I too suffer from chronic back pain which is being treated with long term narcotic therapy thus have both a personal and professional interest in this area.

The study information will be collected in four ways, focus/discussion groups, interviews, participant observation and mailed questionnaires. There will be four separate focus groups made up of female patients, male patients, family members and nurses respectively. Thus, I am seeking:

i) adult (i.e. 18 years and over) chronic, non-malignant, back pain sufferers who have been taking narcotic analgesics for more than three months to join a group of other men/women sufferers to discuss what it is really like to live with chronic back pain which is treated with long term narcotics.

ii) adult (i.e. 18 years and over) family members (or significant others) who reside with persons who suffer chronic back pain, which is being treated with long term narcotic analgesics, to join a group of other patients' family members to discuss what it is really like to live with someone suffering chronic back pain which is treated with long term narcotics.

iii) registered nurses currently working with patients diagnosed with chronic, non-malignant back pain who have been prescribed narcotic analgesics for more than three months, to join a group of other nurses to discuss their experiences of caring for patients suffering chronic back pain treated with long term narcotics.

At the beginning of each focus group participants, participant observation and formal interviews you will also be requested to complete a short questionnaire providing basic demographic information. The process will take approximately 1-2 hours (excluding travel time), and will be undertaken at Hawthorn Private Hospital, Hawthorn, Victoria or another location convenient to participants, or via telephone conferencing if you are unable to travel. There will be a break with light refreshments after 30 minutes of discussion and we will also be able to make transport arrangements if necessary.

Your name or other identification information will not be published with the findings. The anonymity of your participation is assured by our procedure. Access to data is restricted to my supervisors and me. With your permission I will be using a tape recorder to record the group discussions, only first names will be used, which will be erased before transcribing. Tape recordings will be erased by use of magnet in the library of this University.

The data collected in these focus groups will be used to develop four separate questionnaires, which will then be mailed to chronic back pain patients, their family members and nurses working in pain

management throughout Australia. It is envisaged that the questionnaire will take approximately 30 minutes to complete and a prepaid envelope will be provided for its return.

Participant observation involves being observed and having informal discussions whilst you are in hospital and engaging with nurses and other health care practitioners.

Participation in this research is entirely voluntary, and if you agree to participate, you may withdraw your consent at any time by not attending the Group Meetings or not returning the questionnaire. You may also decline to participate in any section of the procedure, by simply not making or marking a response. If you decide to participate in this study, I request you to write your name, address and telephone number on the form provided for the researcher to contact you.

If you have any queries or would like to be informed of the aggregate research finding, please telephone 03 99026639 or fax 051 226 527. Should you have any complaint concerning the manner in which this research is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research on Humans at the following address:

The Secretary
The Standing Committee on Ethics in Research on Humans,
Monash University,
Wellington Road, Clayton, Victoria 3168
Telephone (03) 9905 2052 Fax (03) 9905 1420

Thank you.

Janet R. Gardner RN,Dip.Nsg.,B.App.Sci.(Ed),M.H.Sc., Telephone: (03) 9439 8952

Dr. Gurbai K. Sandhu, Project Supervisor Telephone: (03) 9902 6639

APPENDIX: 6

**Example of Study Notice (initially printed in bright yellow) and
Expression of Interest Form**

MONASH UNIVERSITY*** IMPORTANT NOTICE ***

✓ **DO YOU SUFFER FROM CHRONIC BACK PAIN?**

YES

✓ **IS YOUR PAIN BEING TREATED WITH
NARCOTIC ANALGESICS (EG. MORPHINE)**

YES

**THEN YOU AND YOUR FAMILY ARE INVITED TO
PARTICIPATE IN AN IMPORTANT RESEARCH
PROJECT.**

**PLEASE READ THE ATTACHED GENERAL
EXPLANATORY STATEMENT REGARDING THE
PROJECT.**

**INTERESTED PATIENTS & FAMILY MEMBERS
ARE REQUESTED TO COMPLETE THE
ATTACHED EXPRESSION OF INTEREST FORM
BELOW AND EITHER LODGE IN THE BOX
PROVIDED OR POST TO J. GARDNER, 106
FRANKLIN ST., ELTHAM, VICTORIA 3095.**

**ADDITIONAL INFORMATION CAN BE OBTAINED
BY TELEPHONING THE RESEARCHER, JAN
GARDNER, ON 03 9439 8952.**

Please deposit the completed Expression of Interest Form in the box provided at your pain specialist's reception, nursing station or return to J. Gardner, 106 Franklin St, Eltham, Victoria 3095.

Monash University

*** EXPRESSION OF INTEREST FORM ***

**Research Study into Chronic Back Pain
treated with Narcotics.**

**I have read the General Explanatory Statement
regarding the above research project and am willing to
participate as follows:**

Please tick which form(s) of participation that you are
prepared to be in involved.

1. Attending Discussion Group
2. Participant Observation
3. Completing Postal Survey Questionnaire
4. Taped formal interview

☐
☐
☐
☐

Name.....Telephone Number.....

The following family members are also willing to
participant in the project by:

1. Attending a Discussion Group
2. Complete a Postal Survey Questionnaire
3. Taped Formal Interview

☐
☐
☐

Name.....Relationship to Patient.....

Name.....Relationship to Patient.....

Name..... Relationship to patient.....

Please deposit the completed Expression of Interest Form in the box
provided at your pain specialist's reception, nursing station or return
to J. Gardner, 106 Franklin St, Eltham, Victoria 3095.

If you require further information please do not hesitate to call the researcher, Jan Gardner
on 039439 8952.

APPENDIX: 7**MONASH UNIVERSITY****EXPLANATORY STATEMENT FOR FOCUS GROUP PARTICIPANTS****RE: RESEARCH INTO CHRONIC NON-MALIGNANT BACK PAIN (CNMBP) TREATED WITH LONG TERM NARCOTIC (LTN) THERAPY**

My name is Janet Gardner and I am a nurse studying for my Doctorate degree. A research project is an important component of the course and I am undertaking my research project under the supervision of Professor J. Murtagh, Head, Department of Community Medicine, Monash University, Melbourne and Dr. Chris Beanland, Centre for Graduate Studies in Clinical Nursing, Monash University, Melbourne.

The specific aim of this research project is to learn patients' views about the management of chronic back pain (not related to cancer) that is being treated with long term narcotic analgesics i.e. morphine, pethidine etc. I hope the findings of this research project will be useful in improving the long-term care for chronic back pain sufferers and their families.

The study information is being collected in four ways, a discussion group, participant observation, formal interviews and a mailed survey questionnaire. I am now seeking patients who suffer from CNMBP (experienced at any level of the spinal cord and which may radiate to other areas of the body) and who have been taking narcotic analgesics on a daily basis for a period of six months or more who are prepared to attend a group discussion with other sufferers regarding your experience of suffering CNMBP and being treated with narcotics. The discussion will be audiotaped and take approximately 1-2 hours. Appropriate seating will be arranged and there will be a break for refreshments during the discussion. Transport can be arranged if necessary.

Your name or other identification information will not be published with the findings. The anonymity of your participation is assured by our procedure. Access to data is restricted to my supervisors and me. Coded data are stored for five years, as prescribed by University regulations.

Participation in this research is entirely voluntary, and if you agree to participate, you may withdraw your consent at any time by not returning the questionnaire. You may also decline to participate in any section of the procedure, by simply not making or marking a response.

If you have any queries or would like to be informed of the aggregate research findings, please telephone 03 95506968 or fax 0395502338. Should you have any complaint concerning the manner in which this research is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research on Humans at the following address:

The Secretary, The Standing Committee on Ethics in Research on Humans, Monash University, Wellington Road, Clayton, Victoria 3168. Telephone (03) 9905 2052 Fax (03) 9905 1420.

Thank you.

Janet R. Gardner RN, Dip.Nsg, B.App.Sci. (Ed). M.H.Sc., Telephone: (03) 9439 8952
Prof. John Murtagh, Project Supervisor Telephone: (03) 9579 3188

APPENDIX: 8**MONASH UNIVERSITY****EXPLANATORY STATEMENT FOR PARTICIPANT OBSERVATION****RE: RESEARCH INTO CHRONIC NON-MALIGNANT BACK PAIN (CNMBP) TREATED
WITH LONG TERM NARCOTIC (LTN) THERAPY**

My name is Janet Gardner and I am a nurse studying for my Doctorate degree. A research project is an important component of the course and I am undertaking my research project under the supervision of Professor J. Murtagh, Head, Department of Community Medicine, Monash University, Melbourne and Dr. Chris Beanland, Centre for Graduate Studies in Clinical Nursing, Monash University, Melbourne.

The specific aim of this research project is to learn patients' views about the management of chronic back pain (not related to cancer) that is being treated with long term narcotic analgesics i.e. morphine, pethidine etc. I hope the findings of this research project will be useful in improving the long-term care for chronic back pain sufferers and their families.

The study information is being collected in four ways, a discussion group, participant observation, formal interviews and a mailed survey questionnaire. I am now seeking patients who suffer from CNMBP (experienced at any level of the spinal cord and which may radiate to other areas of the body) and who have been taking narcotic analgesics on a daily basis for a period of six months or more who are prepared to be observed whilst in hospital. It will involve informal discussions relating issues and incidents associated with your CNMBP and your treatment with narcotics. Participation will in no way compromise your care whilst in hospital.

Your name or other identification information will not be published with the findings. The anonymity of your participation is assured by our procedure. Access to data is restricted to my supervisors and me. Coded data are stored for five years, as prescribed by University regulations.

Participation in this research is entirely voluntary, and if you agree to participate, you may withdraw your consent at any time by not returning the questionnaire. You may also decline to participate in any section of the procedure, by simply not making or marking a response.

If you have any queries or would like to be informed of the aggregate research findings, please telephone 03 95506968 or fax 0395502338. Should you have any complaint concerning the manner in which this research is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research on Humans at the following address:

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Thank you.

Janet R. Gardner RN, Dip.Nsg, B.App.Sci. (Ed). M.H.Sc., Telephone: (03) 9439 8952
Prof. John Murtagh, Project Supervisor Telephone: (03) 9579 3188

APPENDIX: 9**MONASH UNIVERSITY****EXPLANATORY STATEMENT FOR PATIENT SURVEY PARTICIPANTS****RE: RESEARCH INTO CHRONIC NON-MALIGNANT BACK PAIN (CNMBP) TREATED WITH LONG TERM NARCOTIC (LTN) THERAPY**

My name is Janet Gardner and I am a nurse studying for my Doctorate degree. A research project is an important component of the course and I am undertaking my research project under the supervision of Professor J. Murtagh, Head, Department of Community Medicine, Monash University, Melbourne and Dr. Chris Beanland, Centre for Graduate Studies in Clinical Nursing, Monash University, Melbourne.

The specific aim of this research project is to learn patients' views about the management of chronic back pain (not related to cancer) that is being treated with long term narcotic analgesics i.e. morphine, pethidine etc. I hope the findings of this research project will be useful in improving the long-term care for chronic back pain sufferers and their families.

The study information is being collected in two stages, a discussion group and a mailed questionnaire. I am now seeking patients who suffer from CNMBP (experienced at any level of the spinal cord and which may radiate to other areas of the body) and who have been taking narcotic analgesics on a daily basis for a period of six months or more who are prepared to complete a questionnaire on their experiences of CNMBP and its treatment with LTN therapy. The questionnaire will take approximately 40-60 minutes of your time, and will be undertaken at your home, at your convenience. A stamped, addressed envelope is provided for you to return the completed questionnaire to the researcher.

Your name or other identification information will not be published with the findings. The anonymity of your participation is assured by our procedure. Access to data is restricted to my supervisors and me. Coded data are stored for five years, as prescribed by University regulations.

Participation in this research is entirely voluntary, and if you agree to participate, you may withdraw your consent at any time by not returning the questionnaire. You may also decline to participate in any section of the procedure, by simply not making or marking a response.

If you have any queries or would like to be informed of the aggregate research findings, please telephone 03 95506968 or fax 0395502338. Should you have any complaint concerning the manner in which this research is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research on Humans at the following address:

The Secretary, The Standing Committee on Ethics in Research on Humans, Monash University, Wellington Road, Clayton, Victoria 3168. Telephone (03) 9905 2052 Fax (03) 9905 1420.

Thank you.

Janet R. Gardner RN, Dip.Nsg, B.App.Sci. (Ed). M.H.Sc., Telephone: (03) 9439 8952
Prof. John Murtagh, Project Supervisor Telephone: (03) 9579 3188

APPENDIX: 10**MONASH UNIVERSITY****EXPLANATORY STATEMENT FOR FORMAL INTERVIEWS****RE: RESEARCH INTO CHRONIC NON-MALIGNANT BACK PAIN (CNMBP) TREATED
WITH LONG TERM NARCOTIC (LTN) THERAPY**

My name is Janet Gardner and I am a nurse studying for my Doctorate degree. A research project is an important component of the course and I am undertaking my research project under the supervision of Professor J. Murtagh, Head, Department of Community Medicine, Monash University, Melbourne and Dr. Chris Beanland, Centre for Graduate Studies in Clinical Nursing, Monash University, Melbourne.

The specific aim of this research project is to learn patients' views about the management of chronic back pain (not related to cancer) that is being treated with long term narcotic analgesics i.e. morphine, pethidine etc. I hope the findings of this research project will be useful in improving the long-term care for chronic back pain sufferers and their families.

The study information is being collected in four ways, a discussion group, participant observation, formal interviews and a mailed survey questionnaire. I am now seeking patients who suffer from CNMBP (experienced at any level of the spinal cord and which may radiate to other areas of the body) and who have been taking narcotic analgesics on a daily basis for a period of six months or more who are prepared to be interviewed regarding their experiences of CNMBP and its treatment with LTN therapy. The interview will take approximately 1-2 hours, and can be undertaken at your home, or in hospital at a time of your convenience. The interview will be audiotaped.

Your name or other identification information will not be published with the findings. The anonymity of your participation is assured by our procedure. Access to data is restricted to my supervisors and me. Coded data are stored for five years, as prescribed by University regulations.

Participation in this research is entirely voluntary, and if you agree to participate, you may withdraw your consent at any time by not returning the questionnaire. You may also decline to participate in any section of the procedure, by simply not making or marking a response.

If you have any queries or would like to be informed of the aggregate research findings, please telephone 03 95506968 or fax 0395502338. Should you have any complaint concerning the manner in which this research is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research on Humans at the following address:

The Secretary, The Standing Committee on Ethics in Research on Humans, Monash University, Wellington Road, Clayton, Victoria 3168. Telephone (03) 9905 2052 Fax (03) 9905 1420.

Thank you.

Janet R. Gardner RN, Dip.Nsg, B.App.Sci. (Ed). M.H.Sc., Telephone: (03) 9439 8952
Prof. John Murtagh, Project Supervisor Telephone: (03) 9579 3188

APPENDIX: 11

Monash University

**INFORMED CONSENT
(PATIENTS)**

Project Title: Chronic non-malignant back pain (CNMBP) treated with long term opioid therapy (LTOT): Reframing long term care.

I agree to take part in the above Monash University research project. I have had the project explained to me, and I have read and understood the Explanatory Statement, which I have retained for my records.

I understand that participation in this project will involve completing a short questionnaire relating to my chronic pain and level of functioning and my attendance and participation in one or two group discussions which will last for approximately 1-2 hours. I also understand that the group discussions will be audiotaped.

I understand that my participation is voluntary, that I can refuse to answer any questions and that I can withdraw from the study at any time when any pre-existing data will be destroyed.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

NAME (Please print)

SIGNATURE
DATE: _____

WITNESS (Please print)

SIGNATURE:
DATE: _____

Researcher: Janet Gardner, RN, Dip.Nsg, B.App.Sci. (Ed.), M.Hs.

Telephone: 03 9439 8952 **Email:** jgardner@netspace.net.au

APPENDIX: 11

Monash University

**INFORMED CONSENT
(FAMILY MEMBERS)**

Project Title: Chronic non-malignant back pain (CNMBP) treated with long term opioid therapy (LTOT): Reframing long term care.

I agree to take part in the above Monash University research project. I have had the project explained to me, and I have read and understood the Explanatory Statement, which I have retained for my records.

I understand that participation in this project will involve answering some questions in relation to my having a family member who suffers CNMBP that is treated with LTOT and my attendance and participation in one or two group discussions which will last for approximately 1-2 hours. I also understand that the group discussions will be audiotaped.

I understand that my participation is voluntary, that I can refuse to answer any questions and that I can withdraw from the study at any time when any pre-existing data will be destroyed.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

NAME (Please print)

SIGNATURE**DATE:**

WITNESS (Please print)

SIGNATURE:**DATE:**

Researcher: Janet Gardner, RN, Dip.Nsg, B.App.Sci. (Ed.), M.Hs.

Telephone: 03 9439 8952 **Email:** jgardner@netspace.net.au

APPENDIX: 11

Monash University

**INFORMED CONSENT
(NURSES)**

Project Title: Chronic non-malignant back pain (CNMBP) treated with long term opioid therapy (LTOT): Reframing long term care.

I agree to take part in the above Monash University research project. I have had the project explained to me, and I have read and understood the Explanatory Statement, which I have retained for my records.

I understand that participation in this project will involve completing a short questionnaire relating to my nursing experience and discussing my experiences of having cared for CNMBP patients who are being treated with LTOT. That it will require my attendance and participation in one or two group discussions, which will last for approximately 1-2 hours. I also understand that the group discussions will be audiotaped.

I understand that my participation is voluntary, that I can refuse to answer any questions and that I can withdraw from the study at any time when any pre-existing data will be destroyed.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

NAME (Please print)

SIGNATURE**DATE:**

WITNESS (Please print)

SIGNATURE:**DATE:**

Researcher: Janet Gardner, RN, Dip.Nsg, B.App.Sci. (Ed.), M.Hs.

Telephone: 03 9439 8952 **Email:** jgardner@netspace.net.au

APPENDIX: 12**INFORMED CONSENT FORM
(PARTICIPANT OBSERVATION)**

Project Title: Chronic non-malignant back pain (CNMBP) treated with long term opioid therapy (LTOT): Reframing long term care.

I agree to take part in the above Monash University research project. I have had the project explained to me, and I have read and understood the Explanatory Statement, which I have retained for my records.

I understand that the study will involve the researcher, a nurse, spending time in various hospitals. During this time the researcher will observe client/patients and their interactions with health providers and the events that occur around them. The researcher will talk to clients/patients who give their consent about their experiences of suffering CNMBP that is treated with LTOT.

I understand that my participation is voluntary, that I can refuse to answer any questions and that I can withdraw from the study at any time and have destroyed data already gathered.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

NAME (Please print)

**SIGNATURE
DATE:** _____

WITNESS (Please print)

**SIGNATURE:
DATE:** _____

Researcher: Janet Gardner, RN, Dip.Nsg, B.App.Sci. (Ed.), M.Hs.

Telephone: 03 9439 8952 **Email:** jgardner@netspace.net.au

APPENDIX: 13**INFORMED CONSENT FORM
(PARTICIPANT INTERVIEW)**

Project Title: Chronic non-malignant back pain (CNMBP) treated with long term opioid therapy (LTOT): Reframing long term care.

I agree to take part in the above Monash University research project. I have had the project explained to me, and I have read and understood the Explanatory Statement, which I have retained for my records.

I understand that the study will involve the researcher, a nurse, discussing with me my experiences of suffering CNMBP that is treated with LTOT and that this discussion will be tape recorded.

I understand that my participation is voluntary, that I can refuse to answer any questions and that I can withdraw from the study at any time and have destroyed data already gathered.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

NAME (Please print)

SIGNATURE

DATE: _____

WITNESS (Please print)

SIGNATURE:

DATE: _____

Researcher: Janet Gardner, RN, Dip.Nsg, B.App.Sci. (Ed.), M.Hs.

Telephone: 03 9439 8952 **Email:** jgardner@netspace.net.au

APPENDIX: 14**Base Data Questionnaire for Patient Focus Groups Participants.**

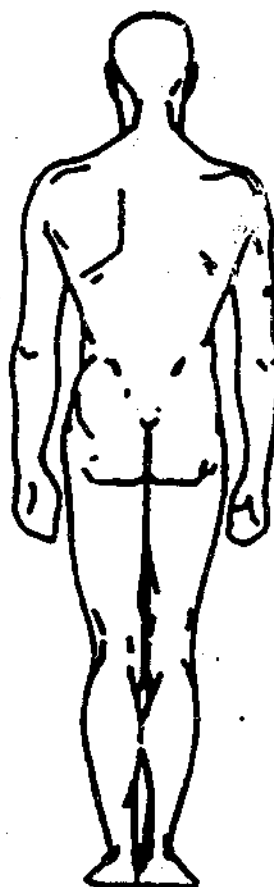
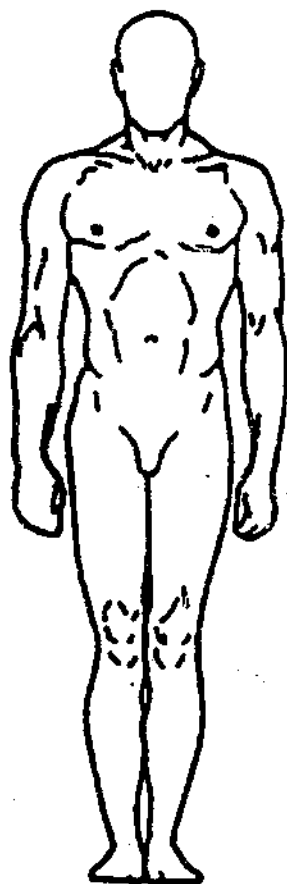
CHRONIC PAIN PROFILE

17. *Where do you experience chronic pain?*

Using the key, please mark on the drawing where you experience chronic pain.

Key: Pins & needles = 00000
Burning = XXXX

Stabbing pain = /////
Deep ache = ZZZZZ



18. *Rate your pain* 0 = *No pain*

10 = *Extremely intense*

1. Right now 0 1 2 3 4 5 6 7 8 9 10

2. At its worst 0 1 2 3 4 5 6 7 8 9 10

3. At its best 0 1 2 3 4 5 6 7 8 9 10

11. What income do you currently receive?
None

Wage ☐
Workcover ☐
TAC ☐
Social Security ☐
Superannuation ☐
Other (please specify) ☐

INJURY/DISEASE PROFILE

12. How long have you suffered from chronic back pain?

Months Years

13. How did you injure your back?

No specific injury (incl.disease) ☐
At work ☐
At home ☐
Road Accident ☐
Playing Sport ☐
Other (Please specify) ☐

14. Please indicate what investigations you have undergone in relation to your back injury?

None ☐
Blood Tests ☐
Plain X-ray ☐
CT Scan ☐
Myelogram ☐
Discogram ☐
M.R.I. ☐
Other (Please Specify) ☐

15. Please indicate what surgical treatment(s) you have undergone in relation to your back injury/disease?

None ☐
Myofasciotomy/Rhizolysis ☐
Laminectomy ☐
Discectomy ☐
Spinal Fusion ☐
Removal of Spinal Fusion Hardware ☐
Other (Please Specify) ☐

16. Indicate what non-surgical treatment(s) you have undergone in relation to your back injury/disease?

None ☐
Physiotherapy ☐
Chiropractic therapy ☐
Nerve blocks ☐
Facet Joint Injections ☐
Radiofrequency treatment ☐
Epidural injections ☐
Heat ☐
Cold ☐
Relaxation ☐
T.E.N.S. ☐
Massage ☐
Meditation ☐
Acupuncture ☐
Biofeedback ☐
Other (Please specify) ☐

21. How long have you been taking narcotic analgesic (eg morphine) on a daily basis?

22. Who prescribes your narcotic analgesia?

<i>General Practitioner</i>	<input type="checkbox"/>
<i>Psychiatrist</i>	<input type="checkbox"/>
<i>Anaesthetist</i>	<input type="checkbox"/>
<i>Surgeon</i>	<input type="checkbox"/>
<i>Pain Clinic</i>	<input type="checkbox"/>
<i>Other (Please specify)</i>	<input type="checkbox"/>

23. List all the medications you are currently taking to help control your pain

[illegible]

PAIN DISABILITY INDEX

The rating scales below are designed to measure the degree to which several aspects of your life are presently disrupted by chronic pain i.e. how much your pain is preventing you from doing what you would normally do, or from doing it as well as you normally would. Respond to each category by indicating the overall impact of pain in your life, not just when the pain is worst. For each of the 7 categories of life activity listed, please circle the number on the scale which describes the level of disability you typically experience. A score of 0 means no disability at all, and a score of 10 signifies that all of the activities in which you would normally be involved have been totally disrupted or prevented by your pain.

24. *Family/home responsibilities*

This category refers to activities related to the home and family. It includes chores or duties performed around the house and errands or favors for other family members (e.g. driving children to school).

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

25. *Recreation*

This category includes hobbies, sports, and other similar leisure time activities

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

26. *Social Activities*

This category refers to activities which involve participation with friends and acquaintances other than family members. It includes parties, theatre, concerts, dining out, and other social functions.

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

27. *Occupation*

This category refers to activities that are a part of or directly related to one's job. This includes non-paying jobs as well, such as that of a housewife or volunteer worker.

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

28. *Sexual behaviour*

This category refers to the frequency and quality of one's sex life

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

29. *Self Care*

This category includes activities which involve personal maintenance and independent daily living (e.g. taking a shower, driving, getting dressed)

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

30. *Life-support activity*

This category refers to basic life-supporting behaviours such as eating, sleeping and breathing

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

APPENDIX: 15**Base Data for Family Members' Focus Group Participants**

BASE DATA FOR FAMILY MEMBERS FOCUS GROUP

Section A. Personal Profile

Please complete the questionnaire by writing in or checking the box(es) as appropriate.

For example : Area Code and .

If you believe that any question does not apply to you, rather than leaving it out, please circle the number of the question which does not apply to you.

All information will remain anonymous and confidential. Thankyou for your assistance.

1. Please record the area code in which you reside.

2. Year of Birth

3. Sex Male ☐

Female ☐

4. Relationship to Patient:

Spouse ☐

Partner ☐

Mother ☐

Father ☐

Sister ☐

Brother ☐

Daughter ☐

Son ☐

Friend ☐

Other (Please Specify) ☐

5. Do you currently live with the patient?

Yes ☐

No ☐

6. How long has your family member suffered from chronic back pain?

Months

Years

7. To what extent are you involved in the care of the patient?

Continually ☐

Occasionally ☐

Rarely ☐

8. What level of education have you achieved?

Year 10 or less ☐

Year 12 ☐

TAFE or College ☐

University ☐

9. What is your current work status?

Student ☐

Unemployed ☐

Employed ☐

Full time ☐

Part time ☐

Voluntary Worker ☐

Retired ☐

Other (Please Specify) ☐

Section B.

This part of the questionnaire relates to your family member's pain and how it affects your life. Under each question is a scale to mark your answer. Read each question carefully and then circle a number on the scale under that question to indicate how that specific question applies to you.

1. On average, how severe was your family member's pain during the past week?
 0 1 2 3 4 5 6
 Not at all severe Extremely severe
2. In general, how does your family member's pain interfere with his/her day to day activities?
 0 1 2 3 4 5 6
 No interference Extreme interference
3. Since the time your family member's pain began, how much has the pain changed his/her ability to work?
 0 1 2 3 4 5 6
 No change Extreme change
4. How much has your family member's pain changed the amount of satisfaction or enjoyment you get from taking part in social and recreational activities?
 0 1 2 3 4 5 6
 No change Extreme change
5. How much has your family member's pain changed your friendship with people other than your family?
 0 1 2 3 4 5 6
 No change Extreme change
6. Rate your overall mood your the past week.
 0 1 2 3 4 5 6
 Extremely low Extremely high
7. How much has your family member's pain interfered with his/her ability to get enough sleep?
 0 1 2 3 4 5 6
 No interference low Extreme interference
8. During the past week how satisfied have you felt with your life in general?
 0 1 2 3 4 5 6
 Not at all satisfied Extremely satisfied
9. How much has your family member's pain changed his/her ability to take part in recreational and other social activities?
 0 1 2 3 4 5 6
 No change Extreme
10. How much does your family member limit his/her activities in order to keep the pain from getting worse?
 0 1 2 3 4 5 6
 Not at all Very much
11. How much has your family member's pain changed the amount of satisfaction or enjoyment you get from family-related activities?
 0 1 2 3 4 5 6
 No change Extreme change
12. How worried are you about your family member's pain problem?
 0 1 2 3 4 5 6
 Not at all worried Extremely worried
13. During the past week how much control do you feel that you have had over your life?
 0 1 2 3 4 5 6
 No control Extreme control
14. On an average day, how much does your family member's pain vary (increase or decrease)?
 0 1 2 3 4 5 6
 Remains the same Changes a lot
15. How much suffering does your family member experience because of their pain?
 0 1 2 3 4 5 6
 No suffering Extreme suffering
16. How often are you able to do something that helps to reduce your family member's pain?
 0 1 2 3 4 5 6
 Never Very Often
17. How much has your family member's pain changed your relationship with them?
 0 1 2 3 4 5 6
 No change Extreme change
18. How much has your family member's pain changed the amount of satisfaction or enjoyment you get from work? (.....Check here, if you are not presently working for reasons other than your family member's pain problem).
 0 1 2 3 4 5 6
 No change Extreme change

19. How attentive are you to your family member's pain?

0 1 2 3 4 5 6
Not at all attentive Extremely attentive

20. During the past week how much do you feel that you have been able to deal with your problems?

0 1 2 3 4 5 6
Not at all Extremely well

21. How much has your family member's pain changed his/her ability to do household chores?

0 1 2 3 4 5 6
No change Extreme change

22. During the past week, how successful was your family member in coping with stressful situations in his/her life?

0 1 2 3 4 5 6
Not at all successful Extremely successful

23. How much has your family member's pain interfered with his/her ability to plan activities?

0 1 2 3 4 5 6
No change Extreme change

24. During the past week how irritable have you been?

0 1 2 3 4 5 6
Not at all irritable Extremely irritable

25. How much has your family member's pain affected his/her friendships with people other than your family?

0 1 2 3 4 5 6
No change Extreme change

26. During the past week how tense or anxious have you been?

0 1 2 3 4 5 6
Not at all tense or anxious Extremely tense and anxious

27. How dependent on you is your family member due to his/her pain problem?

0 1 2 3 4 5 6
Not at all dependent Extremely dependent

28. How much has your family member's pain changed your ability to work?

(...Check here, if you are not presently working for reasons other than your family member's pain).

0 1 2 3 4 5 6
No change Extreme change

29. How much has your family member's pain changed the amount of household chores you do?

0 1 2 3 4 5 6
No change Extreme change

30. How much has your family member's pain changed your ability to participate in recreational and social activities?

0 1 2 3 4 5 6
No change Extreme change

31. How satisfying is your relationship with your family member?

0 1 2 3 4 5 6
Not at all satisfying Extremely satisfying

32. How angry do you get with your family member about his/her pain?

0 1 2 3 4 5 6
Not at all angry Extremely angry

33. How much has your family member's pain changed the amount of satisfaction or enjoyment he/she gets from family-related activities?

0 1 2 3 4 5 6
No change Extreme change

34. How frustrated do you get with your family member about his/her pain problem?

0 1 2 3 4 5 6
Not at all frustrated Extremely frustrated

35. How much has your family member's pain changed the amount of satisfaction he/she gets from work?

(...Check here, if your family member is not presently working for reasons other than his/her pain)

0 1 2 3 4 5 6
No change Extreme change

36. How much has your family member's pain changed the amount of satisfaction or enjoyment he/she gets from participation in social and recreational activities?

0 1 2 3 4 5 6
No change Extreme change

Section C.

This part of the questionnaire relates to how you respond when your family member is in pain. On the scale listed below each question, circle the number to indicate how often you respond in that particular way when your family member is in pain. Please answer all of the 14 questions.

1. Ignore him/her

0 1 2 3 4 5 6
Never Very Often

2. Ask what I can do to help

0 1 2 3 4 5 6
Never Very Often

3. Read to him/her

0 1 2 3 4 5 6
Never Very Often

4. Get irritated with him/her

0 1 2 3 4 5 6
Never Very Often

5. Take over his/her jobs or duties

0 1 2 3 4 5 6
Never Very Often

6. Talk to him/her about something else to take his/her mind off the pain.

0 1 2 3 4 5 6
Never Very Often

7. Get frustrated with him/her.

0 1 2 3 4 5 6
Never Very Often

8. Try to get him/her to rest.

0 1 2 3 4 5 6
Never Very Often

9. Try to involve him/her in some activity

0 1 2 3 4 5 6
Never Very Often

10. Get angry with him/her.

0 1 2 3 4 5 6
Never Very Often

11. Get him/her pain medication.

0 1 2 3 4 5 6
Never Very Often

12. Encourage him/her to work on a hobby

0 1 2 3 4 5 6
Never Very Often

13. Get him/her something to eat or drink

0 1 2 3 4 5 6
Never Very Often

14. Turn on the TV to take his/her mind off the pain

0 1 2 3 4 5 6
Never Very Often

APPENDIX: 16**Base data for Nurses' Focus Group Participants**

BASE DATA FOR NURSE FOCUS GROUP

Please complete the questionnaire by writing in or checking the appropriate box(es)
All information will remain anonymous and confidential. Thank you for your assistance.

PERSONAL PROFILE

1. Year of Birth

2. Sex

Male ☐

Female ☐

PROFESSIONAL PROFILE

4. What year did you first register as a nurse?

3. What nursing qualification(s) do you hold?

General Certificate ☐

Midwifery Certificate ☐

Psychiatric Nursing Certificate ☐

Diploma ☐

Degree ☐

Postgraduate Diploma ☐

Masters Degree ☐

PhD ☐

(Please specify) ☐

5. Have you received any inservice education on chronic pain management?

Yes ☐

No ☐

6. Have you undertaken a formal post registration pain management course?

Yes ☐

No ☐

6. Where do you predominantly practice?

Private sector ☐

Public sector ☐

7. How often do you work with chronic non malignant back pain sufferers?

daily ☐

weekly ☐

occasionally ☐

rarely ☐

8. How long have you worked with chronic non malignant back pain sufferers?

Months

Years

APPENDIX: 17

CHRONIC BACK PAIN TREATED WITH LONG TERM NARCOTIC THERAPY: AN INTERIM REPORT OF PATIENT EXPERIENCES

Participant Personal Profiles

The patients' ranged from 34-57 years, mean age being 41. The majority (71.5%) of patients were married, well educated and were no longer employed, with 70% receiving compensatory payments for back injuries suffered in the workplace.

Pain Profiles

Participants had suffered CNMBP for periods ranging from 5-20 years (mean 9.3 years), and all reported lengthy medical and surgical biographies. All pain profiles revealed that their CNMBP was a multi-sensory experience involving pins and needles, stabbing pain, burning sensations and deep ache. Whilst all reported that their pain was constant, its' level of intensity varied. The lowest levels of pain experienced using a 0-10 scale (0=no pain, 10 worst pain you can imagine) ranged from 1-7 (mean 3.72) and the highest levels ranged 5-10 (mean 9.09). When independently assessed by three clinicians (ie. pain specialist, general practitioner and clinical nurse specialist), the majority of pain drawings were considered indicative of their pain being probably organic in origin. The majority of participants had a moderately high Pain Disability Index score (mean 49/70); all reported being most disabled in relation to occupation, sexual behaviour, and social and recreational activities.

Opioid Profile

CNMBP participants had been prescribed opioids for periods ranging from .5 – 8 year, (mean 3.5 years). Pethidine was the most commonly prescribed opioid, with over half of the patients taking more than one opioid on a daily basis. The most frequent modes of administration were oral (64%), intra-muscular injections (45%) and intra-theal (36%). Whilst the majority of patients were initially commenced on oral opioids, for a significant number (28%) intra-theal opioids, delivered by a DAS pump, was their first opioid pain management regime.

The LTO/CNMBP Journey: Preliminary Findings

Access to Opioids

The majority of patients felt that the decision to commence LTO therapy was not consciously planned, or an informed decision on their behalf. Rather it was generally prescribed during a crisis or "black period" and that it was something they "slipped into". These "black periods", as described by one male patient, represented a time when "there is nothing in your life except pain". Unfortunately, several participants felt abandoned by their treating specialist during this distressing period, having been put in the "too hard basket". The prevailing view

among both male and female patients was that the despair experienced at this time was also related to their CNMBP having profoundly altered their sense of self. For example:

Female Patient 1 "it (CNMBP) changes not only your personality but your whole person ...I just want me back."

Female Patient 3 "it (CNMBP) basically destroys your self esteem"

Male Patient 2 "it (CNMBP) takes your spirit out of you".

Many reported having contemplated suicide during this period, prior to their commencement on opioids. The prevalent view among both patient focus groups was that, with the benefit of hindsight, their pain warranted them being prescribed opioids sooner than they were.

Addiction/Dependence

Although most patients reported that they were now "comfortable" about being on LTO, ie no longer concerned about dependence and addiction, several reported that these were still issues for their spouse and/or family members. Unfortunately, in a few instances concerns about addiction and dependence had led to marital and family conflict and even breakdown. One male patient said he had chosen to conceal from his wife the fact that he was still taking morphine, in order to avoid further conflict and save their relationship.

Legitimacy

Patients and family members were acutely aware and deeply concerned about being stereotyped by health professionals, especially by nurses, as "addicts" and "malingerers". They all had experienced, at some stage in their treatment, prejudicial care from doctors and nurses who lacked understanding regarding their CNMBP and its treatment with LTO. For example:

Male Patient 3 "I'm sorry you'll have to wait for your injection, anyway can't you put up with the pain for another hour?"

Female Patient 6 "I'm sorry, someone's at tea, you will have to wait forty minutes for your injection".

Female Patient 2 "The worst experience was when an older nurse came down and said 'I'll fix her', she slammed two Panadeine Forte down in front of me and said 'you are not having any more Pethidine' even though I was prescribed it by my doctor.

The prevailing view was that this apparent lack of understanding by nurses, was due, in part, to their CNMBP not being visible and that only those persons who knew them well were able to identify their unique "cues" that signaled their extreme pain and suffering. This issue of validating the patient's pain highlights another problem, that of 'concealment'. The majority of patients said that they had learnt to conceal their pain and suffering in an attempt to appear 'normal' to avoid being stigmatized, a factor that appears to work against them when hospitalized. The patients were not completely unsympathetic to the nurses' dilemma of validating patients' pain and their need for opioids for some conceded that there were a few

CNMBP patients who *"conned the system"* which made it difficult for nurses to recognize the *"genuine article"*.

Adverse Effects

All patients reported experiencing side effects from their LTO therapy, ranging from nausea, constipation, diaphoresis, and short-term memory loss to polyarthralgia, amenorrhoea and spontaneous lactation. Several male participants felt strongly that their opioid therapy negatively affected their libido and consequently their self-esteem. For example,

Male Patient 1 "I think the morphine actually affects whether a male can get an erection or not".

Male Patient 2 "The drug mixtures weave their webs with your physiological make-up, and I think the thing about sex too is that it's part of being a man".

Male Patient 4 "The ability to maintain sexual relationships, effects who you are as a person and what other people think of you, and how much you think of your self".

The majority of participants felt they could successfully manage most of the side effects that they experienced and although none believed they were addicted to opioids, they all acknowledged their physical dependence and were fearful of experiencing *"withdrawal"* should their LTO therapy be ceased abruptly.

The prevailing view among all patient participants was that the opioids were just one aspect, albeit a crucial one, of their pain management regime. All patients continued to use a variety of non-medication pain management techniques, the most frequently used being relaxation, heat and meditation.

Criteria for measuring effectiveness of LTO therapy

Patients' measured the effectiveness of their LTO therapy in terms of a significant reduction in pain, measured by their ability to:

- Get a restful sleep at night
- Perform the basic activities of daily living independently
- Engage in a meaningful activity (eg crocheting, ceramics, attending education programs)
- Engage in meaningful relationships (eg social and sexual)
- Reduce the intake of supplementary non-opioid analgesics.

The Future

The majority of patients felt they faced an uncertain future that they feared and many believed that the opioids would probably shorten their lives. However, there were feelings of hope expressed amongst a number of participants with respect to scientists developing new and more potent analgesics and new treatment modalities for severe CNMBP. Most male and female patients agreed that they would continue to require occasional *"time out"* periods in

hospital, even though most found hospitalisation difficult. The prevalent view among male participants was that previous 'time outs' had alienated them from their families, with their families learning to be independent and cope without them. All participants found it difficult returning home after hospitalisation. Some males felt that they had to re-negotiate their role in the family, whilst married women felt they were expected to "perform" immediately they "got in the door".

All participants agreed that the acute care setting was not an appropriate environment for these periods of "time out". There was general agreement amongst all participants that a "rehab" type centre would be preferable where they could access other health care modalities (eg physiotherapy, massage, hydrotherapy), and be more responsible for their own pain management. Several participants strongly felt that these centres needed to be staff by registered nurses trained in chronic pain management and that treatment programs be individualised, acknowledging the patient's specific needs, limitations and LTO therapy. For example,

Female Patient 4 "To be treated like individuals and not just as a group of chronic pain

Patients, be assessed as an individual and not having us stereotyped".

Female Patient 1 "Better understanding and education about that we're not drug addicts and we are normal people that really want to get on with our lives"

Major Issue

There were a number of issues identified by each respective focus group. However, one issue that was generic to all groups, although couched in different terms, was legitimacy that resulted in:

- The negative stereotyping and stigmatisation of CNMBP patients
- Poor to non existent therapeutic relationships between nurse and patient
- Damage to the patient's personhood
- Problems validating the patient's pain and need for opioids
- Poor job satisfaction for nurses caring for CNMBP patients

"The supposition of legitimacy has been fundamental to the sociological analysis of health relating back to the subsequent development of the social constructionist perspective in the sociology of health" (Tarasuk & Eakin 1995 p.205) with the notion of illness and disability as deviance highlights the issue social governance and corroboration in health and illness claims (White, 1991, Freidson 1985, Gerhardt, 1989). Issues of legitimacy are particularly relevant with respect to chronic back pain and its treatment with opioids when claims of malingering and addiction are common especially when the patient is involved in litigation and/or

compensation (Binder 1992, Jayson 1992, Carron, DeGood & Tait 1985, Greenough & Fraser 1989).

The analysis revealed that matters of legitimacy were major issues for most participants. The need to have ones pain believed and legitimized has been previously highlighted by Seers & Friedli 1996, Hitchcock et al 1994 and Reid et al 1991). Many patients reported using the Freedom of Information of Act to access medical reports in order to assemble medical evidence of the authenticity of the person's pain and disability. However, as supported by previous studies (Tarasuk & Eakin 1995, Fagerhaugh & Strauss 1977) medical verification and claim acceptance by a third party (e.g. Workcover, TAC) appeared to hold little relevance with respect to nurses' perceptions and judgments regarding the legitimacy of the patient's pain and their need for opioids. Furthermore, some patients believed the fact that the doctor had prescribed narcotics for the pain automatically legitimized the patients claim of pain and suffering. Whilst it appears that it is common practice for health professionals to question the authenticity of claims of CNMBP (Seers & Friedli 1996, Kleiman 1988, Fagerhaugh & Strauss 1977) from this study it appears that some patients and family members also engage in this practice. Those patients receiving compensation for their CNMBP were particularly vulnerable to having the legitimacy of their pain and need for opioids questioned by patients who were not receiving compensation. As reported by Bendelow & Williams (1995) this process of authentication can be inconclusive resulting in the pain being described as non-organic and functional having "inevitable stigmatizing qualities" (p143). This study supported this finding and revealed that patients whose pain and/or need for opioids was not considered legitimate tended to be further alienated by fellow sufferers and nurses.

Discussion

The preliminary findings from this study lend support to the argument that some CNMBP patients continue to suffer not because their pain is untreatable but because many health care practitioners remain opioidphobic. Practitioners' ignorance, fears, beliefs and biases relating to the role of opioids in CNMBP management not only has the potential to deny CNMBP patients effective pain management but may also increase their risk of suicide. It would appear that CNMBP patients are particularly vulnerable when their pain is overwhelming and doctors and nurses fail to validate their pain and they experience a sense of abandonment. It is also possible that CNMBP patients being treated with LTO who are negatively stereotyped and labelled difficult, manipulating, drug seeking etc., are demonstrating behaviours which reflect greater damage to their 'person' than their physical pain. Given that efficacy is one of the major controversies surrounding the use of LTO in CNMBP it is interesting to note that these patients use the same criteria as many doctors when evaluating the effectiveness of their opioid therapy ie. Pain relief and improved function. The data lends support to findings that responsibly used, opioids can improve pain management for selected patients with CNMBP. However, the fear of addiction remains an issue for some family members and

health care practitioners even though clinical experience shows the risk to be minimal when opioids are used for legitimate pain.

Conclusion

There is a growing body of literature acknowledging the role of long term opioids in the treatment of some CNMBP. However, it appears that many practitioners still have the outdated attitude that opioids are taboo in back pain because they enslave patients to a life of antisocial behaviour. In order for CNMBP patients requiring LTO therapy to be liberated from the social stigma affecting their treatment and lives they need to be empowered by recognising the social, organisational, political, economic and personal constraints which devalue their pain, personhood and care. Through actively engaging consumers in the exploration of these issues through participatory action research it is hoped that they will be empowered to access appropriate pain management, regardless of the cause of their pain and the methods required to relieve it.

7. **Adverse Effects (i.e. side effects of narcotic analgesics)**

Cannot Concur						Strongly Concur
0	1	2	3	4	5	6

8. **Criteria for measuring effectiveness of narcotic analgesics in controlling chronic back pain.**

Cannot Concur						Strongly Concur
0	1	2	3	4	5	6

9. **The Future (i.e. hopes, fears and future pain management).**

Cannot Concur						Strongly Concur
0	1	2	3	4	5	6

10. **Major Issue (i.e. the issue of most concern to the majority of participants)**

Cannot Concur						Strongly Concur
0	1	2	3	4	5	6

11. **Discussion of Findings**

Cannot Concur						Strongly Concur
0	1	2	3	4	5	6

12. **Conclusion**

Cannot Concur						Strongly Concur
0	1	2	3	4	5	6

Other Comments:

PATIENT FOCUS GROUP REPORT COMMENTS

1. Question 5. My family and friends understand I require this drug to keep the pain under control and that it is not an addiction.
2. No comment
3. Excellent study – good level of understanding of a topic that requires deep involvement and participation to even have any concept of what is involved.
4. I felt you have captured the essence of thoughts and feelings expressed. Well done. Currently in hospital, the 'power' games played by some nurses has an enormously adverse effect on chronic pain patient's recovery.
5. Do not really understand questions.
6. Perhaps some distinction could be made between modes addiction/dependence – physical/psychological dependence and addiction. Managing side effects – is successful management simply being able to put up with side effects to gain benefit to opioids (i.e., benefits outweigh side effects). Future only look at treatment rather than hopes, fears, ability to plan, success of treatment, quality of life etc. Major issue to me appeared to be the efficacy of narcotics and achievement of quality of life.
7. A very succinct, yet descriptive preliminary report and very well written. It already feels empowering to see issues that greatly concern me in print. You are certainly telling my story and I thank you for undertaking this study and look forward to the end result which must be published.
8. No comments

APPENDIX: 18

Family Focus Group Discussion Report

Participants' personal profiles

Six family members attended the focus group discussion. Their ages ranged from 30 to 75 years (mean 55 years). Sixty-seven percent were males and 33 percent were females and all were well educated. 3 participants remained in full-time employment, 2 were retired and one received a Carer's Pension to look after her mother full-time. Three were male spouses, two were parents and one was a daughter of a CNMBP sufferer. Sixty-seven percent of them resided with the CNMBP sufferer. Their family member had suffered CNMBP for periods ranging from 5 to 21 years (mean 12 years). Eighty-three percent of participants reported that they were continually involved in the care of the CNMBP sufferer. All reported being extremely worried about their family member's pain.

Impact of CNMBP on their family members and their lives.

The majority of participants felt that CNMBP had an extremely negative impact on their family member's life. The prevailing view was that they experience a relative poor quality of life when, for example, compared to paraplegics who were wheelchair bound. They felt the latter had a better quality of life because they could go to work and be involved in sports etc. There was general agreement among all family members that they had suffered social isolation and even rejection and abandonment.

Family member 1 "The biggest thing we noticed was friends, we hardly see them at all these days, apart from a couple of very close friends.

Family member 3 "Even when you see them its tentative, they don't know what to do or say and get away as quick as they can

Family member 5 "she tended to move away from her friends, she's lost contact with a whole group...complicated by the fact that it was combined with a divorce...he couldn't handle it (CNMBP) so he left".

Family member 1. "I can see that she is in excruciating pain but they can't see it"

Family member 2 "Somebody says your are looking good and I wish they'd shut up"

There was general agreement that each family member displayed unique signs that indicated to their family that they were in extreme pain.

Family member 1 "If you live with it long enough, you know where to look...you can see it in her eyes straight away"

Family member 4 "Her whole face, when she's in a lot of pain her whole face goes grey ...you just look at her colour and you know she's in pain"

The majority of participants reported that they had endured lengthy medical biographies with their family members which although was anxiety producing they had got used to it. Those still working reported that it was sometimes hard to juggle caring for their spouse and working full-time. They reported feeling frustrated but believed they couldn't "go crook" at their family member. One husband said he has resigned himself to the fact that their would come a time when he would have to give up work to look after his wife full-time.

Thoughts on opioids

Whilst the majority of participants had come to terms with respect to their family member's need for opioids they did express a number of concerns. One related to addiction, as they had read from the popular press that people could become addicts after being prescribed narcotics for acute pain. However, there was general consensus that their family members needed the pain relief that opioids could provide now and that they would face any problems if and when they arose.

Family Member 1 "it does worry me...you read of people started on it because of the need, and then carried on because they couldn't do without it"

Family Member 6 "doesn't worry me all that much. It (morphine) has given her some relief and that's all I worry about."

Security was another concern. There was general agreement that one didn't broadcast the fact to friends that their family member is taking opioids and that they tried not to keep too much in stock at home. The parents of a daughter who lived alone were particularly concerned about their daughter's security as she was on injectable opioids and kept a months supply at home.

None had safes to securely store their opioids, and they were stored in a variety of ways including "in a cupboard under junk" and "locked in a cash box". They also reported experiencing embarrassment and apprehension when taking prescriptions for narcotics to the chemists and coming under extra scrutiny even though they were regular customers.

Family member 1 "You've got to worry where you are going to get it and you walk in they look at you like... what are you using this for?"

Family member 4 "They wonder why the hell you're getting needles and syringes"

Family member 2 "When I took the prescription into the chemist which I do all the time, they phoned the doctor to check the prescription before they would dispense it, even though I go there all the time"

Some participants expressed concern about when their family member is hospitalised and their opioid intake increases which often renders them drowsy with poor concentration.

Family member 6 "Over the first few days when you go in they are drowsy. You just can't get used to that"

Family member 1 "My wife usually takes about three days to get on top of the pain and then she's got no memory"

However, regardless of these issues, they believed life was challenging enough without worrying about medications.

Family Member 4 "It's hard enough getting through life day to day to be worrying about medications".

Effectiveness of Opioids

Some family members said they found it difficult to assess the effectiveness of the opioids and that it often came down to balancing out the pain control against the adverse effects of the drugs. Also pain control was very variable.

Family member 2 "It (pain) goes up and down. Better some days than others"

Family member 4 "if they are feeling good and actually want to do something like go shopping for an hour and you take them and when you get back she says "I feel shocking". But she wanted to do it. You've got to have some quality of life."

Balancing activity against 'pay back pain' was a constant struggle for most participants and many felt they had to motivate their family member to engage in some activities.

Family member 1 "they've got to try and do things too, otherwise they just sit at home and do nothing, you've got to try and encourage them too"

Family member 3 "to get her out and get her to do something"

Family member 5 "I'm happy to see her try because I think well otherwise she just lies in bed all the time.... even if I know the next day she's going to be in more pain".

This also posed another dilemma because increased activity results in increased pain and then increased medication. Some expressed frustration and a sense of injustice that their family member had to endure such pain when undertaking activities that other people take for granted. Some expressed a sense of despair that no medication was able to relieve their pain totally, not even opioids.

Family member 6 "What ever medication they're on, it doesn't seem to work, does it?"

However, as alluded to earlier, there was general agreement that their family member exhibited unique cues by which they could assess their level of pain and thus the effectiveness of their opioid therapy.

Pain Management Techniques and Iatrogenic Pain

This led into a general discussion about the various pain management treatments that their family members had tried ranging from various medications to invasive techniques such as nerve blocks and spinal cord stimulators. They all agreed that they all followed a pattern of an initial 'honeymoon' period when their family member achieved good pain control that enabled them to increase their activity and quality of life. However, the 'honeymoon' never lasts and their pain increases and the drugs and techniques lose their effectiveness. There was a sense of frustration, anger and lack of faith in technology and medical profession.

Family member 6 "You get a great feeling of frustration, hey it (pain relief) happened the other day, why can't it happen now?"

Family member 4 "They don't know enough about pumps and stimulators at the moment...they just don't know enough about what they're doing"

Family member 5 "I can't think of any time that she came out of hospital better than when she went in".

Family member 6 "She goes in with severe back pain, and she comes out with back pain and leg pain which she never had before".

Hospital Admissions

Apart from the effect of increased opioids on their family member's functioning, hospitalisations can be stressful and difficult for both themselves and their family members.

Nursing care although improved still left a lot to be desired. There was general consensus that nurses were more understanding in the private hospitals than in the public sector. They had noticed an improvement in care in the private hospitals in which the pain specialist had conducted in-service education on chronic pain and opioids. The general discussion led to the earlier admissions when they were still seeking cures for the back injury. When they would have their hopes raised only to be abandoned when the treatment failed to produce the expected outcome.

Family Member 6 "Hey I've finally found someone who can handle this and then it doesn't work. So it's a big downer again"

Family Member 1 "You lose a lot of faith in the medical profession"

Family Member 4 "I think a lot of us are frustrated with the situation. When they (patient) don't respond how they want them to, they become a burden and then they stop treating you"

There was general agreement that health care practitioners rarely addressed family members' needs and concerns.

Family Member 4 "I don't think they know enough about it (CNMBP) and family members' needs are not considered important"

Role of General Practitioners

For the majority of participants a medical specialist (eg anaesthetist, psychiatrist) initially prescribed opioids for their family member's pain, with general practitioners reluctant to prescribe opioids for non-malignant pain. However, once commenced on opioids by the 'specialist' most participants found that their GP was then willing to participate in their long-term management. Family members considered access to opioids was a matter of "luck". For example:

Family Member 1 "We're very lucky we have a good GP, a really good pain management guy"

Family Member 3 "The biggest problem is finding a good GP to start with, one that's got real understanding and is practical. We've been very lucky"

Family Member 4 "We're fairly lucky our GP looks after all the druggies in the area, so he is handling that sort of thing all the time".

The prevalent view among all participants was that with the benefit of hindsight, the patient's pain warranted them being prescribed opioids sooner than they were.

Concealment

Family members expressed anger and frustration when their family member attempts to conceal their true pain state, especially when doctors and friends ask, "how are you today?"

They expressed understanding of why their family member tries to promote a positive outlook but it often not only denied the patient appropriate treatment but it denied the family member of an opportunity to have their stresses and concerns acknowledged.

Family member 4 "Mum will go in and he would say "How are you today?" and I hate it when she responds "I'm fine thanks".....well why am I here?"

Family member 1 "It changes the perception of the doctor, well she's not that bad when in fact she is really is not coping"

Again they expressed frustration if friends and doctors did not pick up the visible cues that they were in extreme pain.

The future

Most said they lived day to day and tried not to think too far ahead. There was a general acceptance that their family members' pain would deteriorate over time that would make them more dependent. They hoped that their family member could keep fighting and endure the pain for as long as possible. They didn't hold out too much hope for a new treatment that would cure their family member, but perhaps it could be better controlled and thus improve their quality of life. Many believed that the opioids would probably shorten their family member's life.

Family member 1 "You sort of hope. And if a miracle happens a miracle happens and you can all pray for one. You can't build your life around that because miracles don't happen very often".

Family member 2 "I don't think they are going to be able to much down the track. You can only ask them to try and find a regime that manages the pain best to give them some quality of life so they can hang in there as long as they can"

Family member 4 "I think we all tend to live day by day in our family, we don't think long term. You don't know if she's going to be here in five years"

FAMILY MEMBER FOCUS GROUP DISCUSSION REPORT EVALUATION FORM

Your attendance and participation in the research focus group last year was greatly appreciated. Since that time the taped discussions have been transcribed and a synopsis of the analysis is contained in the attached report. In order to further validate the analysis I am seeking participants' response to the key issues outlined in the report. Thus, it would be greatly appreciated if you would take the time to read the report and answer the following questions. Please return the completed form in the stamped, self addressed envelope provided by **30th June 1999**. Thank you for your assistance.

1. What is your gender? Male ☐1 Female ☐2

Please indicate on the following scales your ability to concur with the conclusions drawn
in relation to the various topics and issues.

2. **Participants' personal profiles (i.e. ages, education, occupation etc.)**

Cannot Concur **Strongly Concur**

0	1	2	3	4	5	6
---	---	---	---	---	---	---

3. **Impact of Chronic Non-malignant Back Pain (CNMBP) on your and your family member's lives.**

Cannot Concur					Strongly Concur		
0	1	2	3	4	5	6	

4. **Thoughts on Opioids** (i.e. feelings and concerns about family member taking regular narcotic analgesics e.g. morphine, pethidine)

Cannot Concur Strongly Concur

5. **Effectiveness of Opioids** (i.e. how you measure how well the narcotic analgesics are controlling your family member's pain).

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

6. **Pain Management Techniques & iatrogenic pain (i.e. other pain management procedures your family member has undergone and pain caused by these medical interventions).**

Cannot Concur							Strongly Concur
0	1	2	3	4	5	6	

7. **Hospital Admissions** (i.e. the impact of hospital admission on yourself and the care you and your family received whilst in hospital).

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

8. **Role of General Practitioners** (i.e. the role your general practitioner plays in your family members pain management).

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

9. **Concealment** (i.e. consequences of your family member's attempts to cover up their pain and put on a 'brave face').

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

10. **The Future** (i.e. your hopes and concerns regarding the future with respect to your family members chronic pain).

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

APPENDIX: 19

CHRONIC NON-MALIGNANT BACK PAIN (CNMBP) TREATED WITH LONG TERM OPIOID (LTO) THERAPY: INTERIM REPORT OF NURSES' EXPERIENCES

Two focus groups were conducted, one with three participants and one with six participants. All participants were female with a mean age of 41.22 years. They were generally very experienced nurses, having nursed on average 19.6 years. Only 22.2% of participants had any post registration qualifications. Eighty-eight percent had attended in-service education on chronic pain. They all worked in the private sector, with 77.7% having daily contact with chronic pain patients, working with chronic pain patients on average for 5.6 years.

Perceptions of CNMBP

The general feeling was that CNMBP represented intractable pain, which was normally preceded by long medical and surgical histories and that its cause was multifactorial, although there was not always an identifiable cause. They believed that the pain changed over time and that it damaged the person mentally, physically and socially. CNMBP was often associated with car accidents and workplace injury and sufferers were at risk of being stigmatized, as CNMBP patients were often also involved in litigation and compensation.

Validating CNMBP

There was general agreement that validating CNMBP was difficult and problematic and relied on a sense of mutual trust which was often absent. Most relied on observing the patient's physical appearance, behavior, mobility and opioid intake combined with self-report using a visual analogue scale. A number reported looking for discrepancies in relation to what the patient says about their pain and how they behave. For example,

Nurse 1 "if you have a patient that is coming in extreme pain, but they are able to put their things away, able to tell you they need an injection, and then demand a television".

Night Duty staff said they relied on day duty assessments in addition to assessing sleep patterns which they found problematic.

Nurse 3 "Chronic pain patients don't try to sleep, they have the TV and lights on all night and even if you suggest they turn them off ...no, its sort of like I've got to stay awake"

Nurse 4 "I think if you see someone asleep you do tend to think that they're not in as much pain, you go into the room and can see the eyes closed and the respiration is low... someone appears to be asleep. Then they say "I've been in pain all night", it's a little hard for me to acquaint.

The prevailing view was that there was no agreed diagnostic criteria for assessing CNMBP and the validity of existing pain tools were questionable in terms of their reliability and cultural sensitivity. Assessing CNMBP was complicated by the nurses' self confessed prejudice towards these patients and general lack of trust relating to self reporting of pain:

Nurse 5 "It's a very difficult area. I do acknowledge that I tend to have prejudices and that sort of comes through with mental attitudes of chronic pain patients. Its very hard to assess".

Nurse 2 "I trust these people (pain patients) less and less. Well not completely distrust them, I'd double-question everything they say e.g. do you really need it? Is this person really telling me the truth? Are you manipulating me? I find it difficult".

There was general agreement that an holistic approach was needed when assessing CNMBP but that organization constraints undermined this approach.

Perceptions of CNMBP Patients

Whilst some nurses perceived CNMBP patients to be courageous the majority saw them as depressed, withdrawn, un-animated and highly likely to have family and/or social problems. There was also consensus that these patients were often manipulative as a result of being desperate. In terms of nursing care they considered these patients low dependency physically, but high dependency psychologically. They believed them to be subject to mood swings as a direct result of their medications. CNMBP patients were also perceived to be institutionalized, egocentric and defensive.

Nurse 1 " It's the constant battle for them to think of other people other than themselves, I'd say a good percentage don't think of other people "

Nurse 2 "It's self-centredness which is so characteristic of depression that you can't see beyond what your own problems and don't see any future".

There was general consensus that they were addicted to other substances such as nicotine. When nurses were asked if they thought getting to know the 'person' who is the CNMBP patient would help them better interpret their behavior and understand their pain and suffering, their responses implied that these were undesirable people to know. For example:

Nurse 2 "you wouldn't want to know these people"

Nurse 9 " It's almost impossible to instigate a conversation with these patients because you've developed self-defense mechanisms".

Narcotics and CNMBP

There was general agreement that there was a role for narcotics in the management of some CNMBP. However, the majority of nurses were more comfortable with narcotics being administered orally or through implanted drug pumps rather than IM injections. In addition, they believed it should be supplemented with other non-opioid pain management techniques

that they often perceived CNMBP patients were reluctant to try. The prevailing view was that patients admitted with an acute exacerbation of their pain should only be prescribed IM opioids for a maximum period of 2 days. This was in part due to the basic underlying belief that many 'acute exacerbation's' were psychological rather than physiological in origin.

Nurse 1 "generally a lot of the time these acute episodes are happening because of social problems"

Nurse 1 "If you've got problems with your children or something like that, of course it's going to exacerbate your pain".

It was also felt that some CNMBP patients were the 'wrong' personality type to be prescribed opioids.

Nurse 8 "Those from a lower social economic group, disadvantaged and I would say ignorant, and have a tendency and behaviorally to look to the use of narcotics quite differently from the larger portion of the group".

There was general concern regarding addiction and dependence especially in relation to younger patients. In particular, the general consensus was that a large number of CNMBP patients were psychologically addicted to the way their narcotics were administered e.g. intra muscular injections.

Nurse 3 "There's a psychological dependence, sometimes more so than a physical dependence. I think it's a very fine line and there has to be some form of addiction with it".

Nurse 2 "They got to have it (narcotic injection). It's got to be a psychological dependence. It's there i ant it, don't question me. You've no sooner left the room and they're jumping out of bed to go off and have a coffee and cigarette".

There was also general concern regarding the issues of tolerance and withdrawal and whether narcotics would shorten the patient's life expectancy.

Evaluating the Effectiveness of Narcotics

Similar issues that were raised regarding validating the patient's pain emerged when discussing how they evaluated the effectiveness of the narcotics they administered. They tended to rely on the patient's physical appearance and functioning. However, it was highly problematic because of issues such as lack of trust and lack of knowledge of the person who is the patient.

Nursing practice and CNMBP Management

There was agreement that nursing CNMBP patients was complex, frustrating and often unrewarding. The general consensus was that CNMBP needed a multidisciplinary approach, which was poorly implemented in their facilities. They generally felt powerless and not an equal member of the team. The majority of nurses believed that under the present system they suffered 'professional impotence' with regard to CNMBP management because in the

private sector the doctor was deemed the 'client' who needs and wishes took priority and inter-professional communication was generally poor. Further discussion revealed that what they most desired were patient contracts and protocols that gave them greater control over the patient's management. It was strongly felt that an acute care facility that fostered passivity and dependence was not the ideal environment for the treatment of CNMBP patients. There was general consensus that they should be treated in a rehabilitation environment where they could be more responsible for their own care and where they would not assume the sick role and receive physical and diversional therapy. In the main, nurses felt that it was not their responsibility to assist patients to manage such side effects of opioids as constipation. They believed the patients were responsible at home for managing their bowels, and that regardless of whether their intake of opioids increased in hospital thus exacerbating the problem, they should still take full responsibility for managing the problem. They believed that nursing had an important role to play in terms of psychological support, education of patients and general practitioners, and coordinating care. Participants were ambiguous about working on a designated Pain Unit, as they felt it would be too psychologically demanding and they would be prone to burn out.

NURSES' FOCUS GROUP DISCUSSION REPORT EVALUATION FORM

Your attendance and participation in the research focus group last year was greatly appreciated. Since that time the taped discussions have been transcribed and a synopsis of the analysis is contained in the attached report. In order to further validate the analysis I am seeking participants' response to the key issues outlined in the report. Thus, it would be greatly appreciated if you would take the time to read the report and answer the following questions. Please return the completed form in the stamped, self addressed envelope provided by 30TH AUGUST 1999. Thank you for your assistance.

1. What is your gender? Male ☐1 Female ☐2

Please indicate on the following scales your ability to concur with the conclusions drawn in relation to the various topics and issues.

2. Participants' personal profiles (i.e. ages, nursing experience etc.)

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

3. Perceptions of Chronic Non-Malignant Back Pain (CNMBP)

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

4. Validating a patient's CNMBP

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

5. Perceptions of CNMBP patients as people

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

6. The role of narcotics in CNMBP Management

Cannot Concur Strongly Concur
0 1 2 3 4 5 6

7. **Evaluating the Effectiveness of Narcotics in the Management of CNMBP**

Cannot Concur

0

1

2

3

4

Strongly Concur

5

6

8. **Nursing Practice and CNMBP Management**

Cannot Concur

0

1

2

3

4

Strongly Concur

5

6

Comments:

APPENDIX: 20**PATIENT FOCUS GROUP DISCUSSION SCHEDULE****Opening Question**

Tell me what was the original cause of your back pain, how long have you had chronic pain and what type of narcotic analgesic regime are you currently on (e.g. oral, injections, and pump)?

Introductory Question:

In what ways has chronic back pain impacted on your life?

Transition Question

How do you rate your quality of life, and what criteria do you use to measure it?

Key Questions

Tell me how do you feel about being on long term narcotic therapy?

On what basis did you decide to use narcotics analgesics to control your pain?

What criteria do you use to measure your narcotic analgesic's effectiveness?

What have been your experiences as patients requiring narcotic analgesia?

How satisfied are you with the nursing care you currently receive?

What strategies do you use to assist you in achieving and maintaining control of your pain?

What do you consider to be your long-term health care needs in relation to your chronic back pain?

What do you hope for in the future in relation to your chronic back pain?

Ending Questions:**a) All Things Considered Question**

Of all the issues and needs that were discussed, which were the most important to you?

b) Summary Question

Is this an adequate summary?

c) Final Question

Have we missed anything?

APPENDIX: 21**FAMILY MEMBER FOCUS GROUP SCHEDULE****Opening Question**

Which member of your family has chronic back pain, how long have they had it and what types of narcotic analgesic regime are they currently on (e.g. oral, injections, and pump)?

Introductory Question:

What impact has your family member's chronic back pain had on your life?

Transition Question

How do you rate your quality of life, and what criteria do you use to measure it?

Key Questions

How do you feel about your family member being on long term narcotic therapy?

How effective is the narcotic analgesic in controlling your family member's pain and what criteria do you use to measure its' effectiveness?

Tell me your experiences with the health care system in relation to your family member's need for narcotic analgesics?

What needs do you have in relation to living with a chronic back pain sufferer, which are not currently being addressed by the health care system?

What do you hope for in the future in relation to your family member's chronic back pain?

Ending Questions:**a) All Things Considered Question**

Of all the issues and needs that were discussed, which were the most important to you?

b) Summary Question

Is this an adequate summary?

c) Final Question

Have we missed anything?

APPENDIX : 22

NURSES FOCUS GROUP SCHEDULE

Opening Question

Please tell us your name, which hospital you work for and how long have you been nursing chronic pain patients.

Introductory Question:

Tell me what does the diagnosis of chronic non-malignant back pain mean to you?

Transition Question

What criteria do you use to measure chronic pain?

How would you describe the patients in your Units who suffer from chronic non-malignant back pain?

Key Questions

How do you feel about the use of LTO in the treatment of CNMBP?

What criteria do you use to measure the effectiveness of the narcotic analgesic's you administer?

What do you consider to be the major nursing needs of patients with CNMBP being treated with LTO?

What do you believe nursing has to offer CNMBP patients and their families?

Ending Questions:

a) Summary Question

Is this an adequate summary?

b) All Things Considered Question

Of all the issues and needs that were discussed, which were the most important to you?

c) Final Question

Have we missed anything?

APPENDIX: 23

CLIENT OBSERVATIONAL SCHEDULE

This guide serves only as an outline at the beginning of the study to provide some direction to early participant observation.

Listening and observing the situation.

To identify events, activities and interactional (context and conditions) factors between clients and others that contribute to the clients maintaining control over their pain.

To identify specific contexts and conditions under which clients obtain and maintain control over their pain.

To establish the circumstances under which, nurses do not validate the clients' pain and treatment.

To identify specific contexts and conditions under which clients respond when nurses do not validate their pain and treatment.

To establish the circumstances under which clients attempt to manage their pain that is reinforced by nurses.

APPENDIX: 24**Patient Survey Questionnaire**

Comments:

CHRONIC BACK PAIN TREATED WITH LONG TERM NARCOTIC THERAPY

A survey of patients' experiences

HOW TO FILL IN THE QUESTIONNAIRE

The questionnaire has five components:

- A. Personal Profile
- B. Chronic Pain Profile
- C. Disability Profile
- D. Pain Management Profile
- E. Suffering & Chronic Pain

Please complete ALL sections.

If you believe that any question does not apply to you, rather than leaving it out, please circle the number of the question that does not apply to you.

Eg. (A1.)

Most of the questions can be answered by checking the box next to the answer that best applies to you.

Eg Is your chronic pain:

Constant ☒ 1 Intermittent ☐ 2

Some questions need to be answered by circling the number that best applies to you.

Eg. How would you rate your current level of pain?

0 = No pain

10 = Worst pain you
can imagine

0 1 2 3 4 5 6 7 **8** 9 10

Other questions require you to write the appropriate number in the box provided.

Eg. What is your post code?

3 **0** **9** **5**

Blank spaces have been provided next to those questions requiring a written response. If you wish to write further comments, please do so on the blank page at the end of the questionnaire or attach extra pages if you wish.

All information will remain anonymous and confidential.
Thank you for your assistance.

Please return completed questionnaire to:

Janet Gardner
106 Franklin Street, Eltham, Victoria 3095
in the stamped, self addressed envelope provided
by 31st JULY 1999

Comments:

Comments:

Section A. PERSONAL PROFILE

A 1. Please record post code of the area in which you reside.

A 2. What was your age at 1.1.99? years

A 3. What is your gender? Male ☐ ₁
Female ☐ ₂

A 4. What is your current marital status?

Single	<input type="checkbox"/> ₁	Married	<input type="checkbox"/> ₂
Defacto	<input type="checkbox"/> ₃	Separated	<input type="checkbox"/> ₄
Divorced	<input type="checkbox"/> ₅	Widow/er	<input type="checkbox"/> ₆

A 5. With whom do you reside?
(Please tick all boxes that apply to you)

- | | | | |
|------------|----------------------------|--------------------|----------------------------|
| Alone | <input type="checkbox"/> 1 | Spouse/
Partner | <input type="checkbox"/> 2 |
| Child(ren) | <input type="checkbox"/> 3 | Parent(s) | <input type="checkbox"/> 4 |
| Siblings | <input type="checkbox"/> 5 | Other | <input type="checkbox"/> 6 |
- Please Specify*
-

A 6. What is the highest level of education you have completed?

- | | |
|-----------------|----------------------------|
| Year 10 or less | <input type="checkbox"/> 1 |
| Year 12 or less | <input type="checkbox"/> 2 |
| TAFE/College | <input type="checkbox"/> 3 |
| University | <input type="checkbox"/> 4 |

E12. What strategies did you use to manage the increased pain the last time you engaged in an activity that knowingly exacerbated your pain?
(Please tick all boxes that apply to you)

- | | |
|--|----------------------------|
| Suffered in silence | <input type="checkbox"/> 1 |
| Bed Rest | <input type="checkbox"/> 2 |
| Increased non-narcotic pain medication dose and/or frequency of administration | <input type="checkbox"/> 3 |
| Increased narcotic analgesic dose and/or frequency of administration | <input type="checkbox"/> 4 |
| Sought medical help | <input type="checkbox"/> 5 |
| Admission to hospital for pain management | <input type="checkbox"/> 6 |
| Other <i>Please specify</i> | <input type="checkbox"/> 7 |

E13. How would you rate your current quality of life?

- | | | | | | | |
|---------------------------|--------------|---|---|---|---------------------------|---|
| Totally
Unsatisfactory | Satisfactory | | | | Extremely
Satisfactory | |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

E10. Do you ever engage in activities that you know will increase your pain?

No ☐1 *Please go to question E13*

Yes ☐2 *Please go to question E11*

E11. Why do you engage in activities that knowingly increase your pain? (Please tick all boxes that apply to you)

To appear 'normal' ☐1

To avoid being negatively stereotyped as a malingerer ☐2

For personal fulfilment ☐3

To please others ☐4

Other *Please specify*..... ☐5

A 7. What qualifications do you hold?

None ☐1

Trade ☐2

Certificate/
Diploma ☐3

Tertiary
Degree ☐4

Other ☐5
Please Specify
.....

A 8. Are you currently in paid employment?

No ☐1 *Go to question A9*

Yes ☐2 *Go to question A10*

A 9. How long have you been unable to work because of your chronic back pain?

Years _____ Months _____

A 10. Do you work:

Full-time ☐₁ Part-time ☐₂
Casual ☐₃

A11. What is your current source of income?
(Please tick all boxes that apply to you)

None ☐₁ Wage ☐₂
Workcover ☐₃ Transport Accident ☐₄
Commission
Social Security ☐₅ Superannuation ☐₆
Other ☐₇ Please Specify.....

E 9. Which of the following factors do you believe contributes to people questioning the legitimacy of chronic back pain and/or need for narcotic analgesics? (Please tick all boxes that apply to you)

Absence of visible evidence of pain ☐₁
Involvement in litigation and/or Compensation ☐₂
Social Status ☐₃
Ethnicity ☐₄
Lack of knowledge regarding chronic pain and narcotics ☐₅
All of the above ☐₆
None of the above ☐₇
Other Please Specify..... ☐₈

E 8. What strategies do you use to overcome the feelings caused by having your pain and/or need for narcotics questioned? (Please tick all boxes that apply to you)

Try to conceal pain/disability ☐1

Challenge the person(s) who are questioning the legitimacy of your pain and/or needs for narcotics ☐2

Find another doctor ☐3

Avoid contact with other chronic pain patients who take narcotics to relieve their pain ☐4

Seek professional counselling ☐5

Attend a support group for chronic pain sufferers ☐6

Ignore such instances ☐7

Other Please specify..... ☐8

A12. The following bipolar adjectives are designed to seek your evaluation of yourself as a person. Please examine each set carefully and circle the response on the scale that best reflects your view of yourself.

Weak	0	1	2	3	4	5	6	Strong
Unsure	0	1	2	3	4	5	6	Confident
Negative	0	1	2	3	4	5	6	Positive
Private	0	1	2	3	4	5	6	Outgoing
Sensitive	0	1	2	3	4	5	6	Hard
Unimportant	0	1	2	3	4	5	6	Important
Unsuccessful	0	1	2	3	4	5	6	Successful

A13. Has the way you think about yourself as a person changed since suffering chronic back pain?

No ☐1 Go to question 15

Yes ☐2 Go to question 14

A14. How has chronic back pain changed the way you think about yourself as a person?

A15. What effect has your chronic back pain had on:
(Circle the appropriate number)

(a) Your perception of yourself as a sexual being?

Extremely Negative			No Effect			Extremely Positive
0	1	2	3	4	5	6

(b) Your libido?

Extremely Negative			No Effect			Extremely Positive
0	1	2	3	4	5	6

E 6. When your pain and/or need for narcotic analgesics has been questioned has it:

a) Increased your physical pain?

No ☐₁ Yes ☐₂

b) Increased your emotional suffering?

No ☐₁ Yes ☐₂

c) Provoked thoughts of suicide?

No ☐₁ Yes ☐₂

E 7. Have you at any time since suffering chronic back pain seriously contemplated suicide?

No ☐₁ Yes ☐₂

E 4. How have you felt when the legitimacy of your pain or need for narcotic analgesics has been questioned? *(Please tick all boxes that apply to you)*

- | | | | | | |
|-----------|--------------------------|---|---------------------|--------------------------|---|
| Nothing | <input type="checkbox"/> | 1 | Frustrated | <input type="checkbox"/> | 2 |
| Angry | <input type="checkbox"/> | 3 | Intimidated | <input type="checkbox"/> | 4 |
| Resentful | <input type="checkbox"/> | 5 | Shameful | <input type="checkbox"/> | 6 |
| Guilty | <input type="checkbox"/> | 7 | Abandoned | <input type="checkbox"/> | 8 |
| Other | <input type="checkbox"/> | 9 | Please specify..... | | |

E 5. What effect does this questioning of legitimacy (genuineness) have on how you feel about yourself as a person?

- | No Effect | | | | | Extremely Negative Effect | |
|-----------|---|---|---|---|---------------------------|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

A16. How would you describe your sexual relationship(s) before the onset of your chronic back pain? *(Circle the appropriate number)*

- | Unsatisfactory | | | Satisfactory | | Highly Satisfactory | |
|----------------|---|---|--------------|---|---------------------|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

A17. How would you describe your current sexual Relationship(s)? *(Circle the appropriate number)*

- | Unsatisfactory | | | Satisfactory | | Highly Satisfactory | |
|----------------|---|---|--------------|---|---------------------|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

A18. What effect do the following have on your current sexual relationship(s)? *(Circle the appropriate number)*

- (a) Chronic back pain?**
- | Extremely Negative | | | No Effect | | Extremely Positive | |
|--------------------|---|---|-----------|---|--------------------|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |
- (b) Narcotic analgesics?**
- | Extremely Negative | | | No Effect | | Extremely Positive | |
|--------------------|---|---|-----------|---|--------------------|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

A18. Continued.

(c) Other pain medications?

Extremely Negative					No Effect			Extremely Positive
0	1	2	3	4	5	6		

(d) Fatigue?

Extremely Negative					No Effect			Extremely Positive
0	1	2	3	4	5	6		

(e) Depression?

Extremely Negative					No Effect			Extremely Positive
0	1	2	3	4	5	6		

A19. Has a health care practitioner ever inquired as to whether your chronic pain was having a negative effect on your ability to have a satisfying sexual relationship(s)?

No ☐₁ Yes ☐₂

If you answered **YES** please specify which discipline(s) (eg. Doctor, nurse).....

E 2. Has the legitimacy (genuineness) of any of the following been questioned at any time?

(a) the severity of your chronic pain

No ☐₁ Yes ☐₂

(b) your need for narcotic analgesics to relieve your chronic pain

No ☐₁ Yes ☐₂

*If you answered NO to both (a) and (b) go to question E9
If you answered YES to (a) or (b) Please go to question E3*

E 3. Whom do you perceive as having questioned the legitimacy (genuineness) of the items ticked in question E2? (Please tick all boxes that apply to you)

Family members	<input type="checkbox"/> ₁	Friends	<input type="checkbox"/> ₂
Work Colleagues	<input type="checkbox"/> ₃	General Practitioner	<input type="checkbox"/> ₄
Orthopaedic Surgeon	<input type="checkbox"/> ₅	Neurosurgeon	<input type="checkbox"/> ₆
Psychiatrist	<input type="checkbox"/> ₇	Pain Specialist	<input type="checkbox"/> ₈
Nurses	<input type="checkbox"/> ₉	Other	<input type="checkbox"/> ₁₀
		Please specify	

D32. Were your admissions to hospital for pain management planned ahead of time?

No ☐₁ Yes ☐₂

If you ticked YES, how many were planned admissions?

All ☐₁ Most ☐₂ Few ☐₃

Section E. SUFFERING & CHRONIC BACK PAIN

E 1. Have you ever felt stigmatised because you:

	No	Yes
(a) suffer chronic back pain	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
(b) require narcotic analgesics for for your chronic pain	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

A20. Have you ever been offered professional counselling with respect to any sexual relationship problems you have experienced related to your chronic back pain?

No ☐₁ Yes ☐₂ Not Required ☐₃

A21. Would you be willing to receive counselling regarding any sexual relationships problems related to your chronic back pain?

No ☐₁ Yes ☐₂ Don't Know ☐₃

A22. What is the best thing about your life in general at present?

A23. What is the worst thing about your life at present?

A24. What are your hopes for the future?

Section B. CHRONIC PAIN PROFILE

B 1. How long have you suffered from chronic back pain?

Years

 Months

D30. Which of the following pain management services were offered during your last admission?

- Clinical Nurse Specialist in Chronic Pain ☐ 1
- Physiotherapy ☐ 2
- Hydrotherapy ☐ 3
- Massage ☐ 4
- Occupational Therapy ☐ 5
- Psychological counselling ☐ 6
- Relaxation sessions ☐ 7
- Group therapy sessions ☐ 8
- None of the above ☐ 9
- All of the above ☐ 10

D31. Did you consider the nurses who cared for you during your last admission possessed the necessary knowledge and expertise regarding chronic pain and its treatment with narcotic analgesia?

Never 0 1 2 3 4 Always 5

D27. On average, how long did these admissions last?

- 7 days or less ☐₁
8 – 14 days ☐₂
15 days or more ☐₃

D28. What kind of hospital were you admitted to?

- Public Hospital ☐₁
Private Hospital ☐₂

D29. What kind of unit did you stay in?

- Designated Pain Unit ☐₁
Medical Unit ☐₂
Surgical Unit ☐₃
Orthopaedic Unit ☐₄
Other ☐₅
Please Specify

B 2. How did you first injure your back?

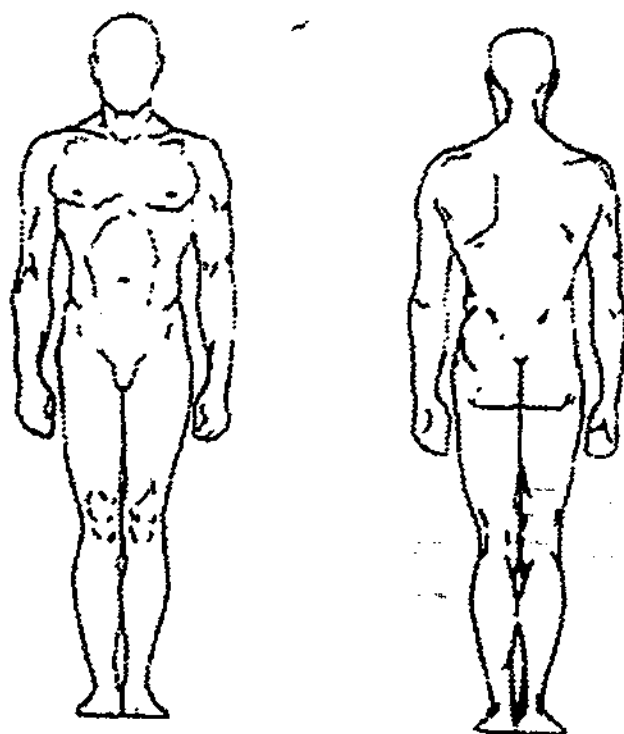
- No specific injury or disease ☐₁
At work ☐₂
At home ☐₃
Road Accident ☐₄
Playing Sport ☐₅
Other ☐₆
Please Specify:

B 3. Please indicate what surgical procedures you have undergone in relation to your back injury/disease
(please tick all boxes that apply to you in the first column & write number of times the procedure was performed in second column))

- | | | | |
|---------------|---------------------------------------|---|--------------------------|
| None | <input type="checkbox"/> ₁ | | |
| Laminectomy | <input type="checkbox"/> ₂ | x | <input type="checkbox"/> |
| Discectomy | <input type="checkbox"/> ₃ | x | <input type="checkbox"/> |
| Spinal Fusion | <input type="checkbox"/> ₄ | x | <input type="checkbox"/> |

B 4. Where do you experience chronic pain?
Using the following key, please mark on the drawing where you experience chronic pain.

Key:
Pins & needles = 00000
Stabbing pain = ///////////////
Burning = XXXX
Deep Ache = ZZZZZ



D.24 Continued....

Prothiadin	<input type="checkbox"/> 11	Tegratol	<input type="checkbox"/> 12
Epilim	<input type="checkbox"/> 13	Rivitol	<input type="checkbox"/> 14
Clonidine	<input type="checkbox"/> 15	Ketamine	<input type="checkbox"/> 16
Tramal	<input type="checkbox"/> 17	Other	<input type="checkbox"/> 18
		Please Specify	
		

D25. Have you been admitted to hospital during the past 12 months for pain management (excluding admissions for pump refills and replacements)?

No ☐1 Please go to question E1

Yes ☐2 Please go to question D26

D26. How many admissions to hospital have you had in the past 12 months for pain management?

One	<input type="checkbox"/> 1	Two	<input type="checkbox"/> 2
Three	<input type="checkbox"/> 3	Four	<input type="checkbox"/> 4
Five	<input type="checkbox"/> 5	Six	<input type="checkbox"/> 6
Seven or more	<input type="checkbox"/> 7		

D22. What effect have these adverse effects of narcotic analgesics had on your quality of life?

No effect							Extreme Negative Effect
0	1	2	3	4	5	6	

D23. Do you believe the positive effects of narcotic analgesics outweigh the adverse effects from taking them?

No ☐1 Yes ☐2 Don't know ☐3

D24. What other medications do you take on a daily basis for your chronic pain? (Please tick all boxes that apply to you)

None	<input type="checkbox"/> 1	Panadiene Forte	<input type="checkbox"/> 2
Mersyndol Forte	<input type="checkbox"/> 3	Naprosyn	<input type="checkbox"/> 4
Voltaren	<input type="checkbox"/> 5	Valium	<input type="checkbox"/> 6
Baclofen	<input type="checkbox"/> 7	Rohypnol	<input type="checkbox"/> 8
Tryptanol	<input type="checkbox"/> 9	Surmontil	<input type="checkbox"/> 10
		Continued.....	

B 5. Please rate your chronic pain:

0=No pain

10=Worst pain you
can imagine

(a) Right Now:

0 1 2 3 4 5 6 7 8 9 10

(b) At its worst:

0 1 2 3 4 5 6 7 8 9 10

(c) At its best:

0 1 2 3 4 5 6 7 8 9 10

B 6. Is your chronic pain:

(a) Constant ☐1

(b) Intermittent ☐2

Section C. DISABILITY PROFILE

The rating scales below are designed to measure the degree to which several aspects of your life are presently disrupted by chronic pain ie. how much your pain is preventing you from doing what you would normally do, or from doing it as well as you normally would. For each of the 7 categories of life activity listed, please circle the number on the scale that describes the level of disability you typically experience. A score of 0 means no disability at all, and a score of 10 signifies that all of the activities in which you would normally be involved have been totally disrupted or prevented by pain.

C 1. Life-support activities

This refers to basic life-supporting behaviours such as eating, sleeping and breathing.

0	1	2	3	4	5	6	7	8	9	10
No										Total
Disability										Disability

D.20 Continued....

- Ability to engage in meaningful relationships (eg family, intimate relationships) ☐ 9
- A reduction in other pain medications ☐ 10
- Other Please Specify..... ☐ 11

D21. Which of the following adverse effects of narcotic analgesics do you currently experience? (Tick all boxes that apply to you)

- | | | | |
|-------------------|-----------------------------|---------------------------|-----------------------------|
| None | <input type="checkbox"/> 1 | Nausea | <input type="checkbox"/> 2 |
| Vomiting | <input type="checkbox"/> 3 | Itching | <input type="checkbox"/> 4 |
| Rash | <input type="checkbox"/> 5 | Constipation | <input type="checkbox"/> 6 |
| Sweating | <input type="checkbox"/> 7 | Drowsiness | <input type="checkbox"/> 8 |
| Agitation | <input type="checkbox"/> 9 | Joint Pain | <input type="checkbox"/> 10 |
| Lactating breasts | <input type="checkbox"/> 11 | Cessation of Menstruation | <input type="checkbox"/> 12 |
| Memory Loss | <input type="checkbox"/> 13 | Other Please Specify | <input type="checkbox"/> 14 |

D20. Please select the 4 (four) most important criteria that you use to measure the effectiveness of your narcotic analgesic(s) in controlling your chronic pain and rank them in order of importance?
(Assign 1 to the one that is the most important, 4 least important)

Ability to perform basic living tasks
(eg showering, dressing).

☐ 1

Ability to walk necessary distances
(eg to front gate, to shower).

☐ 2

Ability to sit for necessary periods.
(eg for meals, craft work)

☐ 3

Ability to stand for necessary periods.
(eg whilst cooking, shopping)

☐ 4

Ability to get adequate sleep

☐ 5

Ability to go to work

☐ 6

Ability to engage in social activities
(eg going out to dinner, to movies)

☐ 7

Ability to engage in a meaningful hobby

☐ 8

Continued over page....

C 2. Self Care

This includes activities that involve personal maintenance and independent daily living (eg showering, driving, and getting dressed).

0 1 2 3 4 5 6 7 8 9 10
 No Disability Total Disability

C 3. Family/home responsibilities

This refers to activities related to the home and family. It includes chores and duties performed around the house and errands or favours for other family members (eg driving children to school).

0 1 2 3 4 5 6 7 8 9 10
 No Disability Total Disability

C 4. Recreation

This includes hobbies, sports and other similar leisure time activities.

0 1 2 3 4 5 6 7 8 9 10
 No Disability Total Disability

C 5. Social Activities

This refers to activities that involve participation with friends and acquaintances other than family members. It includes parties, theatre, dining out, and other social functions

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

C 6. Sexual behaviour

This refers to the frequency and quality of ones sex life.

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

C 7. Occupation

This refers to activities that are a part of or directly related to one's job. This includes non-paying jobs as well, such as that of a housewife or volunteer worker.

0 1 2 3 4 5 6 7 8 9 10
No Disability Total Disability

D17. How do you feel now about being prescribed narcotic analgesics for your chronic pain?

Extremely Uncomfortable Totally Comfortable
0 1 2 3 4 5 6

D18. Has the doctor had to increase the dose of your narcotic analgesic(s) since they were commenced?

No ☐₁ Yes ☐₂

D19. How effective is your current narcotic analgesic regime in controlling your chronic pain?

Extremely Ineffective Extremely Effective
0 1 2 3 4 5 6

D14. Do you believe you were commenced on narcotic analgesics for your chronic pain at the appropriate time?

No ☐1 please go to question D15

Yes ☐2 please go to question D16

Don't know ☐3 please go to question D16

D15. When do you believe you should have been offered narcotic analgesics for your chronic pain?

Sooner ☐1

Later ☐2

Never ☐3

D16. How did you initially feel about being prescribed narcotic analgesics for your chronic pain?

Extremely
Uncomfortable

Totally
Comfortable

0 1 2 3 4 5 6

Section D. PAIN MANAGEMENT PROFILE

D 1. Which of the following non-invasive pain management techniques do you currently use on a regular basis to help control your pain? (Please tick all boxes that apply to you)

None ☐1 Heat ☐2

Cold ☐3 Meditation ☐4

Massage ☐5 Relaxation ☐6

Music ☐7 Reading ☐8

T.E.N.S. ☐9 Guided imagery ☐10

Biofeedback ☐11 Other ☐12

Please Specify.....

D 2. Which of the following invasive pain management procedures have you undergone to help control your pain? (Please tick all boxes that apply to you)

- | | | | | | |
|------------------------|--------------------------|---|-----------------------------|--------------------------|---|
| None | <input type="checkbox"/> | 1 | Chemical Nerve Blocks | <input type="checkbox"/> | 2 |
| Facet Joint Injections | <input type="checkbox"/> | 3 | Radiofrequency Nerve Blocks | <input type="checkbox"/> | 4 |
| Epidural injections | <input type="checkbox"/> | 5 | Spinal Cord Stimulator | <input type="checkbox"/> | 6 |
| Acupuncture | <input type="checkbox"/> | 7 | Implantable Drug Pump | <input type="checkbox"/> | 8 |
| Other | <input type="checkbox"/> | 9 | Please Specify..... | | |

D 3. How long have you been taking narcotic analgesics (eg morphine, pethidine, fentanyl) on a daily basis for your chronic pain?

Years _____ Months _____

D12. Was your commencement on long term narcotic therapy for your chronic back pain planned in advance?

No ☐

Yes ☐

D13. Prior to commencement on long term narcotic therapy for your chronic back pain were you informed of:

a) the various preparations of narcotic analgesics and how they were administered.

No ☐ Yes ☐

b) the adverse effects of narcotic analgesics

No ☐ Yes ☐

c) the long term effects of long term narcotic therapy?

No ☐ Yes ☐

D 9. How would you describe your General Practitioner's response to you taking narcotic analgesics for your chronic pain?
(Circle appropriate number)

Extremely						Totally
Unsupportive						Supportive
0	1	2	3	4	5	6

D10. Is your general practitioner currently actively involved in your pain management?

No ☐1 Go to question D11

Yes ☐2 Go to question D12

D11. Why is your general practitioner not actively involved in your pain management? (Please tick all boxes that apply to you)

Refuses to prescribe narcotics for Chronic pain ☐1

Prefers specialist to coordinate Pain management ☐2

Lacks expertise in chronic pain Management ☐3

Other Please Specify..... ☐4

D 4. Which narcotic analgesic(s) are you currently taking on a daily basis for your chronic pain?
(Please tick all boxes that apply to you)

Morphine ☐1 Hydro Morphine ☐2

Pethidine ☐3 Fentanyl ☐4

Sufentanyl ☐5 Methadone ☐6
(Physeptone)

Prolodone ☐7 Fortral ☐8

Endone ☐9 Other ☐10

Please Specify.....

D 5. How is your narcotic analgesic(s) administered?
(Please tick all boxes that apply to you)

Oral ☐₁ Rectal ☐₂

Nasal Spray ☐₃ Intra-muscular Injection ☐₄

Sub-Cutaneous Infusion ☐₅ Epidural Infusion (via porta-cath) ☐₆

Intrathecal Infusion (via implanted drug pump) ☐₇ Intra-venous Infusion (via Hickmans catheter) ☐₈

Other ☐₉ Please specify.....

D 6. Has the way your regular narcotic analgesic(s) is administered changed since it was first prescribed?

No ☐₁

Yes ☐₂ Please Specify.....

D 7. Who first prescribed you regular daily narcotic analgesics for your chronic pain?

General Practitioner ☐₁

Psychiatrist ☐₂

Surgeon ☐₃

Pain Specialist ☐₄

Other ☐₅

Please Specify.....

D 8. Who currently prescribes your regular daily narcotic analgesic(s)? (Please tick all boxes that apply to you)

General Practitioner ☐₁

Psychiatrist ☐₂

Surgeon ☐₃

Pain Specialist ☐₄

Other ☐₅

Please Specify.....

PATIENT QUESTIONNAIRE EVALUATION FORM COMMENTS

1. No comments
2. I think answering all or any of this type of questioning opens up that big area of having to face everything. I always find it extremely difficult to bring it all up and then have to put it to rest again. But what you are doing is fantastic and I applaud you. I did not mind opening my chest!
3. I'm extremely hopeful something positive will evolve from this study. Although some progress is evident in recent times, I still only have to front up to Casualty/Emergency at a public hospital in need of one pethidine/maxalon injection to meet a doctor with a negative attitude and deny me an injection that can sometimes stop the pain cycle.
4. Possibly too much emphasis on analgesics/opioids and insufficient on other forms of use. Strong concern in my case about caused by tablets to intestines, hence preference for internal administration.
5. Great job Janet.
6. Nil
7. Congratulations. You've produced a very professional, relevant and though provoking questionnaire. The format is terrific - easy to read, follow and handle. Thank you for putting in all this energy and effort to undertake this research project. I believe it's sorely needed and believe the outcome will be a fantastic, relevant and representative report.
8. I hope and pray that your study helps people to understand chronic pain and how it changes ones life so drastically.
9. I do feel vulnerable and protective of my privacy and hope that this information will be treated with respect. I am also excited of the prospects that this long-term research will offer sufferers and carers for the future.

APPENDIX: 25

CLIENT UNSTRUCTURED INTERVIEW SCHEDULE

Interview schedules are a beginning guide to the direction and overall aim of the interview. The participant largely determines the nature of the discourse.

Prior to the commencement of the interview the participant has completed a short questionnaire relating to demographics, pain history, opioid regime etc.

Tell me, what is it like to suffer chronic non-malignant back pain that requires narcotics to treat it?

How has it effected you as a person?

What does losing 'me' mean to you?

What strategies do you use to address some of the losses you have incurred as a result of your CNMBP and treatment with narcotics?

Describe to me, if you can, an instance when you have felt discredited or stigmatized as a result of suffering CNMBP that is treated with narcotics?

Tell me how you have responded to such experiences?

How do you assess the effectiveness of your narcotic therapy?

How, where and when, and to what extent and under what conditions do you achieve and maintain control over your pain?

What strategies do you use to maintain control over your pain?

What factors limit your capacity and or opportunity to achieve and maintain control over your pain, treatment and life?

What are the benefits and limitations to you in having a sense of control over your pain and health?

APPENDIX 26.

MEMO

16.12.97

Re: **Concepts of concealing and validating**

The concepts of **concealing** and **validating** possibly give rise to the phenomenon of **conflict** between patient/nurse, patient/family. The concept of **concealing** appears to be related to the phenomenon of '**striving for normalcy**' which may involve both conscious/unconscious processes of denial with respect to the patient's level of pain and disability. These processes have the potential to produce internal conflict, as well as conflict with persons trying to understand and validate their pain and disability.

Need to explore with patients whether they are aware of these incongruences and potential for conflict.

APPENDIX: 27

Field Note A5. 3.3.2000

Palpable tension between nursing staff and the pain management specialist's patients. Tension most apparent when patients request analgesia. Most narcotics are ordered 3 hourly and participants express frustration at not being able to get their analgesia on time. They are acutely aware that it requires two registered nurses to check the drugs and if they are assigned a State Enrolled Nurse as their primary nurse, she has to find two free Registered Nurses to administer the drug that can take some time. Given that the ward admits medical patients who are high dependency, 'pain patients' are considered low dependency hence the assignment of State Enrolled Nurses as their primary care givers. Some participants have tried to overcome the problem of not getting their medications on time by buzzing the nurse for the analgesia ten minutes before it is due so that it can be organized. However, this is often met with the response "you are not due yet". The manner of the nurse's response to a patient's request for narcotic analgesia could at times reduce the patient to tears. This tended to be early on in their admission when they were visibly exhausted and not coping generally. (? Gender differences) Many are hesitant to press the call button for the nurse because they know they are busy and anxious how the nurse will respond to their request for an injection. Like most health care facilities they are short staff and the ward generally has full occupancy with a number of aged high dependency patients who have many physical needs. One participant stated "it is ironical that the reason you are admitted is to bring your pain under control by having regular analgesia. Yet regardless of ones other needs, like help in the shower, the only nursing care you receive is the administration of medications, and yet not even that can be given on time regardless of the education they receive from Dr. X".

I inquired of one nurse if she enjoyed looking after chronic pain patients and she said she found it extremely frustrating, because she perceived them has not benefiting from their admission. Saying, "they don't seem to be any better when they go home". She also said she felt uncomfortable with chronic pain patients having narcotics, especially injections. When I asked her why, she said that "it is hard to judge their pain, and then there is the problem of addiction, and those who have been having them at home, their muscles get fibroses and it is difficult to find a place to inject. On this ward with all our CVAs we don't have time to spend with them to find out why they are in pain".

APPENDIX: 28

Development of fragility

Overwhelming pain	Losing control
Losing of independence, identity, work, finance	Being Discredited
Living with uncertainty	Low self esteem
Lack of empathy	Suffering
Darkness (in vivo)	Black Periods (in vivo)
Stereotyping (malingerer, addict)	Stigmatising
Uselessness	Hopelessness
Worthlessness	Wanting to die
Not being believed	Feeling depressed
Feeling Guilty	it's in your head
Nurses ignoring	Un-responsive health care practitioners

Development of Discrediting

Malingerer, nothing wrong with you	Think you are bludging
Workcover advertisements	Punished for other people's actions
Doctors & nurses unresponsive	Lack of empathy
Lack of respect	Lack of validation
Use of narcotics	Addiction
Nurses just think you are drug addict	Stigma
Being stereotyped	Demoralizing
Made to feel embarrassed getting Endone scripts filled	It's chronic pain that has got the stigma
Compensation	Litigation
No longer treated as an equal	Psychosomatic

APPENDIX: 29

Development of Not Being Believed (in vivo)

Not being believed	Nurses ignore requests for analgesia
Analgesia a low priority	Behavior blamed on narcotics
Told it is in your head	Told you are bored, get a job and a life
Low pain tolerance	Psychosomatic
Accusations of exaggerating symptoms	Ignored by General Practitioner
You can't have such bad pain if you can go a smoke a cigarette	Mind over matter

Development of 'Losing me' (in vivo code)

Wanting me back	Low self esteem
Feeling useless	Feeling guilty
No longer valuable member of society	Decreased ego
No longer treated as an equal	Declining self worth
Having less confident	Doesn't matter if I am here or not
Feeling inadequate	Withdrawing
Failure	Being boring
I don't like myself	Worthless
Suffering	

Development of undergoing losses/changes

Losing me	Loss of employment
Loss of dignity	Loss of independence
Loss of control	Life changing
Losing hope	Altered body image
Loss of income	Divorce
Loss of utility	Inability to pursue recreational interests
Role reversal	Loss of career

APPENDIX: 30**Development of experiencing compromised health**

Nausea

Vomiting

Constipation

Apnoea

Depression

Amenorrhoea

Polyarthralgia

Diaphoresis

Memory loss

Loss of libido

Gynaecomastia

Diabetes

Atonic bladder

Urinary incontinence

Faecal incontinence

Fatigue

Muscle wasting

Development of vulnerability

Overwhelming Pain

Low self esteem

Stereotyping – addict, malingerer, Workcover

Reliant on technology

Losing control

Living with uncertainty

Feeling rejected

Appearing normal, pain invisible

Not being believed (*in vivo*)

Contemplating suicide

Losing identity, work, finance, relationships

Role erosion

Emotional distress

Depression

Development of passively resigning

Overwhelmed by pain

Hopelessness

Nothing else in life

Feeling useless, helpless and worthless

Giving up

Giving up control

You can't rehabilitate yourself

Spirit taken out of you

Losing self

My life taken away

Disengaging

Being dependent

Low self esteem

Wanting to die

APPENDIX: 31

Development of Authenticating & Repairing

Hoping	Re-assessing
Struggling to maintain independence	Self-advocacy
Want me back	Struggling for a valued life
Accepting	Reconciling
Knowledge of pre & post morbid personhood	Trying to survive
Seeking help	Seeking spiritual guidance
Transcending	Connectedness
Legitimizing	Truth
Taking risks	Endure
Time out	Loss
Setting goals	Strengthening relationships
You control pain	Validating
Moving on	Creating
Reconstructing	Healing

Development of Finding Hope

Doctor believes I have pain	Family gave me hope
Faith	Spiritual guidance
Wanting to achieve	Access to LTOT
Self-belief	Friends support
Inspired by other CNMBP sufferers on LTOT	Miracle cure
Being optimistic	Sense of future
Pain tolerable	Wanting to be creative
Wanting to work	Wanting to be in control

APPENDIX: 32

Development of reconciling losses

Confronting	Evaluating
Accepting	Re-adjusting
Grieving	Moving on
Wanting me back	Letting go
Negotiating	Legitimizing
Where to from here?	Faith
Spiritual guidance	What is me?

Development of Self-determining Normalcy

Making choices	Being honest
Self belief	Being responsible for pain
Hating being labelled	Hating being stigmatised
Self governing	Retaining aspects of pre-morbid life
Reconstructing	Self-advocacy
Creating	Planning
Communicating	Having goals
Seeking out resources	Accepting help
Setting boundaries	Being active
Robust personhood	Acting
Concealing	

Development of Taking Control

Being responsible	Self-advocacy
Communicating	Setting boundaries
Self reliant	Knowledge of resources
Connecting	Making decisions
Making choices	Suffering consequences
Faith	Confidence
Spiritual guidance	Setting goals
Being informed	Understanding roles
Questioning	Asking for advice
Knowledge re LTOT	

APPENDIX: 33

Development of Setting Goals

Having a sense of future	Planning
Communicating	Don't like being hopeless
Wanting to participate	Dreams
Professional support	Seeking information
Seeking help	Rewarding
Setting boundaries	Family support
Achieving	Being active
Balancing	Pacing
Being in control	

The development of 'Time Out' (in vivo code)

Respite	Family respite
Recharging the batteries	Hospitalisation
Pain intolerable	Side effects intolerable
Changing pain management regime	Insurance
Resigning	Fragility
Restoring	Maintaining
Temporary relinquishing control	Sleep
Undergoing procedures	Trialing
Alienating	Being labelled

The development of Striving for Normalcy

Being treated as a normal person	Having a robust personhood
Engaging	Being ordinary
Reconciling	Pacing
Connecting	Helping others
Contributing	Communicating
Having fun	Accepting responsibility for 'pay back pain'
Limiting	Balancing
Utilising aids	Respected
Not being labelled	Not being stereotyped
Having optimum pain control	Family & professional support
Working	Learning
Having hobbies	

APPENDIX: 34**Poster Presentation:**

**Stigma & Enigma of Chronic non-malignant back pain
treated with long term opioid therapy. 9th World
Congress on Pain, Vienna 1999.**

STIGMA & ENIGMA OF CHRONIC NON-MALIGNANT BACK PAIN TREATED WITH LONG TERM OPIOID THERAPY:

CONSUMERS' PERSPECTIVE

Janet Gardner, Department of Community Medicine, Monash University, Victoria, Australia.

Board N

BACKGROUND

Long term opioid (LTO) therapy, whilst well accepted for the management of cancer pain remains controversial for those with chronic non-malignant back pain (CNMBP). However, there is growing evidence that LTO can be beneficial in the treatment of some patients with severe refractory CNMBP caused by a primary lesion or dysfunction in the nervous system. At present there is a lamentable shortage of outcome studies in relation to CNMBP treated with LTO therapy. Few studies have addressed the use of LTO therapy in the management of CNMBP from the consumer's perspective. Consumer's views regarding levels of satisfaction with treatment, outcome and future prospects are now considered important indicators not only of quality of care but also of patients' quality of life. A collaborative, action research study provides opportunities to engage CNMBP patients in evaluating all aspects of their management, and to identify consumer constructed outcomes through which to evaluate care.

AIM

To determine patients' profiles, perceptions and feelings regarding the use of LTO therapy in the management of CNMBP including the criteria they use to substantiate and evaluate its use.

METHODS

Focus groups were used to explicate major consumer issues relating to LTO therapy in CNMBP management and to develop a questionnaire which was used in an analytical, postal survey of 50 subjects throughout Australia.

SAMPLE (n=50)

Gender: Male n=17 (34%) Female n=33 (66%)
Age: Range 30-85 47.5 ± 8.6 yrs (Mean ± SD)
How long had CNMBP: Range 1.1-26 10.5 ± 8.2 yrs (Mean ± SD)
How long on LTOs: Range .6-15 5.9 ± 3.5 yrs (Mean ± SD)

RESULTS

Commencing LTO therapy was not a planned, informed event for 80% of subjects.

52% subjects reported being initially uncomfortable about taking opioids for their pain, however this discomfort decreased over time with only 8% of subjects remaining uncomfortable with their LTO therapy.

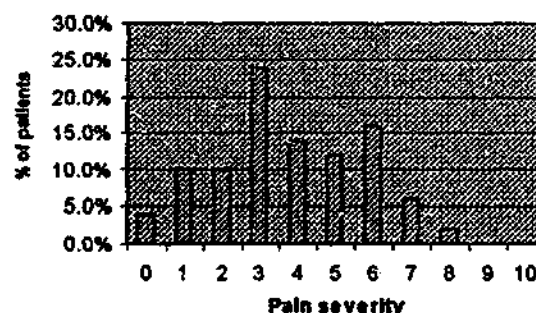
43% of subjects did not believe they were commenced on opioids at the appropriate time, of these 67% believed they should have been offered LTO therapy sooner.

The initial prescriber of opioids was predominantly Pain Specialists (54%).

32% of respondents accessed opioids through more than one prescriber.

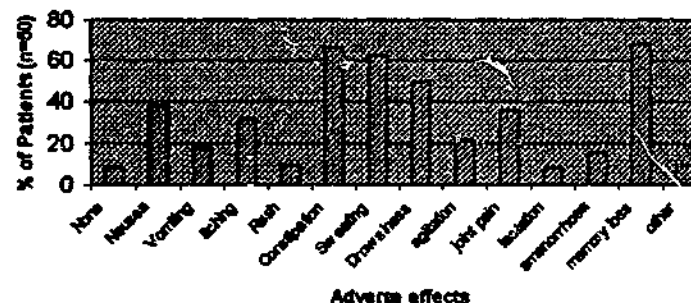
Morphine was the most commonly prescribed opioid. However, 40% of subjects took more than one narcotic (mean 3).

LTO PAIN CONTROL



88% of subjects rated the best pain relief they achieved on LTO therapy to be 4 or below using visual analogue scale of 0=no pain, 10=worst imaginable pain.

LTO ADVERSE EFFECTS



The majority of subjects (88%) reported suffering a range of adverse effects ranging from constipation to memory loss which negatively impacted on their quality of life. However, all subjects believed the positive analgesic effects of their LTO outweighed these negative adverse effects.

Oral was the most frequently used mode of administration, followed by IM injection and intrathecal infusion. 48.9% reported that the route of administration had changed since first taking opioids.

93.8% of sample reported having had the dose increased since commencing LTO.

The three major criteria that subjects used to measure the effectiveness of their LTO therapy included the ability to:

- perform basic living tasks e.g. showering (63%)
- get adequate sleep (42.5%)
- engage in meaningful relationships e.g. intimate (37.5%)

83.7% reported feeling stigmatised because they took opioids to manage their pain, and 81.6% stated their legitimate need for opioids to manage their pain had been questioned at some stage.

Family members, friends, work colleagues and nurses were cited as those who had questioned the legitimacy of their pain and need for opioids.

95.2% reported that this stigma and questioning of legitimacy had resulted in increased emotional pain, with 58.5% reporting that it had provoked serious thoughts of suicide.

DISCUSSION

Many patients commence opioids during a 'pain crisis' which may negatively impact on their ability to make an informed decision to commence LTO therapy. Whilst general practitioners became increasingly involved in the patient's pain management over time, the Pain Specialist remained the primary pain manager. However, contrary to Australian Pain Society recommendations, 32% of subjects reported accessing their opioids from more than one practitioner, usually GP & Pain Specialist. LTO therapy appears to be a balancing act, whereby patients weigh up the positive analgesic effects against significant systemic adverse effects. Memory Loss was the most frequently occurring adverse effect, and one which was of most concern to family members. Like practitioners, patients also use change in function as a measure of LTO effectiveness. To be effective, an opioid had to reduce their pain to a level which enabled them to perform basic living tasks. The majority of subjects believed they had been stigmatised & discriminated against within the health care system, especially by nurses because they took opioids to manage their pain. An alarming finding was that 50% respondents seriously contemplated suicide.

IMPLICATIONS FOR FURTHER RESEARCH & PRACTICE

Effects of patient education and information provided at time of commencement on LTO therapy need to be developed, implemented & evaluated.

The role of general practitioner as primary pain manager needs to be trialed & evaluated.

Implementation and evaluation of education programs for public, nurses, general practitioners regarding severe CNMBP and its legitimate treatment, opioids in reducing the stigma and emotional wounding of patients.

Development and evaluation of education programs for family members, health care practitioners regarding the surveillance of patients on LTO therapy, risk of suicide.

Access to support groups and counseling for CNMBP patients receiving therapy needs to be implemented and evaluated.

Research to determine the possible relationship between memory loss and therapy.

Development of an assessment tool using consumer identified criteria (e.g. ability to perform ADLs, get adequate sleep, engage in meaningful relationship) which health care practitioners could use to evaluate LTO therapy.

APPENDIX: 35**Poster Presentation****Who takes opioids for chronic back pain?****21st Annual Scientific Meeting of the Australian Pain Society, Melbourne 2000.**

WHO TAKES OPIOIDS FOR CHRONIC BACK PAIN?

Janet Gardner, Department of Community Medicine, Monash University, Victoria, Australia

BACKGROUND

Long term opioid (LTO) therapy, whilst well accepted for the management of cancer pain, remains controversial for those with chronic non-malignant back pain (CNMBP).¹ However, there is growing evidence that LTO can be beneficial in the treatment of some patients with severe refractory CNMBP caused by a primary lesion or dysfunction in the nervous system.^{2,3} At present there is a lamentable shortage of outcome studies in relation to CNMBP treated with LTO therapy. Few studies have addressed the use of LTO therapy in the management of CNMBP from a consumer's perspective. Consumers' views regarding levels of satisfaction with treatment, outcomes and future prospects are now considered important indicators not only of quality of care but also of patients' quality of life.⁴ A collaborative, action research study provides opportunities to engage CNMBP patients in evaluating all aspects of their management, and to identify consumer profiles and construct scenarios through which to evaluate care.

To determine the personal, medical and disability profiles of persons who are treated with LTO therapy in the management of their CNMBP.

METHODS

Two groups were used to explicate personal profiles and major consumer issues relating to LTO therapy in CNMBP management and to develop a questionnaire which was used to evaluate these profiles and issues in an analytical postal survey of subjects throughout Australia.

SAMPLE (n=50)

Gender:	Male n=17 (34%)	Female n=33 (66%)
Age:	Range 30-65	47.5 ± 8.6 yrs (Mean ± SD)
How long had CNMBP:	Range 1.1-26	10.5 ± 8.2 yrs (Mean ± SD)
How long on LTOs:	Range .6-15	5.9 ± 3.5 yrs (Mean ± SD)

RESULTS

A majority of subjects (72%) were either married or living in de facto relationships and were well educated (refer figure 1).

Pain profiles revealed that their CNMBP was a multi-sensory experience. Whilst reported that their pain was constant, the level of intensity varied. When independently assessed by three clinicians (ie pain specialist, general practitioner, clinical nurse specialist), the majority of pain drawings were considered indicative of their pain being organic in origin.

A majority of subjects had a moderately high Pain Disability Index Score (refer figure 2).

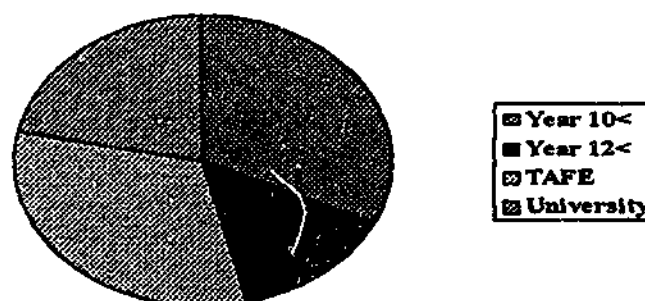
Commencing LTO therapy was not a planned, informed event for 60% of subjects.

80% of subjects reported being initially uncomfortable about taking opioids for their pain, however this discomfort decreased over time with only 8% of subjects remaining uncomfortable with their LTO therapy.

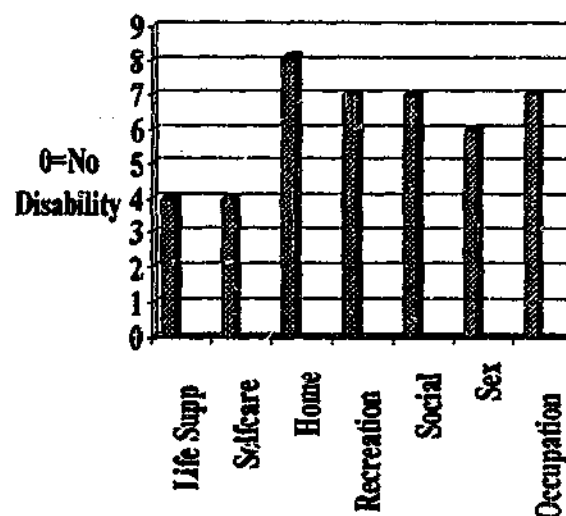
A majority of subjects were no longer in employment, with 70% of subjects living on compensatory payments for back injuries suffered in the workplace.

A majority of subjects all reported lengthy medical and surgical biographies related to their CNMBP. 70% of subjects having undergone on average 2 surgical procedures (range 1-3). 94% of subjects reported undergoing numerous invasive management techniques (eg nerve block, acupuncture) (range 2-8 mean 4.05).

Figure 1. EDUCATION



Pain Disability Index



Morphine was the most commonly prescribed opioid. However, 40% of subjects took more than one narcotic (mean 3).

Oral was the most frequently used mode of administration, followed by IM injection and intrathecal infusion. 48.8% reported that the route of administration had changed since first taking opioids.

83.7% reported feeling stigmatised because they took opioids to manage their pain, and 81.6% stated their legitimate need for opioids to manage their pain had been questioned at some stage.

95.2% reported that this stigma and questioning of legitimacy had resulted in increased emotional pain, with 58.5% reporting that it had provoked serious thoughts of suicide.

83.7% reported feeling stigmatised because they took opioids to manage their pain, and 81.6% stated their legitimate need for opioids to manage their pain had been questioned at some stage.

95.2% reported that this stigma and questioning of legitimacy had resulted in increased emotional pain, with 58.5% reporting that it had provoked serious thoughts of suicide.

DISCUSSION

Many patients commence opioids during a 'pain crisis' that negatively impacts on their ability to make an informed decision to commence LTO therapy. Patients' attitudes towards opioids appear to change over time with the majority becoming more comfortable with their use. These patients carry much 'baggage' from failed treatments, litigation, stigma and discrimination within the health care system. However, many participants credited their opioid therapy for their ability to successfully reinvent themselves through education, arts and crafts. The data lends support to the findings that responsibly used on responsible individuals, opioids can improve pain management and quality life for selected patients with intractable CNMBP.

IMPLICATIONS FOR FURTHER RESEARCH & PRACTICE

Effects of patient education and information processes provided at time of initial commencement on LTO therapy need to be implemented and evaluated.

Implementation and evaluation of education programs for public, nurses and general practitioners regarding severe CNMBP and its legitimate treatment with opioids in reducing the stigma and emotional wounding of patients.

Exploration and identification of strategies employed by CNMBP patients receiving LTO therapy whom are deemed 'successful in reinventing themselves'.

Development and evaluation of education programs for family members and health care practitioners regarding the surveillance of patients on LTO therapy for risk of suicide.

Access to support groups and counselling for CNMBP patients receiving LTO therapy needs to be implemented and evaluated.

Identification and evaluation of those complementary therapies that consumers deem helpful in managing their CNMBP.

Bibliography available on request.