

Living and Doing with Chronic Pain: Clients' and Occupational Therapists' Perspectives

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STATEMENT OF AUTHORSHIP

I, Helen van Huet, declare this thesis titled “Living and doing with chronic pain: Clients’ and occupational therapists’ perspectives” is my own original work and has not been submitted in whole or in part for a higher degree at any other University or institution. To the best of my knowledge it does not contain any materials previously published or written by another person except where due reference is made in the text.

Helen van Huet

Ms. Helen van Huet

STUDENT DECLARATION

I certify that this thesis titled “Living and doing with chronic pain: Clients’ and occupational therapists’ perspectives” will be available to the public after examination

Helen van Huet

Ms. Helen van Huet

Abstract

The purpose of this research was to investigate how people with chronic pain manage their pain in the long term and what factors influence that management. The perspectives of past participants of a chronic pain management program (PMP) and occupational therapists working with people with chronic pain were sought to see if there was compatibility or difference in their points of view.

The overarching research questions that arose from a review of the literature were:

- What factors predict successful pain management in the long term?
- How do people live and do with chronic pain in their everyday lives?

These questions formed the foundation for further detailed exploration of how social factors, personal beliefs and meanings, individual attributes and strategies influenced pain management.

The study design was based on qualitative methods, in this instance narrative inquiry, to gain stories from PMP participants of living with pain and therapist-participants of working in pain practice. Narrative inquiry was selected as it allowed participants to tell their stories of living and working with chronic pain. Stories inherently contain aspects of the past, present and future. This was an important element to capture in relation to the time contingent process of chronic pain management (Charmaz, 1991).

Fifteen PMP participants were recruited in Stage 1 of the research, both males and females, with ages ranging from 31 to 64 years. Nine therapist-participants were recruited in Stage 2, who worked across a range of chronic pain settings including private practice, community-based and hospital-based pain programs. Data were gathered through semi-structured interviews predominantly conducted at PMP participants' homes and therapist-participants' places of work. Interviews were tape-recorded and transcribed verbatim, with all participants receiving a summary of interviews for comment.

Data analysis used an iterative and interpretive approach. Transcripts were read as whole stories, with initial researcher impressions noted and recorded. Transcripts were then subjected to closer scrutiny, with key themes, words and phrases noted using the participants' language. These detailed themes were sorted into common groupings and compared across participants. Idiosyncratic themes were not discarded. The main themes that emerged related to the categories of self/identity, meaning ascriptions about pain, strategies used, and the influence of the social world. Within each of these categories, factors became apparent that influenced whether a person was predominantly agentic, active in their pain self-management, or victimic and passive, relying on external support (Polkinghorne, 1995).

A conceptual model is proposed based on (a) knowing (meanings ascribed to chronic pain), (b) doing (strategies and methods used to engage in everyday activities), and (c) being (aspects of the self intrinsically and socially constructed) as critical to managing chronic pain. These factors are significant when considering how people live with chronic pain within the community in the long term and also how and when health care services specific to chronic pain might best be utilised to achieve favourable outcomes.

Acknowledgements

The creation of the thesis is a journey that involves many different people at different stages of the voyage, from the initial tentative research question to the final editing and submission. Colleagues have compared a thesis to giving birth, acknowledging that the pregnancy is difficult and error fraught. However with nurturing guidance and supervision a rewarding end point is reached.

I would like to acknowledge the supervisors who have guided me on this journey in order of their involvement:

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I sought professional editorial assistance for consistent formatting, grammar and spelling, however this was not related to content.

The support I have received from family particularly my partner Craig, has meant that I have been able to progress albeit unevenly towards my goal. My children, Dan, Kat and Luka, have often wondered “why the hell Mum has to write so much and spend so much time doing work” while the house falls into disarray! The process has been difficult especially when working part-time and bringing up three children, however the personal and professional benefits have been worth it. I have learnt to think more critically, reflect at a deeper level and approach research as an opportunity rather than a chore. I believe the thesis is ready to launch into the occupational therapy profession and look forward to publishing more findings from the thesis to hopefully inform theory and practice.

The Mystery of Pain

Pain has an element of blank;
It cannot recollect
When it began, or if there were
A day when it was not.

It has no future but itself,
Its infinite realms contain
Its past, enlightened to perceive
New periods of pain.

Emily Dickinson (1880)

CHAPTER 1: INTRODUCTION

1.1 Introduction

This chapter introduces research entitled “Living and doing with chronic pain: Client and occupational therapist perspectives”. It details the background to the study, rationale for topic selection, and the researcher’s personal interest in the topic. The purpose and relevance of the research are then described. The context or scope of the study and the assumptions and meanings that were brought to the research are also discussed. Following this the structure of the thesis is stated and the research is situated diagrammatically within the existing body of knowledge.

1.2 Background/rationale for topic selection

Chronic pain incurs major health-related costs every year in Australia. This was estimated in 2007 at seven billion dollars of expenditure. The prevalence of chronic pain is projected to increase from 3.2 million people in 2007 to 5 million in 2050 (Access Economics, November 2007).

Occupational therapists are recognised as integral members of the chronic pain health care team. In 1994 the International Association for the Study of Pain prepared a draft curriculum to guide occupational therapy and physiotherapy education in this area (International Association for the Study of Pain, 1994). Since this time research into best practice in chronic pain management has increased exponentially.

I have worked as an occupational therapist in chronic pain management programs for over 15 years. These programs typically use a biopsychosocial approach that addresses the psychosocial, biomechanical and medical aspects of the individual (Martensson & Dahlin-Ivanoff, 2006). The psychosocial component is addressed using predominantly cognitive behavioural methods. These methods challenge the person’s beliefs about chronic pain as being harmful (if that is the individual’s perception) and aim at the person recognising and correcting those beliefs (Turk, 2002).

This includes techniques of stopping negative thinking and diverting thoughts away from pain (Turk, 2002). Although these methods are widely used there has been debate about their short- and long-term usefulness (Thorn, Cross, & Walker, 2007). When I used these methods in practice I found that some clients had difficulty ignoring their pain symptoms. Indeed, clients preferred to talk about their pain, often at length, and the impact it was having on their lives. This was actively discouraged by health care staff, as it was seen as dwelling on the pain rather than thinking positively about the future. For me, therefore, a tension existed about applying these methods as a blanket approach to clients with chronic pain. This perceived tension was therefore a subject of research interest, resulting in client participants being selected from a chronic pain management program that used cognitive behavioural methods.

The research was also informed by a previous quantitative study into outcome measures of a chronic pain program with a focus on self-efficacy, occupational performance and satisfaction with performance (van Huet & Williams, 2007). The findings from that study indicated that many factors could influence successful pain management and subsequent activity engagement. Because of the multiplicity of subjective influences on management it was deemed appropriate to use a qualitative paradigm that could best capture the subjective nature of the chronic pain experience in depth. After deliberation about the various research methods available to the qualitative researcher, I selected narrative methods as they provide a “narrative theory of human existence” with a “a focus...on existence as it is lived, experienced, and interpreted by the human person” (Polkinghorne, 1988, p. 125), in this case people living with chronic pain. Identity emerged as an element of narrative studies that warranted consideration, as how people perceive themselves influences the story told to others. This also related well to my previous impressions of people wanting to tell their pain story within pain treatment settings. Initially I was interested in the occupational aspects of self, which include a person’s roles in relation to the occupations performed.

For an occupational therapist, occupation is central to practice. The literature on chronic pain, however, evidenced only limited research into the value and meaning of occupation. As chronic pain causes significant life disruption, the impact on identity and occupations would seem obvious. Yet research into how this disruption is dealt with in the long term is limited for people who have been through pain management programs (Jensen, Bergström, Lundquist & Bodin, 2005; Sutherland & Morley, 2008).

1.3 Purpose

The purpose of this research was to explore the factors that facilitate long-term management for those who experience chronic pain and the occupational therapists who practise in chronic pain management. I sought both perspectives, to examine whether there was congruence or dissonance between the two groups on what influenced ongoing management. Chronic pain is ongoing by term and nature, and its impact on individuals, families and health care providers is significant.

The principal questions that guided the research were:

- *How do people live and do (perform) their everyday roles and activities when they have chronic pain?*
- *What factors do participants perceive influences successful long-term pain management?*

These principal questions generated specific questions that arose on examination of the literature on chronic pain, occupational therapy and the meaning and experience of illness, as seen through illness narratives.

1.4 Relevance of the research

This research has relevance to occupational therapy practice in chronic pain management by increasing the level of knowledge of how people live with long-term pain. Occupational therapists work in chronic pain settings that utilise both evidence-based and non-evidence-based interventions. Within health care there is an ongoing focus on increasing quality and

expediency of care by using the best available evidence. In her doctoral study of physiotherapists' use of evidence-based practice, Carpenter (2004) noted the tension associated with being purely evidence-based when working with people, if it "effectively silences the client's voice" (Carpenter, 2004, p. 6). Although current evidence-based methods do take into account client preference, it could be argued that they are not wholly client-centred. Thus, although the primary focus of evidence-based research has been quantitative and measurable, qualitative methods that explore subjective experience have been increasingly valued (Curtin & Fossey, 2007; Wicks & Whiteford, 2003). Hammell (2004, p. 139) asserted that "research is undertaken for the benefit of clients and with the goal of informing theory and improving practice". This has particular relevance to health and social care "where research can – and should – have consequences for those people we study" (Hammel, 2002, p. 182).

This research provides qualitative evidence about perceptions of the efficacy of interventions provided by occupational therapists to people who live with chronic pain. By exploring the perspectives of these health care providers and their recipients, I obtained views from both groups as to what is effective. Common themes revealed across therapist and PMP participants' narratives related to what strategies and interventions continue to be useful in the long term.

Cognitive behavioural methods have been commonly applied to chronic pain management programs. This research highlighted that some PMP participants and indeed therapists also see these methods as prescriptive. Although evidence supports the use of these methods, emerging psychological interventions are generating research interest. Acceptance and commitment therapy (ACT) (Hayes, Luoma, Bond, Masuda, & Lillis, 2006) and mindfulness approaches (Vowles & McCracken, 2010) have shown the relevance of psychological flexibility in chronic pain management. Acceptance of ongoing pain and readiness to change thinking and behaviour around chronic pain were strongly represented in this research. These were found to be significant factors in determining ongoing pain management from participants overall. This finding is

important, as researchers have documented the difficulty in determining the best time for clients to benefit from pain programs (Biller, Arnstein, Caudill, Federman, & Guberman, 2000). The findings provide support for exploring acceptance and readiness for change as indicators of program readiness. This could improve the delivery of timely cost-effective interventions.

This research also supports the use of narrative inquiry as a suitable method for examining chronic pain in depth. Narrative methods have proved to be a credible approach to explore the meaning and experience of chronic pain (Corbett, 2007; Keponen & Kielhofner, 2006; van Huet, Innes, & Whiteford, 2009). Perhaps most importantly, narrative methods give voice to the stories of those living with unremitting pain and the effort required to maintain a semblance of an active life. Frank (2005) has advocated the use of narrative in clinical care as a reparative way of making sense of illness and providing a way of validating a person's illness experience. PMP participants in this research reported finding the opportunity to discuss their chronic pain to be a liberating process, especially when living with the ongoing stigma attached to chronic pain.

1.5 Scope

The geographic context of this research was situated around chronic pain management programs in Australia and New Zealand. PMP participants were sourced from a pain program in the Albury-Wodonga region on the New South Wales/Victorian border. The Albury-Wodonga area has a population of over 90,000 and is one of the largest inland population centres in Australia. A further 180,000 people live within a 100 kilometre radius (Albury-Wodonga.com, 1997). Historically the area has predominantly been used for farming and agriculture, as the Murray River flows through the centre of the region.

This regional pain program was multidisciplinary and delivered on an inpatient basis. PMP participants completed the program between 2002 and 2003 and were interviewed in 2005. A higher representation of women

(11 of 15) consented to participate in the research. This finding is consistent with other chronic pain studies (Kaur, Stechuchak, Coffman, Allen, & Bastian, 2007; Miller & Newton, 2006). The majority of PMP participants were aged 50 years and over (n=11); only four were engaged in part-time or full-time employment. Five participants were on a disability pension or other health care benefit. Most participants lived in rural towns with limited access to health care services and community resources. Socio-culturally most participants came from middle to lower-middle class backgrounds. Five participants came from farming backgrounds and continued to live, work or be involved in farming in some way. Nine participants had not completed their secondary education, and five participants had a tertiary qualification.

Occupational therapists were recruited from a variety of practice areas, including private, hospital and community-based practice. Six therapist-participants were sourced from the metropolitan centres of Melbourne, Adelaide, Brisbane and Auckland. Three participants were sourced from regional areas, with two therapists having worked in the same program as PMP participants. Therapist-participants had worked in the area of chronic pain from 2½ to over 20 years. All had worked within group chronic pain management programs. Eight of the nine therapists were female, a ratio that is representative of the profession overall (Allied Health Professional Workforce Planning Group, 2002).

1.6 Assumptions and meanings

Qualitative research is presumed to be subjective and therefore a-theoretical. Denzin and Lincoln (2000, p. 18), however, have noted that qualitative researchers “approach the world with a set of ideas and values, a framework (theory, ontology) that specifies a set of questions (epistemology)” that can be “examined in specific ways (methodology, analysis)”. Debate about the value of qualitative research has focused on its generalisability and issues of presumed validity. These epistemic issues are addressed by the application of rigour, transferability and reflexivity to achieve trustworthiness (Curtin & Fossey, 2007).

This research is based on a subjectivist ontology, where personal perceptions are considered legitimate and individual. This interpretive paradigm supports the method of analysis of narrative data that contributes to theory development (Wicks, 2003). Theories and conceptual models generated by the research are based on a reflexive process, that considers “the invisible assumptions that pervade everyday theorising and practice” and seeks to “interrogate what is in place” to “envision new possibilities”(Kinsella & Whiteford, 2009, pp. 251-252).

The philosophical foundations of occupational therapy practice include being client- or person-centred and valuing engagement in occupation. Being person-centred involves an appreciation of personal, social and environmental factors that influence individuals (National Aging Research Institute, 2006). The potential of engagement in occupation in providing meaning, satisfaction and purpose in person-centred care has been noted (Townsend & Polatajko, 2007; Wilcock, 1998, 2005). This has led to the generation of theories and models that guide practice, based around the intersection of person, occupation and environment and the resulting occupational performance (Chapparo & Ranka, 1997; Keilhofner, 1995; Law et al., 1994). People who have chronic pain are idiosyncratic in the way they manage their performance contexts. Consideration of these subjective elements is thus needed to fully understand their pain experience.

The philosophical and theoretical assumptions that guided the conduct of this study are that:

- humans are occupational beings and value and gain benefit from engagement in occupations (Wilcock, 1998)
- being human is a subjective experience that involves a complex interaction between person, occupation and environment (Law, Baptiste, & Mills, 1995)
- qualitative methods can provide an insight into the subjective experience of people who live with chronic pain.

Operational Definition of Terms

Key terms used extensively within this thesis are defined as follows:

Chronic pain: Pain persisting beyond the expected healing point of an injury that does not respond to routine methods of pain control and has concurrent social, emotional, psychological and occupational impacts on the person.

Occupations: Activities that people perform every day or as part of their routine alone and with others.

Occupational therapy: A discipline utilising a social model of health focused on engaging in everyday occupation, with occupation as its therapeutic tool.

Identity: Also referred to as “self”, comprising self-knowledge, self-esteem and the socially formed aspects of identity.

Occupational identity: Recognition by what a person does productively, whether alone or with others.

Role: A designated position in society, from a sociological perspective.

Occupational role: A role related to what a person does, be it familial (e.g., parent), social (e.g., basketball player), or occupational (e.g., homemaker).

Occupational performance: The engagement in and performance of occupations across the lifespan.

Illness narratives: Stories told by individuals who have experienced illness, of the life changes that result from illness and impact on the person's past, present and future.

1.7 Structure of thesis and overview

There are eight chapters in this thesis. The purpose of this first chapter is to provide an introduction to the research overall and to situate it within the existing body of knowledge. The second chapter provides a comprehensive review of the literature on chronic pain, occupational therapy, narrative methods and the meaning and experience of illness.

Chapter 3 describes the methods used within the research. This chapter presents the purpose of the research, research questions generated by

the literature review, and the research approach. The study design, research processes and participant details are also described. Data collection methods are specified for both Stage 1 and Stage 2 of the research. Stage 1 consisted of the collection of data from PMP participants. Stage 2 was conducted with therapist-participants. Rigour to ensure the authenticity of the research process leads into a description of data analysis. The final section of the chapter introduces the researcher (me) and my interest in the research area.

Chapter 4 introduces the PMP- and therapist-participants, a summary of their narratives and a graphical representation of significant life events or turning points for PMP participants. Chapter 5, details the findings from the narratives of PMP participants, tabled and grouped under agentic (active pain self-management) and victimic (passive pain self-management) headings. Chapter 6 uses a similar heading structure but applies it to the findings from the therapist-participant narratives. These chapters are pivotal to understanding participants' stories of living with and working with chronic pain. It is significantly detailed to capture the multiplicity of themes that arose from the narratives.

Chapter 7 focuses on in-depth and critical discussion of the findings in relation to the literature. The discussion centres on a synthesis of the findings under the areas of self/identity, meaning ascriptions, strategies used to manage pain, and social world influences. Complementary and contrasting findings within and across narratives are discussed with reference to the knowledge generated. How the findings inform occupational therapy practice is also discussed with reference to long-term pain management. A conceptual model of factors influencing agentic and victimic ways of managing pain is then presented. Following this, implications for occupational therapy theory and practice are detailed.

The final chapter summarises the importance of and recommendations arising from the research, research issues encountered, and future research directions. A closing message is offered to acknowledge the contribution of the participants.

1.8 Locating the study within the existing body of knowledge

The process of locating the study within existing knowledge is useful to determine the literature pertinent to consider. It is also a constructive way of highlighting the theoretical and conceptual background to the research. Figure 1.1 provides a schematic representation of the study's location. It is recognised that this is a broad representation rather than a comprehensive view, but it provides a preamble to the Literature Review (Chapter 2) that follows.

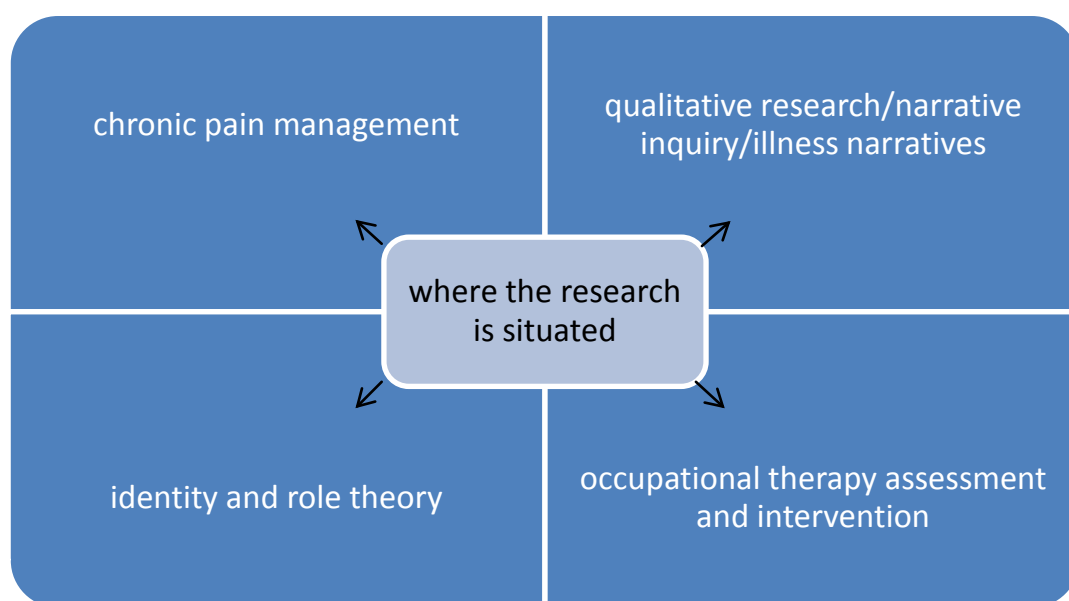


Figure 1.1: Where the research is situated in the existing body of knowledge.

CHAPTER 2: LITERATURE REVIEW

2.1 Purpose of the Literature Review

This chapter details the literature considered within this study. It highlights the process undertaken to determine the literature considered, the questions of interest that arose from the literature, and the conceptual framework developed as a result of those questions.

The purpose of this review is to provide a synopsis of the literature related to:

- Chronic pain and treatment models/methods used to manage chronic pain
- The use of narrative as a research method and how illness narratives have been applied to relate the meaning and experience of people with chronic pain
- Identity and life roles as they relate to people with chronic pain;
- Occupation, occupational roles and identity
- Adaptation to illness and disability.

2.2 Literature Review Process

Key words were entered into the following data bases: Ovid (including CINAHL, Medline, Psych Info, Sociofile), EBSCOhost (including health, education and psychology databases), Cochrane Database of Systematic Reviews, and OTSeeker (an evidence-based data base specific to occupational therapy).

Examples of key search terms entered are:

Chronic pain, qualitative research + chronic pain, chronic pain management, chronic pain + self efficacy, chronic pain + occupational therapy, chronic pain + psychological methods, chronic pain + PMPs, identity + chronic illness.

The following topic areas emerged from the literature, informed the research and were key to the formulation of the research questions:

- Chronic pain: definition, prevalence, pathophysiology, current psychological approaches, emerging treatment approaches, occupational therapy philosophy, assessment and intervention for chronic pain
- Qualitative methods for exploring life meaning and experience, narrative philosophy, illness narratives
- Identity/self: definition, theories on identity from psychology and sociology, and role theory
- Occupation: definition and concept, occupational identity/self, occupational roles, occupational role performance, meaningful occupations, impact of illness and adaptation.

These topics are considered in detail within this chapter in the sections that follow.

2.3 Chronic Pain

2.3.1 Definition

The International Association for the Study of Pain defines chronic pain as “A 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” (1994, p. xii). Although this definition has been widely accepted by pain researchers, its focus is on the biomedical aspects of pain and does not encompass the complexity of the impact of pain on the person experiencing it.

Having chronic pain has been recognised as a multi-dimensional experience. A definition that encompasses the modern understanding of pain recognises the “emotional, psychological, socio-political and existential aspects of pain as well as physiological and anatomical factors” (Borell, Asaba, Rosenberg, Schult, & Townsend, 2006, p. 209). Bendelow and Williams (1996) described pain as the “intersection between body, mind and culture” (p. 1127). The “body” takes into account the physiological aspects of pain, the “mind” the psychological, and “culture” the learned beliefs and attitudes surrounding the pain experience. The outcome of chronic pain, from an occupational therapy perspective,

includes its impact on “daily activities, routines and role performance” (Fisher et al., 2007, p. 209). Wall (1984) discussed the complex clinical picture that chronic pain presents and how in the absence of tissue damage it is psychologised by practitioners for their clients as being “in their head” (P. Wall, personal communication, March 21, 1999).

2.3.2 Prevalence

Chronic pain affects many people in Australia, as in other parts of the developed world. In the U.S. alone it is estimated that 50 million people have some form of chronic pain (Renn & Dorsey, 2005). In 2001 a prevalence study was undertaken by telephone survey of a randomly selected sample ($N= 17,543$) of Australians. Chronic pain was reported by 17.1 % of men and 20.0 % of women. In that study, older age, being female, lower education levels and lower socio-economic status were identified as prognostic indicators for chronic pain (Blyth et al., 2001). In 2007 the prevalence of chronic pain in Australia was estimated to be approximately 3.2 million people, with 1.4 million males and 1.7 million females (Access Economics, November 2007).

The economic impact of chronic pain in terms of reduced productivity, caregiver burden and decreased quality of life was estimated at a gross cost of \$34.3 billion Australian dollars in 2007. The majority of this was taken up by reduced work performance, loss of employment, burden of disease, and health system costs (Access Economics, November 2007). That report supported the previous findings by Blyth et al. (2001) as to the prognostic indicators for developing chronic pain (Access Economics, November 2007).

2.3.3 Pathophysiology

Two broad categories of pain have been identified; acute and chronic. Acute pain has a short duration, can be linked to an identified cause and is self-limiting (Renn & Dorsey, 2005). Chronic pain persists beyond the point of tissue healing and has no biological purpose (Merskey & Bogduk, 1994). Current thinking about the pathophysiology of chronic pain is that it

is an abnormal response of the peripheral and/or central nervous system, to a varying level of physiologic pain that generally has a severity beyond that of the eliciting injury (Pasero, 2004). This abnormal processing of sensory input can occur spontaneously or in response to environmental conditions (heat and cold) and serves no purpose in terms of protecting the body from further injury.

Research into the causes of various types of chronic pain has recently focused on the theory of central sensitisation and brain plasticity theory (Devor & Tal, 2009; May, 2008; McLean & Clauw, 2005). The theory of central sensitisation posits that there is a disruption to pain processing at both a peripheral to central nervous system level, which results in noxious and even non-noxious stimuli being interpreted as painful by the central nervous system. This is beyond the level experienced by people who do not have chronic pain (McLean & Clauw, 2005). Central sensitisation results in increased sensitivity and reduced inhibition of pain mechanisms due to abnormal chemical changes in pain membrane potentials at a cellular level (Hulsebosch, Hains, Crown & Carlton, 2009). Brain plasticity research has identified changes in the brain structures of people who had different types of chronic pain, suggesting a common “brain signature” with deficits in multi-integrative areas involved with pain regulation (Alschuler, Theisen-Goodvich, Haig, & Geisser, 2008, p. 7). This would suggest that the pathophysiology involved could be influenced by a multiplicity of factors. Accompanying this disrupted regulation and heightened awareness of pain is the increase in psychological reactions such as threat appraisal of any potential noxious stimuli and concurrent anxiety (Jackson, Huang, Chen & Phillips, 2009). As pain is a subjective experience, its impact on behavioural, environmental and occupational dimensions for individuals is of particular importance to this study and is discussed in relation to treatment models and methods.

2.3.4 Treatment Models and Methods

2.3.4.1 *Current treatment approaches – Individual and group treatment*

Treatment approaches for chronic pain vary from individual to group interventions, dependent on whether a health care provider, health care specialist or PMP is utilised. Individual approaches include psychological (e.g., counselling), physical, (e.g., physical therapy treatments), invasive (e.g., spinal nerve-block, surgical and pain management implants) and lifestyle management approaches (Strong, 2002). Self-management approaches initially used for people with arthritis (Lorig & Holman, 1993) have also been developed for chronic pain (Le Fort, 2000). Group treatments tend to be based on methods that arose initially in multidisciplinary PMPs in the U.S. in the 1980s in response to injured workers who developed chronic pain. Biopsychosocial models are utilised in group-based PMPs, which are aimed at representing a holistic view of a person (Martensson & Dahlin-Ivanoff, 2006). These models therefore encompass the psychosocial, biomechanical and medical management of the pain experience.

Biopsychosocial programs focus on reactivation (i.e., getting people moving and engaging in everyday activities) and commonly include cognitive behavioural therapy or other behavioural methods. Most programs would also include physical therapy such as exercise and hydrotherapy; occupational therapy and work hardening; resumption of previous activities and preparation for return to work. The focus of these programs is ultimately self-management for the person with chronic pain. The health professionals involved, the type of program (in/out patient) and length of program (2 weeks to 3 months) all vary (Biller, et al., 2000; Jensen, Bergström, Ljungquist, & Bodin, 2005; Nicholas, Wilson, & Goyen, 1992; Strong, 1998; van Huet & Williams, 2007).

2.3.4.2 *Current Behavioural Methods – Cognitive Behavioural Therapy (CBT)*

Cognitive behavioural therapy (CBT) for chronic pain consists of “learning new behaviours, abandoning or revising existing ones and challenging and changing unhelpful or negative ways of interpreting and constructing their experience” (Curran, Williams, & Potts, 2009, p. 178). Turk and colleagues first applied CBT to pain treatment in the 1980s (Turk, Meichenbaum, & Genest, 1983). It is now the most widely used behavioural method in

interdisciplinary PMPs (Curran et al., 2009; Strong, Unruh, Wright, & Baxter, 2002). Although this method has been extensively used and researched there continues to be variation in treatment effects in the short or long term (Curran et al., 2009; Turner, Holtzman, & Mancl, 2007).

2.3.4.3 *Effectiveness of CBT: Quantitative and qualitative points of view*

The effectiveness of cognitive behavioural interventions has been explored through systematic review, randomised control trials and outcome measure studies. A systematic review of 29 experimental studies of the use of CBT for chronic pain found that although CBT had a positive effect compared to placebo, once other forms of treatment (education, exercise) were provided to control groups the results became inconclusive (Law et al., 1999). A meta-analysis of 25 randomised control trials found that CBT produced significantly greater changes than waiting list controls and alternative treatments; however, changes were only in certain domains of measurement, such as cognitive coping and appraisal, but not mood and social role functioning (Morley, Eccleston, & Williams, 1999). As noted by McCracken and Turk (2002, p. 2564), "Differences across studies in sample characteristics, treatment features, and assessment methods seem to produce varied treatment results". Person-related factors such as self-efficacy, readiness to change and perceived pain control have influenced treatment outcomes using CBT (Nicholas et al., 1992; Turner et al., 2007). Potential external moderators that may influence CBT effectiveness have included the number of sessions of CBT individuals received, therapists' skill and competence using CBT approaches, and group versus individual delivery (Vlaeyen & Morley, 2005).

Qualitatively, research has focused on the person's experience of being within a chronic pain program using CBT approaches and how effective such approaches may be to overall chronic pain management. A focus group study of people with chronic pain who had undertaken a biopsychosocial rehabilitation program with a CBT focus found divergent viewpoints about effectiveness (Martensson & Dahlin-Ivanoff, 2006). The opinions were based on whether participants had played an active or passive role in the program as determined by themes of contributing to the

program or “being regarded as a sick person” (p. 989). The perceived efficacy of the group leaders was evidenced in participant themes related to the level of support given and sense of belonging and the participant’s level of commitment to the program were seen in terms of themes of self-responsibility. Richardson, Adams and Poole (2006) discussed the importance of communication and patient-practitioner interaction, as well as the way coping strategies training was administered, as being significantly related to outcomes of chronic pain interventions. This supported the findings from studies previously considered. The clinical encounter has been further highlighted in other studies as significant to the pain management process within pain programs using CBT approaches (Bullington, Nordemar, Nordemar, & Sjöström-Flanagan, 2003; Harding, Parsons, Rahman, & Underwood, 2005).

As noted above, there is a significant body of quantitative research demonstrating that programs utilising CBT methods result in improvements in pain distress, behaviour and daily functioning (McCracken & Turk, 2002; Turner et al., 2007). However, variability in improvement across programs has indicated that not all participants appear to benefit. This has been related to a broad range of factors including the outcome measures used, treatment program components and the personal characteristics of the pain program participants (Thorn et al., 2007). There is limited qualitative research available that explores CBT approaches, treatment methods and the personal characteristics of program participants, and how these factors contribute to successful pain management (Bendelow & Williams, 1996; Peolsson, Hydén, & Sätterlund Larsson, 2000). Moreover, there is no indication of how these factors affect long-term ongoing management.

2.3.4.4 *Longitudinal studies of pain program outcomes*

Few studies have explored the long-term outcomes (12 months or more) after pain program completion (Jensen et al., 2005; van Huet et al., 2009). Peat, Moores, Goldingay and Hunter (2001), studying pain programs in the United Kingdom (U.K.), found substantial differences in the length of participant follow-up (1 month to 3 years) and the outcome measures used to evaluate pain management over time. There are, however, several

longitudinal studies of chronic pain in the general population. In a 4-year follow up study of people with chronic pain living in the community in an English county (Elliot, Smith, Hannaford, Smith, & Chambers, 2002), high incident rates and low recovery rates were reported. A 12-year study of chronic pain in Sweden indicated a higher mortality rate than the general population for those who experienced widespread chronic pain (Andersson & Andersson, 2004). The high incidence of chronic pain and limited effectiveness of existing approaches has warranted research interest in new methods of addressing chronic pain.

2.3.5 Emerging Treatment Methods

2.3.5.1 Acceptance and Commitment Therapy

Hayes (2004, p. 639) has proposed a so-called “third wave” of cognitive-behavioural intervention approaches. Among these approaches are methods based on “mindfulness” (McCracken & Thompson, 2009, p. 75), which is focused on how a person perceives the reality of a situation, an acknowledgment about how the person thinks and feels about the situation, and acceptance of those thoughts and feelings, be they positive or negative. One of these mindfulness methods is Acceptance and Commitment Therapy (ACT), which has been the subject of extensive experimental study since 2005. This method is based on the cognitive aspects of Relational Frame Theory (RFT) or the empirical analysis of human cognition, but it also encompasses individual aspects such as “spirituality, values and self” (Hayes, 2004, p. 640). Whereas CBT is aimed at challenging, changing and restructuring thoughts, ACT is aimed at accepting thoughts and feelings (Fletcher & Hayes, 2005). Vowles and McCracken (2008, p. 398) sum up the difference as follows:

Key therapeutic processes of this treatment model differ from traditional CBT and include acceptance, or the willingness to experience pain or other distressing events without attempts to control them, and values-based action, or the aligning of actions with desired, personally meaningful purposes rather than with the elimination of unwanted experiences.

Research using ACT is supportive of its use with people who have chronic pain and indicates that ACT has evidenced improvement in physical and

emotional functioning, reduction in health-care visits and medication use (Hayes et al., 2006; McCracken, 2005). Research has focused on the measurable aspects of mindfulness and ACT, rather than the subjective experience for users. Although this method is emerging as an alternative to traditional CBT, and shows exciting possibilities as a therapeutic medium, it has yet to be adopted in chronic PMPs in Australia.

An increasing number of clinical and experimental studies based on both qualitative and quantitative methods have highlighted the importance of accepting pain as part of the pain management process (Clarke & Iphofen, 2008; Delmar et al., 2005; McCracken & Vowles, 2006; Nicholas & Asghari, 2006; Van Damme, Crombez, Van Houdenhove, Mariman, & Michielsen, 2006; van Huet et al., 2009; Viane, Crombez, Eccleston, Devulder, & DeCorte, 2004). McCracken and Yang considered that for people with chronic pain “acceptance of pain, rather than avoidance... is associated with better emotional physical, social and work-related functioning and less use of health resources” (2006, p. 137). Associated with acceptance in some studies has been the concept of readiness for change (Glenn & Burns, 2003; Keefe, Rumble, Scipio, Giordano, & Perri, 2004; van Huet et al., 2009). This is discussed in relation to chronic pain self-management.

2.3.5.2 *Readiness for change*

Readiness for change has been of interest in the field of psychological research since the 1930s (Walker, 2004). The concept has more recently been the subject of chronic pain research, particularly as chronic pain programs are, in the main, aimed at self-management of pain both physically and psychologically. The premise of readiness for change is that people may be at different stages of being prepared for behaviour change, which can affect their ability or willingness to implement change in their lives (Zenker et al., 2006). Prochaska and DiClemente (1992) described a Stages of Change Model that includes the following stages: Precontemplation (not recognising a problem or not wanting to change), Contemplation (considering change), Determination (deciding to change), Action (actually changing behaviour), Maintenance (continuing with change), and Relapse (returning to previous behaviours). Although the

Stages of Change Model has existed for some time, Hadjistavropoulos and Shymkiw (2007, p. 260) noted that “theoretical based research on readiness or motivation for pain self-management is lacking”.

The Pain Stages of Change Questionnaire (PSOCQ) is a quantitative measure developed to determine a person’s stage of change level (Kerns & Rosenberg, 2000). Studies using the PSOCQ have reported similar findings related to positive outcomes for people with chronic pain (Glenn & Burns, 2003; Hadjistavropoulos & Shymkiw, 2007). Hadjistavropoulos and Shymkiw used the PSOCQ to assess 102 participants of multidisciplinary rehabilitation, and found that high Precontemplation scores were associated with beliefs about others controlling pain and a decreased locus of control, whereas being satisfied with treatment provided was significantly related to higher Action scores.

People who are ready for change and are able to change behaviour do better on pain outcome measures. Administration of the PSOCQ before treatment has shown that pain coping and self-management were best predicted by using the individual’s Action scores as they showed the most promise of positive treatment outcomes (Hadjistavropoulos & Shymkiw, 2007; Jensen, Nielson, Turner, Romano, & Hill, 2003). Therefore, people with higher Action scores and lower Precontemplation scores “show the most promise in the prediction of treatment outcomes” (Hadjistavropoulos & Shymkiw, 2007, p. 259).

There is limited research into the qualitative nature of readiness for change. A qualitative study by van Huet, Innes and Whiteford (2009) supported previous quantitative findings (Glenn & Burns, 2003; Hadjistavropoulos & Shymkiw, 2007) that participants who were ready to implement change benefited the most from attending pain programs. More qualitative research in this area is warranted to explore this concept further. How these various psychological methods are utilised and researched by occupational therapists in practice is also of importance here.

2.3.6 Occupational Therapy Views of Practice Using Psychological Methods

Within occupational therapy, psychological methods have been adopted into practice fields including mental health, community-based programs and chronic pain management. Occupational therapists have commonly adopted CBT interventions within PMPs (Strong & Unruh, 2002). Shannon (2002) noted that occupational therapists who worked in chronic pain programs in the U.K. and the U.S. used a variety of treatment models including the cognitive behavioural approach and functional restoration. The model used influenced the way occupational therapy assessment and treatment sessions were provided. Strategies specific to CBT taught by therapists included cognitive restructuring of thinking around pain and facilitating a shift in client thinking from being passive to being proactive in their self-management (Shannon, 2002).

Although a body of evidence exists as to the use of CBT in chronic pain programs (Morley et al., 1999), there is little available evidence of the use of CBT and its efficacy specific to occupational therapy in chronic pain practice (Brown, 2002). This could be attributed to: (a) the fact that psychologists traditionally provide the CBT component in PMPs, or (b) if aspects of CBT are used by occupational therapists it is difficult “to isolate individual components of psychological interventions” or to compare “specific treatment components delivered in highly variable and complex treatment designs” (Brown & Pinnington, 2007, p. 53). Occupational therapists do, however, use a number of different approaches in chronic pain practice that are specific to their role within PMPs (see Section 2.3.7).

2.3.7 Philosophical Stance of Occupational Therapy: Relevance to the Study

For an occupational therapist and researcher, it is important to consider the philosophical premise of the profession, that is, that occupation is both our epistemology and our therapeutic domain. Within models of theory and practice, occupational therapists recognise the complexity of the relationship between the person, the environmental context and the actual

performance or doing of an activity. One recent model that encapsulates these forms is the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko, Townsend, & Craik, 2007). This model considers aspects of the person at its core, namely the spiritual, affective, physical and cognitive components, and how these personal components interact with the environment to afford or constrain occupational performance and engagement. This model exemplifies the relationship between the abilities of individuals (person), what they do (occupation) and the context (environment) in which they do it. An outcome of the transaction between the person, environment and occupation is occupational performance or the actual “doing” of an occupation, activity or task. This theoretical model has informed the research by providing consideration of the above aspects in relation to chronic pain and occupational therapy practice.

2.3.8 Client/Person-Centred Practice

The philosophy and practice of occupational therapy has as one of its basic tenets the concept of client/person-centred practice. The concept of client-centred practice was developed by the Canadian Association of Occupational Therapists and has been applied to the development of client-centred assessment tools within occupational therapy models of practice such as the Canadian Occupational Performance Measure (COPM) (Law et al., 1994). Law, Baptiste and Mills (1995) outlined seven key aspects of being client-centred. They are: (a) providing autonomy and choice; (b) providing partnership and responsibility; (c) taking an active role in decision making; (d) enablement from illness to wellness; (e) contextual congruence; (f) accessibility to services and flexibility of services; and (g) respect for diversity. Client-centred practice has been studied in chronic pain by the use of the COPM (Law et al., 1994) to gauge actual performance and satisfaction with performance around goals set by clients (Carpenter, Baker & Tyldesley, 2001; van Huet & Williams, 2007).

Recently the term *person-centred practice* has been adopted by occupational therapists. Person-centred care has been defined by the Department of Human Services Victoria (2003, p. 18) as “treatment and care provided by health services [that] places the person at the centre of their own care and considers the needs of the older person’s carers”. The adoption of this term in aged care policy is influenced by the large number of occupational therapists working in that sector.

For occupational therapists who work in chronic pain management, client/person-centred practice is also mandated. Meeting the diverse needs of people with chronic pain has been acknowledged as challenging; however, enabling the person to have “autonomy, control and responsibility” (Strong, 2002, p. 301) by active participation in decision making goes some way to address this. Occupational therapists “provide advice on body mechanics, environmental modifications, relaxation techniques or assistive devices” (Strong, 2002, p. 301). Some of these approaches to chronic pain management are detailed below.

2.3.9 Occupational Therapy Approaches to Pain Management

Occupational therapists have worked as members of multidisciplinary health care teams within pain programs over the last 30 years. Their role within such programs has been supported by the International Association for the Study of Pain that recommends inclusion of occupational therapists (Shannon, 2002). Although the roles of the occupational therapists may vary according to type of program (in/out patient), health care setting (hospital or community-based), and funding model (private or public), it is primarily involved with enabling people to participate in their daily activities. More specifically, occupational therapists may be involved in any/all of the following:

- Activity pacing
- Education about correct use of body mechanics, lifting and manual handling procedures
- Energy conservation and work simplification strategies
- Goal setting

- Home and work assessment
- Pain assessment
- Prescription of assistive devices
- Cognitive-behavioural therapy
- Relaxation training
- Stress management
- Biofeedback
- Sleep Hygiene
- Sexuality management

(Robinson, Kennedy & Harmon, 2011; Shannon, 2002; Strong, 2002; Strong & Unruh, 2002).

It has been acknowledged that the importance of the occupational therapists' role is related to the re-engagement of their clients back to occupational roles and activities that have meaning and purpose in their lives (Lequerica, Donnell, & Tate, 2009). Although it is not within the scope of this literature review to detail all the assessment and treatment strategies used, a few common approaches occupational therapists use in chronic pain settings within the author's practice experience are explored in more detail. These include activity pacing, goal setting and relaxation training.

2.3.9.1 *Activity pacing*

People experiencing chronic pain often have changes in their activity patterns as a result of pain limitation. Activity levels may be reduced or individuals may complete activities to the limit of their pain tolerance and then have to endure the resulting pain exacerbation (Strong et al., 2002). The impact on daily routines can be extreme and can lead to activity avoidance due to fear of pain, or a period of heightened activity followed by a prolonged period of rest. In the chronic pain literature this "overactivity-underactivity cycle" (Birkholtz, 2004, p. 447) was noted as common.

The concept of pacing was introduced by Fordyce (1976), who described it as participating in periods of moderate activity followed by brief periods of

rest. Strong (1996) noted that pacing involved breaking down activities into smaller parts and having regular short rest breaks, and doing activities regularly, rather than trying to complete everything in one day. Pacing is recognised as a commonly used intervention for chronic pain management (Gill & Brown, 2009), but it has been poorly researched, with no standard definition, and has been applied in various ways within pain programs (Engel, 1994). Studies within occupational therapy have advocated the use of timers to set up time increments to assist people in activity-rest cycling. Birkholtz (2004), however, found that timer use was seen by some study participants as embarrassing and not necessary.

Due to the paucity of available measures for pacing, Nielson, Jensen and Hill (2001) developed a brief six-item pacing scale that can be administered as part of another measure, the Chronic Pain Coping Inventory (CPCI). They applied this scale to 110 people presenting with fibromyalgia to a multidisciplinary pain program, and reported that it had reliability and validity as a measure (Nielson et al., 2001). It is difficult to extrapolate these results to practice, however, as this study used the measure pre-program only. A structured review of the evidence for the use of pacing recognised that it lacked consensus and a demonstrable evidence base to apply to chronic pain intervention (Gill & Brown, 2009). Yet some recent literature supports the use of pacing as a useful strategy within pain programs. A study of 2345 pain program participants in the U.K. explored adherence post-pain program to cognitive-behavioural strategies they had been taught. Pacing was the strategy used most consistently by participants (Curran et al., 2009). Approximately 47% of the sample reported a frequency of pacing use of at least once per day, with less than 9% using it less than once per week. These results support previous qualitative research by Sofaer et al. (2005), who found that among 63 study participants with chronic pain, pacing was often mentioned as a strategy used in daily activity.

PMP participants recruited for this study were taught activity pacing by occupational therapists. Therapists had participants practise activity pacing, using time increments of 10-20 minutes, to structure daily

activities. There was an expectation that this was a strategy that PMP participants could use on their return home, which was reinforced within the program (van Huet et al., 2009).

2.3.9.2 Goal setting

Goal setting is another common component included in chronic pain programs. Goals may be directed towards increasing sitting, standing and walking tolerances. In occupational therapy practice, goals may be related to increasing amounts of activity or returning to previous activities that have been discarded due to pain. Goal setting is individualised within programs, reflecting client-centred practice, and may be formalised by the use of measurement methods to determine whether a goal has been achieved. Two measures commonly used in occupational therapy practice are the Canadian Occupational Performance Measure previously mentioned (COPM; Law et al., 1994) and the Goal Attainment Scale (GAS; Kiresuk, Smith, & Cardillo, 1994).

The COPM is administered using a semi-structured interview that “examines the individual’s performance and satisfaction with performance in the areas of self-care, productivity and leisure” (McColl & Pollock, 2001, p. 68). It is used to identify an individual’s problems with activity. The five highest rated problems are the focus of intervention and subsequent outcome measurement. The reliability, validity, and client utility of the COPM have been established (Walsh, Kelly, Johnson, Rajkumar, & Bennetts, 2004) and its use as a pain program outcome measure has also been documented (Carpenter, Baker, & Tyldesley, 2001; van Huet & Williams, 2007). van Huet and Williams (2007) utilised two measures: the Pain Self-Efficacy Questionnaire (PSEQ; Nicholas, 1988) and the COPM (Law et al., 1994). Scores on the two measures were recorded pre- and 6 weeks post-program and compared for differences. van Huet and Williams found a positive association between self-efficacy beliefs and actual performance and satisfaction related to goals set using the COPM. The GAS is used to identify the main problem areas for an individual who works with the therapist to identify suitable goals related to the problems. These goals then become the focus of therapy. Goal attainment is then scaled at program completion (Kiresuk et al., 1994). Positive outcomes

have been recorded in the chronic pain literature using the GAS (Fisher & Hardie, 2002). In general, the formulation of realistic achievable goals related to problems in activity for people with chronic pain is a useful strategy for improving performance and chronic pain management (Davis & White, 2008; Filoramo, 2007).

2.3.9.3 *Relaxation training*

Various forms of relaxation have been used in pain programs since their inception in the 1980s. The administration of relaxation techniques within these programs has primarily been the domain of psychologists, physiotherapists and occupational therapists. Relaxation has both physical and mental dimensions, and is aimed at reducing body strain, stress and providing skills for everyday coping (Strong, 2002). The types of relaxation techniques used in clinical settings include progressive muscle relaxation, muscle tense/relax techniques, breathing methods, imagery and meditation (Strong, 2002).

In a systematic review of the effectiveness of relaxation techniques, Seers and Carroll (1998) found insufficient evidence to support the use of relaxation therapy as a useful technique for chronic pain management. However, some studies within the review did report that the use of relaxation resulted in lower pain scores on a variety of outcome measures (Seers & Carroll, 1998). A randomised control trial of 156 people with temporomandibular pain, allocated to either a CBT-based pain program or an education only control group, showed improvement in the CBT group, where therapy included relaxation (Turner, Mancl, & Aaron, 2006). Of the number of pain coping measures utilised in that study, only relaxation showed a significant treatment effect for people within the CBT group.

Although the evidence for the use of relaxation therapy has not been thoroughly evaluated, both individual and group relaxation sessions continue to be integral parts of pain programs within Australia (Nicholas, Molloy, Tonkin, & Beeston, 2006; van Huet & Williams, 2007). Brown (2003), however, found incongruence between service users (chronic pain patients) and occupational therapists about what treatments were important. Occupational therapists valued their strategies more highly than

service users, who saw individual and hands-on treatment as more worthwhile. Brown and Pinnington (2007) noted that although relaxation was endorsed by both occupational and physical therapists in pain programs as a useful technique, evidence as to its effectiveness was lacking.

The following section of this literature review discusses life meaning and experience for people with chronic pain. This is considered from the philosophical perspectives of time and narrative as a way of framing a person's life lived with chronic pain and the meaning and experience of ongoing illness.

2.4 Ways of Explicating Life Meaning and Experience

2.4.1 Time and Narrative: A Ricoeurian Perspective

Significant to this research is consideration of the narratives or stories told by participants who had either attended a chronic pain program or were therapists working with people with pain. People situate themselves in enfolded stories about their past, present and future selves with others. Thus, stories consider the narrator's view of his/her personal story, the audience the story is being told to, and how the person wants to be represented in the story.

In the first of his four volumes of work entitled *Time and Narrative* Ricoeur (1984, p. 7) addressed what he saw as the "aporia" (or serious perplexity) of the being and the nonbeing of time. Ricoeur (1984) debated that if measuring time chronologically can only be done as it is passing, then the aporia is that if measurable time is in transit "how can time exist if the past is no longer, if the future is not yet and the present is not always?" (p. 7). He compared this to the phenomenology of what he called the "three-fold present" (p. 12). This is the present of past things or memory, the present of present things, which is attention, and the present of future things, which is expectation. This is seen as a way of time existing and having a "being". This is applied to narrative, as it implies memory on the part of the narrator; so to remember is to have an image of the past and prediction

implies expectation on the part of the listener about what the future of the story will be.

The concept of “*distentio animi*” is considered in relation to the three-fold present (Ricoeur, 1984, p. 5). This sees past, present and future time as elastic and capable of distension in either direction. Consider the person with chronic pain telling his/her story about his/her time before, during and after attending a chronic PMP. Before the story is told there is an expectation (on the part of the listener) about what the story will be. Once the story starts, however, it passes through the present into the past and memory. Thus, what is in the future passes through the process of becoming the past; therefore the memory is extended and expectation is reduced, until the end of the story when expectation has been absorbed. This philosophical stance in consideration of time in narrative sees the extension of time in either direction (future becoming present becoming past, and expectation becoming memory) as important. Stories encompass the past (what has been), the present (what is now) and the future (goals, hopes and a projection of what the future self might be).

The narrative plot is the intersection between the progression of events over time, where the person’s situation may become better or worse (Kielhofner et al., 2008). Ricoeur (1984, p. ix) wrote, “By means of a plot, goals, causes and chance are brought together within the temporal unity of a whole and complete action”. He explained that the composition of the plot is grounded in the world of action, its meaning structures (environments), its symbolic resources (social symbols), and its temporal characteristics (past, present and future). Thus the narrative is meaningful in that it portrays the features of human lived existence in relation to self and others. Actions, events and interactions within stories can be symbolic in terms of relationships (e.g., mother to daughter), or be imbued by cultural symbols (e.g., a family gathering at a meal every Sunday night), and all elements of stories contain a temporal existence of human lived and living time.

Polkinghorne (1995, p. 300) described Ricoeur's consideration of the operation of narrative as:

(a) orienting actions and events towards an outcome; (b) organizing actions and events in a temporal sequence in which they provide a beginning, a middle and an end of a project; and (c) exhibiting the meanings of actions and events according to their contribution to an outcome.

Mattingly (1994, p. 254) stated that "story time is human time rather than physical time: It is shaped by motive and intention". Seeing oneself within a story takes into account what has gone before, why the story is being told and what influenced the ending of the story coming about in the way that it did. Stories are imbued with suffering. Actions are not always guaranteed to occur according to plan. Mattingly noted that stories told are mostly about movement from a difficult situation to an acceptable conclusion; even simple everyday stories may contain elements of what could have gone wrong between a perceived victor and adversary. McAdams (1993) saw people as natural storytellers regardless of cultural background. He regarded stories as having an organisational aspect of life events as well as allowing the expression of feelings or emotions to others.

Criticisms of narrative theory have concerned the authenticity of the story told and how it can be understood to be a truthful account of events (Frank, 2000). This pragmatic view has been challenged by exponents of narrative as a therapeutic medium by acknowledging that the person's story will be bound by the limits of believability and acceptability to self and others (Frank, 2000). A particular story told by a particular person at a particular time may differ slightly from the story told at another time in another environment, but the elemental aspects of the story would remain the same. Both versions of the story would be equally real to the storyteller, and the listener would be allowed an opportunity to view one of many aspects of the life of that person.

Kielhofner et al. (2008, p. 127) stated that "narratives are open-ended and thus allow us to comprehend emergent events and circumstances of life tying them to what has gone before and what might come next". Narrative

plots have been described as having tragic, comic or heroic aspects influenced by how the protagonist has interpreted what has gone before and what is envisaged for the future. Researchers of life narratives explore people's stories for transitions or changes in the narrative (Kielhofner et al., 2008; Riessman, 1993). The exploration may take the form of graphing out significant events to determine whether the narrative is dominated by positive or negative events, or noting whether there were significant turning points, when behavioural or other change was made (i.e., from negative to positive). The above has import for research about the human experience of chronic pain, as narratives provide an opportunity through which to view the meaning of what has happened to the person, to how he/she is presently, to what is expected in the future. These temporal aspects of past, present and future are considered in relation to illness narratives.

2.4.2 Meaning and Experience of Chronic Pain Reflected in Illness Narratives.

Kleinman (1988, p. xii) pioneered an understanding of how "chronic illness is lived and responded to" in his exploration of illness narratives. Narrative methods have since been used to explore the meaning and experience of illness, disability and chronic pain and the impact on the self, role and occupational engagement (Aegler & Satink, 2009; Alsaker & Josephsson, 2003, 2010; Keponen & Kielhofner, 2006). As previously stated, narratives elementally contain aspects of trouble and suffering (Mattingly, 1994). This is certainly the case in illness narratives. As illness endows instability and discord within the person's life, narrative pulls together these elements within the framework of the whole life, providing a semblance of order about what has occurred (Mattingly, 1998). The meanings attributed to what has happened, however, are subject to what is possible depending on how the past is interpreted and acted upon.

2.4.2.1 Narrative as remaking a life

In his work *The Wounded Storyteller*, Frank (1995) detailed how illness can provide power to a person's life story by providing an authentic account that describes how the illness has impacted on one's life. He saw

the importance of the body needing to give voice to what has occurred, in order to make sense of the illness and enable the person to gain restitution by remaking his or her self. This remaking process is time contingent and often achieved only when the person has reached his/her lowest point. This turning is seen as critical to allow the person to make meaning out of suffering and enable the “future still to arrive” (Frank, 1995, p. 89) to the possibilities of a remade life lived with illness or pain.

Charmaz (1991) also saw remaking a life as critical to managing illness. The experience of chronic pain was seen as “biographical disruption” (Bury, 1982, p. 169), where the person’s life story is affected by the assumptions of a changed self, the meaning given to the events around the disruption and the manner in which resources are utilised to deal with the disruption (Corbett, 2007). Charmaz (1991) saw that solutions to problems of living with chronic illness were related to organisation. Control was gained by organising elements of time, environment, self and support from significant others. Temporal aspects were related to “altered time structures and shifting time perspectives” (p.171). Here the participants in the Charmaz study told of living one day at a time or from moment to moment, taking time to do things and sometimes merely existing. As in Frank’s (1995) study, Charmaz found that remaking was related to a turning point in a person’s life. She described this as an individual’s shift in direction and self-concept when acknowledging who one was prior to illness, who one is at the present, and what might happen in the future.

2.4.2.2 *Turning points in narrative*

These turning points are critical to acknowledge within narrative as they provide insight into influences that lead to remaking of an acceptable self. McAdams and Bowman (2001) noted that the turning points, while not necessarily being an epiphany, were indicative of significant life change. For the ill person these changes were characterised by a change in the self, difference in relating to others, and taking on a different philosophy on life. Times of transition appear significant to the remaking or emancipation of the person within the illness.

2.4.2.3 *Agentic and victimic plots*

Polkinghorne (1995) described how narratives had a transformative ability influenced by a person's sense of agency. People with chronic pain, he noted, may manifest one of two narrative types, "agentic" or "victimic" (pp. 301-302). Agentic life plots were characterised by motivation and persistence in developing skills in problem solving around the chronic pain. The stories were imbued with a confidence and a sense of personal agency that people would achieve their goals. Conversely, victimic life plots were characterised by passivity, with people seeing others as controlling life events and being unable to influence the outcome.

Agentic narratives contain elements of action related to doing something positive to achieve set goals. Victimic narratives are essentially non-active, where the person appears stuck in place and unable to move forward towards personal agency. The occupational elements of the narrative are evident in the "doing" or "not doing" of something that will effect change and achievement.

Terms such as "meaning out of chaos" (Bullington et al., 2003, p. 325) describe the process of identity restitution and a re-emergence of agency for pain program participants, as identified by clinicians working within a chronic pain program. Clinicians described people needing to have their pain validated by being given a diagnosis. Once this was given, however, it had to be integrated into personal meaning and identity. Rediscovering personal agency was seen as a later part of the process related to people understanding the nature and relationship of their pain to their thinking and bodily functions and being able to reconnect to the outside world with their reformed identity.

2.4.2.4 *Illness narratives and health care politics*

The political role of the illness narrative has been considered by Sakalys (2000). Adopting the sick role provides a temporary exclusion from daily responsibilities. Placing oneself in another's care (in the case of this study, the health professional), however, puts the person in the place of "patient", with subsequent loss of autonomy and removal of decision making. This power is transferred to the medical practitioner or health care provider,

who is able to assert authority over the individual. Foucault (1975) studied the characteristics of institutions and the power relations inherent within them. These ideas can be applied to the health care system (as an institution), as the ill person is subject to regimentation, is low on the hierarchy of social importance, and must be manifestly compliant in order to gain attention to health care needs (Foucault, 1975). Although there is recognition that a reductionist perspective focused on illness has been useful in allowing an enhanced understanding of illness and disease, there has been limited consideration of the subjective illness experience within this perspective (Sakalys, 2000).

The illness narrative therefore provides a counterpoint to a health care system where a biophysical focus dominates illness discourses. The experiential aspects of illness can be understood and explicated only through the use of the person's own voice rather than via a story of medical experiences. This perspective arises from the need for those who are disempowered to have records of their experiences so that they can communicate their own identity.

2.4.2.5 *Stigmatisation and depersonalisation*

Stigma may also be associated with illness. Being ill implies a loss of control of oneself or one's bodily functions. Society demands that control is maintained, so the ill self must manage the loss of control and also manage the impact of this loss on others who should be protected from the embarrassment associated with the stigma (Goffman, 1963). Worth consideration here is a qualitative study of 18 patients of a pain clinic presenting with chronic low back pain (Holloway, Sofear-Bennett, & Walker, 2007). The concept of stigmatisation arose and was noted in the responses of family, friends, health care professionals and community members to the person with chronic pain. Holloway et al. found that people with chronic back pain, particularly when an underlying pathology could not be identified, were subject to disbelief by health professionals, a common misconception being that the pain was "in the head", not in the back. If people were unable to return to the socially valued role of worker, and the injury had occurred at the place of work, they were stigmatised with the idea that they were seeking the secondary gain of compensation.

Hiding how the person was feeling, so as not to impact on the sensibilities of others, was also a common theme. The response of “I am fine” when asked about their condition was seen as the required response in order to avoid subjecting others to how they really were feeling (Holloway et al., p. 1460).

Personal conceptions around chronic pain have been identified as a gap in occupational therapy research, and scholars have attempted to address it using auto-ethnographic methods. In her study of living with chronic pain Neville-Jan (2003), an occupational therapist, explored her experiences of dealing with health professionals who referred to her pain as psychogenic or “the pain is in your head” (p. 90). She described the depersonalisation she experienced with a range of health professionals who ignored her apparent symptoms, which she later attributed to an adherence to methods of behavioural therapy. She saw this approach as patronising, when what she wanted was acknowledgement of what she was going through. Behavioural methods of avoiding talking about pain and challenging her pain beliefs did not provide her with a sense of pain control but stimulated an ongoing search for a cure. She challenged the view that for a condition to be accepted there needs to be objective evidence. It is often not possible to relate chronic pain to an injury or disease process, particularly if the expected time of healing has elapsed and there is no other apparent aetiology. Neville-Jan described health professionals as characterising her pain as a mental disorder, further devaluing her view of self. She argued that health professionals should have an authentic and respectful relationship, where what the person says is seen as authentic and taken into account during treatment. She noted the importance of continuing to work in her valued career and that having goals for the future maintained her motivation to manage her pain.

Other studies support Neville-Jan’s (2003) assertions, noting the depersonalisation of the ill-person by focusing on the presenting complaint and not on its emotional consequences. Peloquin (1993) noted how practitioners distanced themselves from patients when unable to provide answers or when treatment was not effective. In her ethnographic study of

a pain clinic Jackson (2000) noted that the clinical perspective was often disrespectful of pain patients, with disregard for the impact on the whole person and a focus only on the pain component.

2.4.2.6 *Powerlessness and helplessness*

Issues of powerlessness and helplessness dominate the literature on the meaning and experience of ill health and chronic pain (Corbett, 2007; Harding et al., 2005; Strandmark, 2004). In a qualitative study of 25 pain program participants, Bendelow and Williams (1996) found that participants felt a sense of resignation when medical interventions could not provide relief. They found that feelings of hopelessness and despair predominated, with 20 respondents reporting suicidal thoughts. This was related to the length of time in pain and the number of interventions previously used. The female participant in Charmaz's (1999) longitudinal case study described feelings of worthlessness when living with chronic pain and illness over 7 years. Charmaz described the deterioration in her participant's "moral status" (p. 369) that occurred from trying to manage her pain at work and being seen as a bother to other staff.

2.4.2.7 *Narrative and pain language*

Clear articulation of what a person with pain is experiencing is also an issue of language. It is difficult to convey the personal, physical and psychological aspects of pain within socially acceptable categories of language (Corbett, 2007). For pain to be established as a recognisable experience to both self and others, there needs to be a repertoire of words used that are culturally accepted (Kleinman, 1988). The language used may differ, however, depending on the audience (i.e., family, work colleagues, health professionals). Ong, Hooper, Dunn and Croft (2004) explored the narrative reconstructions that people with low back pain used to legitimise their pain to health care providers. Being able to present a believable story that was acceptable to the health practitioner was seen as critical when modern clinical pain measurements and tests failed to detect or underestimated the person's pain (Ong et al., 2004). More assertive people with low back pain were noted to elevate their experience to expertise, where they could speak the clinical language and address the power relationships within the clinical setting. The main tension for most

people of giving credible voice to their internal experience of pain, however, was when they were unable to translate their pain into language that matched that of assessment/treatment measures used (Ong et al., 2004).

2.4.2.8 *Gender and the meaning and experience of illness*

Issues of gender arise in both quantitative and qualitative studies of chronic pain. In Australia, women tend to have a higher rate of pain prevalence (Access Economics, November 2007; Blyth et al., 2001), present in greater numbers to health professionals, and have a higher representation in chronic pain program studies (Burns, Kublius, Bruehl, Harden, & Lofland, 2003; Kaur et al., 2007; Martensson & Dahlin-Ivanoff, 2006; van Huet & Williams, 2007). Women have also been noted to have lower pain thresholds and higher pain ratings, and to experience severe pain more often (Miller & Newton, 2006). Social and cultural factors may influence this, such as women being more ready to share their pain stories, and having lower self-efficacy expectations (ability to complete desired roles and tasks) (Miller & Newton, 2006).

In a study of ten women's pain narratives within a pain group, Werner, Isaksen and Malterud (2004) found that stories were characterised by personal strength, with whining and complaining about pain seen as a shame and weakness. That strength, however, appeared to the researchers to be out of character with the women's actual reduced physical capacities in a range of daily activities (Werner et al., 2004). Their storytelling was interpreted as being about providing a credible pain story acceptable to others, with an idealised version of self, similar to the findings of Ong et al. (2004). In another study based on the same women, Werner, Steihaug, and Malterud (2003) noted that their group experience had facilitated the recovery of some personal competence, which enabled them to have a better life when living with pain. This was related to the pain group's goals, initially for reducing pain and increasing physical fitness, then changing to developing tools and strategies to handle pain and strengthen resources.

2.4.2.9 Use of metaphor

The use of metaphor within stories was studied in depth by Ricoeur (1977) and Schon (1979). Ricoeur saw metaphor as representing the semantics of language, in that the meaning of the metaphor has no relation to the words used, but is still understood by others. For example, the metaphor “kicking the bucket” symbolises someone dying. There is no direct relationship between death and kicking a bucket, but there is an inference that the metaphor used is understood by both narrator and listener.

Metaphors are used in stories to identify aspects that might be emotionally challenging, or difficult to explain using plain language. They add an extra symbolic dimension to the story being told. They are euphemistic, in that the narrator believes the alternative term to be easier for the listener to hear, rather than interfering with the plot of the story being told. Schon found that metaphors are primarily used to describe difficult events or things that have gone wrong in people’s lives. He saw that metaphors can have a reparative role by indicating what people need to do to fix their problems. The use of metaphor within pain narratives has been noted by Ong et al. (2004), when everyday descriptive words do not meet the individual’s image of the pain. In her ethnographic study of pain program participants, Jackson (2000, p. 95) discussed that “although everyday-world language has trouble describing the lived experience of non-everyday worlds (living with chronic pain), it becomes adequate to the task – indeed, often eloquent – if it is allowed metaphor”. Metaphor therefore adds another dimension to chronic pain stories, where pain as a construct can be represented in a subjective sense but represented in a way that others can understand.

The following sections of this literature review focus on theories of identity and self and the relation of this to social roles. This is relevant when the aspects of identity/self are recognised within chronic pain narratives and the personal nature of the meaning and experience of illness. Occupation and occupational self/identity are defined and discussed with reference to how engagement in occupation adds a unique dimension to identity/self. Occupational self/identity are related to the concept of occupational roles

and role performance. The above informed the research and influenced the research process.

2.5 Identity, Self and Role

When human stories are told the plot is considered from the standpoint of the protagonist or narrator. How the person places him/herself within the narrative may be influenced by how the person sees him/herself as perceived by others. The relating of self stories requires, therefore, a consideration of what constitutes self or one's identity. The terms "identity" and "self" have been used interchangeably in health literature. The problematic nature of defining exactly what self and identity are has been the subject of rigorous debate and discourse in the fields of philosophy, sociology and psychology over the past 50 years. The following reflection on identity/self is considered from the viewpoints of psychology and sociology, as these two disciplines are relevant to the foundational aspects of this research and have been influential in occupational therapy theory and practice.

2.5.1 Historical View of Self/identity

Mediaeval Western societies viewed people not as individuals but more by the form and function that they took within the collective. People were identified by their class or position in society and their work occupation rather than their personality traits. Life goals were related to living a good Christian life and being delivered into salvation at life's end (Baumeister, 1997). Within the last 500 years there has been a profound interest in what makes individuals different from each other. This was accompanied by the emergence of autobiographical and biographical writing about the details of people's lives, primarily notable people. The modern Western assumption of being able to choose a desired identity arose from what was termed "identity crisis" (Erikson, 1968), where people actively questioned who they thought they were and what they wanted from life. This focus on the inner self has been manifest ever since, with everyday terminology referring to people going through mid-life crises, finding

oneself and so on, in response to societal influences, illness or impairment.

A sociological perspective of self was detailed in the 1930s in the work of G. H. Mead in *Mind, Self and Society* (Mead, 1934). Mead, a social psychologist, saw the self as socially constructed out of social experience. He rejected the idea of mind and body dualism and believed that the complex human system operated as part of the whole. He saw community as controlling the conduct of individuals residing in it, and the individual being influenced by the community in terms of behavioural expectations. He saw self as taking one of two forms, the “I” and the “me”. As stated by Mead (1934, p. 175) “The ‘I’ is the response of the organism to the attitudes of the others; the ‘me’ is the organised set of attitudes of others that one himself assumes”. The “I” in this case is how one identifies oneself and social position. The “me” is the reflexive element of self that has taken account of the views of others and subsumed them. Mead’s assumptions resulted in the formation of the symbolic interactionist movement that has continued to influence social theory strongly to the present day (Charon, 2007).

2.5.2 Psychology of Self

In his work *Acts of Meaning*, Jerome Bruner (1990) attempted to describe the emergent view of self in the discipline of psychology. Psychology’s view of self has been influenced by this in-depth study. Bruner introduced the notion of the “conceptual self” (p. 100). He theorised that the conceptual self could be created by one’s reflection on self as part of a social group (e.g., family), or could be a composite of different possible selves or personality traits that all affected the self currently presented to others. This view of self was seen as a transaction of the process of being in action (doing something) in a socially situated context (with others) and could be dialogue-dependent (i.e., created in relationship to others).

Bruner (1990) surmised that psychology at that time (mid-1980s) had largely disregarded this transactional view of self and had instead focused

on the measurable attributes of the self such as self-concept and intelligence, in an attempt to objectify them. Bruner, however, recognised the importance of both the self-concept (as an aspect of self) and the socially situated characteristics of self and how these were affected by actions or doing in the social and cultural world. He wrote, “Self can be seen as a product of the situations in which it operates” (p. 109), and recognised that this was also time-contingent. He discussed the emergence in the 1970s-80s of the narrative self, or that created by the person telling stories about action. He described the idea of human reflexivity – our capacity to turn around on the past and alter the present in its light. This re-conceptualisation means that there are alternatives to affect future change in how things will be done. These ideas support the concept of the past linked to the future as espoused in the work of Ricoeur (1984).

Bruner (1990) saw the self as having permanent and changing aspects according to the particular situation and the values and beliefs of the person. Culturally, there is a concept of self that applies to a given situation and a given discourse about self that accompanies that situation. As later similarly expressed by Frank (2000), Bruner thought that no final interpretation about the discourse is possible, as there can be no certainty as to what has been told. Although there can be no absolute truth applied to the narrative, generally the social nature of the told narrative places limits on what is plausible and can be interpreted as likely to have happened.

Bruner (1990) considered the use of narrative as the only way to know the self, and referred to the use of autobiography. He saw it as not subject to accounts of external witnesses, not concerned with self-deception or truth, but what the person thought he/she did, why he/she did it and what he/she thought about it. The concept of a protagonist in the here and now, telling an account of a person bearing his/her name in the there and then, has distinct links to the work of Ricoeur (1984) and his theoretical discussions of emplotment and the temporal elements of “*distentio animi*” (p. 5) as discussed in earlier sections of this chapter. This view was also supported

by Polkinghorne (1988, p. 116), who stated, “Self, then, is not a static thing or a substance but a configuring of personal events into a historical unity which included not only what one has been but also anticipations of what one will be”. Thus the goals and aspirations of the person in part drive the narrative and influence the narrative turn (McAdams & Bowman, 2001).

People with chronic pain experience narrative disruption that affects the construction of the self, with the future often seen as uncertain. Alsaker and Jossephson (2010, p. 172) explored the negotiation of identity when living with chronic illness. The “suspense and unpredictability” of living with pain and disability everyday affected how participants saw themselves in the present, while they avoided talking about the future.

2.5.3 Identity, Self-knowledge and Self-esteem

Building on the self as known through the narrative is Baumeister’s (1999) perspective of the human experience of self, based on the aspects of reflexive consciousness or looking back on one’s life and experiences, and how this moulds or alters the current self. This includes the interpersonal being that focuses on self in relation to others and the relationship with others, and executive functions or the cognitive aspects of self that enable action, change and control over the self. Baumeister (1997) described different components that made up these aspects, namely (a) self, or “the direct feeling each person has of privileged access to his or her own thoughts and feelings and sensations” (p. 681); (b) self-knowledge, or what people know and believe about themselves; (c) self-esteem, or the evaluative aspect of the self and identity; and (d) the socially outward appearance of the self, which reflects the public persona that is termed as identity.

Self-knowledge had previously been synonymous with self-concept, but self-knowledge has subsumed this term (in psychology) due to the recognition that only part of the self-concept might be in a person’s consciousness at a given time, whereas self-knowledge can include that which has been stored or assimilated into the self. It includes

consideration of a person's individual personality traits and an understanding of relationships and roles enacted with others in social settings. Emotions appear to be particularly related to self-knowledge when the desired and non-desired aspects of the self are recognised.

The development of self-knowledge begins in childhood. It is related to an understanding of abstract concepts, such as object permanency, and also to social interactions and feedback from peers. As such it develops over time, whereas identity is immediate (i.e., you are your mother's daughter). As a child grows older self-knowledge is related to capabilities and competencies, such as being good at maths and being a fast runner. In adolescence children become more concerned with issues of perceived rights, choices and values. The development of self-knowledge is therefore time-contingent to the particular context in which the person is developing. By adolescence and adulthood, people have a collection of concepts about who and what they are, although they continue to refine these based on life events (Baumeister, 1997).

The development of self-esteem may begin early in a child's life. Concepts of goodness and badness become ingrained at an early age and are directly linked to competent performance in activities and behaviour associated with this. Self-esteem has been seen as a central trait impacting on the formation of self-knowledge in that it is influenced by the evaluation the person receives from others, but also relates to self-efficacy, successful performance or failure (Baumeister, 1997).

As identity is socially constructed it demands public recognition to validate it. This may be related to work and family roles and to enacting these roles convincingly, to prove to others who the person is, and it is influenced by the person's own ideal about how he/she should behave (Baumeister, 1997). To examine this further, role and a critique of role theory are discussed.

2.5.4 Role

Identity and its construction are influenced by the roles that a person enacts in life. The concept of role originated from the storytelling of ancient Greek legends by wandering minstrels. These legends were later enacted as plays in amphitheatres, where characters took upon themselves roles related to being a hero or a villain, a lover or a betrayer, enacting the stories based on historical accounts (Heard, 1977, Mc Adam, 1993). To portray a role realistically, an actor played a part constrained by a script of expected actions and behaviours related to the character. This idea formed the basis of role theory, with the metaphorical transference of the “players” to social contexts, with behaviours enacted by social “actors” and understood by others.

Role has been defined as “behaviour referring to normative expectations associated with a position in a social system” (Allen & van de Vliert, 1984, p. 3). Sarbin and Allen (1968) wrote a definitive summary of the then current understanding of role theory in the 1960s. They defined role as “a metaphor intended to denote conduct that adheres to certain parts” or positions in society (p. 489). They also coined the term “role enactment” (p. 489) to describe the way that roles were acted out in daily life. Life roles may be related to familial obligations, employment or social requirements. Life narratives can be interpreted as being situated within a temporal context and enacted by the adoption of roles, as the protagonists in the story have designated roles that are played out.

Parsons (1951) took a social systems view of role, in that enactment of a role had to meet certain standards of behaviour to be seen as legitimate and that legitimacy was reinforced by others. Within this view, individual differences were discounted, as roles were seen as collectively based on consensus and interdependence (Raffel, 1999). Sarbin and Allen (1968) stated that for a role to be recognised it had to imply the appropriateness, propriety and convincingness of the enactment. Thus, the correct role had to be enacted to a certain level to ensure its credibility, including that the person be what he or she claims to be. Sarbin and Allen also recognised that people enacted a number of roles as part of their social repertoire,

and that some roles required various levels of involvement depending on the cognitive and/or physical skills required. The temporal and spatial aspects of roles were also recognised, as the time a person spends on a given role will differ according to the ascribed component of that role. For example, being a mother of a young child will mean that the person will spend the majority of time enacting that role and that it will be performed at a proper time and place. Roles could further be seen as general (e.g., a person in a crowd) or specific (e.g., a bank manager) and could also be formal or informal within the broader social system (Sarbin & Allen, 1968).

Merton (1969) and Sarbin and Allen (1968) recognised that the prescribed social order could be disrupted, introducing the concept of role conflict. The premise of role conflict is that compliance within a certain role is influenced by the role expectations of others and may need to be altered to allow for this difference. Also, role conflict can occur when there is simultaneous enactment of two roles with incompatible expectations (e.g., being a child-carer while trying to write a doctoral thesis!). Merton saw the conflict being resolved by the person conforming to the dominant role “player” that the person interacted with, or by the heightened expectations of significant others determining the role that predominated.

The development of role theory has been influenced by symbolic interactionism, which views roles as evolving solely through social interaction and how the person views his/her and other’s conduct. People make judgements of others based on expectations about performance based on norms or a set of imperatives that guide behaviour (Biddle, 1986). Roles have determined social positions within society and behavioural expectations related to those positions (i.e., worker status, parent) (Christiansen & Baum, 1997).

Debate in role theory has been based on the perspective of various researchers regarding the meaning of the term “role” as to whether it refers to characteristic behaviours, social parts to be played, or the scripts for social conduct (Biddle, 1986). Role scripts are seen as internalised and are based on the developmental level of the person. They are based on

expected behaviours, but can be subject to improvisation according to the situational context. Society has expectations about how roles are to be performed and what scripts are acceptable. Those with chronic pain, for instance, may fall outside accepted roles if their role enactment is affected and their role script becomes laden with dialogue around pain. There are also disagreements among role theorists as to whether role theory should take an individual perspective or consider the person as representative of a certain position in society, thus expecting all in that role to exhibit the same beliefs and behaviours (Biddle, 1986).

2.5.4.1 Critique of role theory

An ongoing problem for role theorists has been where to recognise and position aspects of the self and the self as dominated by social construction. A symbolic interactionist perspective of self has been confounded by the notion that “to be an object to one-self... is always, then, a matter of taking the role of some other” (Biddle, 1986, p. 13). The ongoing problem for social theorists has been how people can be themselves and still fulfil social roles.

Role theorists have been concerned with issues of consensus and conformity across societal roles. Jackson (1998a) detailed that consensus and conformity appear essential to social acceptance and integration. However, she also argued that there are people in society who cannot meet the normative expectations of society and are therefore considered deviant and maladaptive (Jackson, 1998b). She argued that taking a collective standpoint would marginalise people, particularly the elderly, the ill and those with a disability. It must be stated that Jackson’s views were based on a functional consideration of role theory that saw inequality as being in society because not everyone can occupy the same social position (Parsons, 1951). This viewpoint of Parsons has been largely discarded by social scientists (Biddle, 1986). It is relevant, however, in reference to chronic pain, as identity and roles can both be affected in relation to adjustments to activities undertaken and the way these adjustments and related behaviours are perceived by others. These issues are considered further in the following sections, which define and discuss

occupation, occupational identity, occupational role and occupational performance.

2.6 Occupational Terms

2.6.1 Occupation

The views of the disciplines of psychology and sociology have undoubtedly influenced occupational therapy, but the advent of the scholarly consideration of occupation through the discipline of occupational science has seen the importance of occupation enhanced. Occupational science is devoted to the consideration of how occupations provide meaning, structure, and wellbeing in everyday life (Hocking, 2000). Occupation is considered as the activities that one does every day, and is categorised in a variety of ways, most classifications including self-care, productivity, and leisure (Christiansen & Townsend, 2004). Occupations may be spiritual or symbolic, depending on the beliefs and values of the individual. Occupations can be performed alone or in a social context, but are generally seen to be culturally and socially bound and to occur over time (Hocking, 2000). Wilcock (1999, p. 2) referred to “doing, being and becoming” as inherent to occupation, in that “doing” informs the person of who he/she is within a given context and provides a process of becoming competent and recognised as a social being. Within these definitions is recognition of the complexity of factors influencing what is done when and how it is done. There is also recognition of the personal, social and cultural importance of engagement in occupation and how people perceive themselves based on their level of competency. Thus, the performance of action (or occupation) provides personal meaning when placed within a sociocultural context as interpreted by self and others.

2.6.1.1 Occupational self/identity

The concept of the occupational self/identity has been developed in occupational therapy literature to consider how occupations contribute to identity and have particular meaning and purpose to an individual. Christiansen (1999) explored the concept in detail, noting that occupations structure our day, provide routine and are fundamental to being a

particular person. He saw occupations as a primary way of relaying to others what it means to be a competent person. He stated that “identities are closely tied to what we do and the interpretations of those actions in the context of our relationships to others” (p. 549). Competent performance of occupations is seen as critical to maintaining one’s self-esteem and perceived wellbeing.

Kielhofner (2002, p. 119) defined occupational identity as “a composite sense of who one is and wishes to become as an occupational being generated from one’s history of occupational participation”. This definition provides a sense of the complexity of the relationship between what people do and how they see themselves in relation to their past, present and future.

Unruh (2004) emphasised the interaction between occupational identity and environment based on the intrinsic elements of (a) the person, including physical, emotional, cognitive and spiritual; (b) the environment, including physical and social; and (c) occupations of self-care, productivity and leisure. The cultural aspects of identity are also related to particular occupations and their significance to families and communities. Implied here are behavioural expectations about what one will do in a given context that is validated by others as being appropriate. Public aspects of occupational identity are primarily attached to productivity occupations or work, gender and social roles. Private aspects of identity may be those performed in isolation or with few others, including sexual, spiritual and creative occupations. When living with an illness or disability confounds the ability to be independent and competent, the ability to perform desired occupations may be disrupted. This can create a crisis in identity when the expectation of a particular self-image cannot be met. This was also considered in Section 2.3.9 on the meaning and experience of illness.

2.6.1.2 Occupational role

The importance of the interaction between occupation and role performance has been highlighted in a significant body of occupational therapy research. Heard (1977, p. 244) defined occupational role as “the activity in one’s daily life that allows a person to contribute to society,

thereby defining the person's societal worth". She identified three critical dimensions of occupational role: (a) habits and skills are inherent in role; (b) roles provide an organisational component to gain competence in daily activities; and (c) the adaptive nature of the individual determines the ease of occupational role acquisition. She further proposed a model of occupational role enactment that took into account internal and external expectancies inherent in roles and the transaction between the person and others in role performance. Jackson (1998b) noted the potential inconsistencies between traditional role theory and occupational role as situated in occupational science. These inconsistencies included looking beyond the linear way role was considered to develop an understanding of how multiple occupations and indeed occupational roles can be enfolded or embedded within each other. As occupational science took a humanistic approach, another tension existed between the objectivity of role theory from a functionalist perspective (Parsons, 1951) and the subjectivity of actual human experience and meaning. The idea of socially sanctioned occupations occurring within roles is counterpointed by the consideration of unique perspectives that can contradict social norms. Role expectations and role conflict were also considered by Merton (1969) as societal constructions that did not recognise personal choice and agency about how roles could be performed, dependent on the satisfaction of the individual with actual role enactment.

According to Hillman and Chapparo (2002, p. 88) "occupational roles are patterns of self maintenance, work, leisure and rest activities that are done on a regular basis and are strongly associated with social, cultural roles". Occupational role performance, then, is the way that activities linked to these roles are carried out. In their Model of Occupational Role Performance, Hillman and Chapparo (2002) noted the relationship between perceived control when performing roles, the personal meaning attached to the performance and the active engagement in terms of repertoire, time, and role change over the life span. These aspects could be seen as relevant to people with chronic pain, particularly when roles become disrupted and role performance is consequently affected. There is little research exploring the value and meaning of occupational role,

particularly for people with chronic illness (Hillman & Chapparo, 1995, 2002).

2.6.1.3 Occupational performance

The characteristic or recognisable aspects of occupation, such as materials, environment, and human and temporal contexts, have been referred to as “occupational forms” (Nelson, 1988), whereas the actual doing or action of carrying out the occupational form has been termed “occupational performance” (Nelson, 1988, p. 634). With a more comprehensive view of occupational performance, Chapparo and Ranka (1997) defined it as “the ability to perceive, desire, recall, plan and carry out roles, routines, tasks and sub-tasks for the purpose of self-maintenance, productivity, leisure and rest in response to demands of the internal and/or external environment” (p. 58). The performance of occupations can be directly related to roles and routines performed each day. Occupational performance models of practice (e.g., the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al., 2007); Occupational Performance Model – Australia (Chapparo & Ranka, 1997) and measures of occupational performance (e.g., Canadian Occupational Performance Measure (COPM) (Law et al., 1994) have been formulated and applied to practice.

The following section considers how occupations provide meaning in people’s everyday lives. Chronic illness and pain can necessitate change in how valued occupations are performed, leading to adaptation of performance.

2.7 Occupations of Meaning and Adaptation

2.7.1 Occupations of Meaning

Wilcock (2005) researched and demonstrated how engagement in occupation is essential for health, wellbeing and survival. People engage in doing for reasons beyond necessity and obligation. People choose which occupations they engage in related to interests, values and competence with performance. Occupations can be seen as being health

promoting when they provide people with choice, meaning, purpose, creativity, and capacity to change or cope with the environment (Wilcock, 2005). The implication of occupational engagement for people with illness and disability is central to occupational therapy, because occupation is the therapeutic medium that underlies practice.

People experiencing chronic illness report restrictions in what they can do every day. In a study of the life stories of 15 people with chronic fatigue syndrome, Gray and Fossey (2003) found that their participants were restricted in the range of activities they could do, that activities required more effort, and that their capacity to participate fluctuated from day to day. In order to complete activities, participants in Gray and Fossey's study modified activities or used assistive devices and planned how to best use the energy available on the day.

Charmaz (1991) also found that people in her study of chronic pain reported good and bad days, with good days being a time to get things done and bad days being characterised by limited activity or prolonged bed rest. There would appear to be a tension between these findings and the concept of activity pacing (Strong, et al., 2002) as a time/quota contingent technique used by therapist-participants with their clients, as discussed in Section 2.3.9.1.

Although a change in usual occupational performance has been noted in chronic pain studies, the value and meaning of actually doing something has been the subject of limited research interest. In a study of occupational participation for six participants with chronic pain, Borell et al. (2006, p. 79) noted that "doing something physical" and "doing something social" were significant motivational drivers to occupational engagement. Another study of 13 people with chronic pain showed that performing a favoured activity gave comfort, whereas activities perceived to give discomfort were avoided (Fisher et al., 2007).

Changing the way in which the person performs a given task has been seen as a way of adapting to the pain while still engaging in valued occupations. A study of eight participants of an interdisciplinary outpatient

pain program found that keeping occupied, although a challenge, was also seen as meaningful (Aegler & Satink, 2009). Activities were adapted, avoided or changed in some way, so that an acceptable level of daily performance was reached. The challenge to finish occupations sometimes resulted in the person continuing with the activity despite pain in order to complete it.

Although the above studies give some insight into the meaning of occupation, further consideration of why occupations are meaningful, particularly for those with chronic pain, is lacking in the research literature. The following section considers the concept of occupational adaptation as critical to living with a disability such as ongoing pain.

2.7.2 Occupational Adaptation

Nelson (1996) discussed the various forms of occupational adaptation that have appeared in occupational therapy literature. He noted that adaptation could be a process of change or a state of reaching an acceptable level of competence, or could involve a change in the person and/or a change in the environment. This was based on the work of Schkade and Shultz (1992), who examined occupational adaptation as a process that allows a person to respond masterfully and adaptively to life's challenges. They saw that adaptation provided the tools to achieve competence in life roles. Kielhofner (2008, p. 121) similarly viewed occupational adaptation as "the construction of a positive occupational identity and achieving occupational competence over time in the context of one's environment". Kielhofner noted that over the life course most people will be faced with occupational adaptation in response to illness or impairment. This would require rebuilding occupational identity and would involve a review of the person's view of personal competence.

There has been limited occupational therapy research into occupational adaptation specific to chronic pain. Klinger, Spaulding, Polatajko, MacKinnon and Miller (1999) focused on rating occupational adaptation for 30 elderly individuals with osteoarthritis. They found that participants

adapted the “doing” element of occupation by changing habits and routines, stopping activities or replacing them with other activities. They found a relationship between pain levels, depression, level of social support and occupational adaptation. Higher pain levels and reduced social support resulted in lower ratings of occupational adaptation. Sofaer et al. (2005), in their qualitative study of 63 older people with chronic pain, found that the first step to adaptation was the acceptance of learning to “live with what could be done” (p. 464). Again, their study highlighted adaptation as involving change for the person, environment, and function as well as noting participants who saw others as “worse off than oneself” (p. 465) and as able to maintain a sense of wellbeing. Considering change in oneself was also found in a study of people with traumatic brain injury (Klinger, 2005). Participants discussed a change in self-identity following injury that influenced occupational adaptation. Klinger found that “acceptance of a new self was fundamental to successful occupational adaptation” (p. 9). In a recent study, Wiseman and Whiteford (2009) investigated the transition to retirement for older rural men. This involved “negotiating a turning point in life” (p. 104) with gradual occupational adaptation over time. These studies consider the self in relation to life transitions and adaptation to this change such as that experienced by people with chronic pain.

2.8 Summary: A Conceptual Framework for the Study

In this chapter I considered the impact of chronic pain on identity and occupation. I also discussed the meaning and experience of having a chronic illness. I explored the use of narrative forms as being a useful way of becoming aware of a person’s pain story and the way the person integrates this into the past, present and future. As a result of this review, I have developed a conceptual frame to guide the design and conduct of the study.

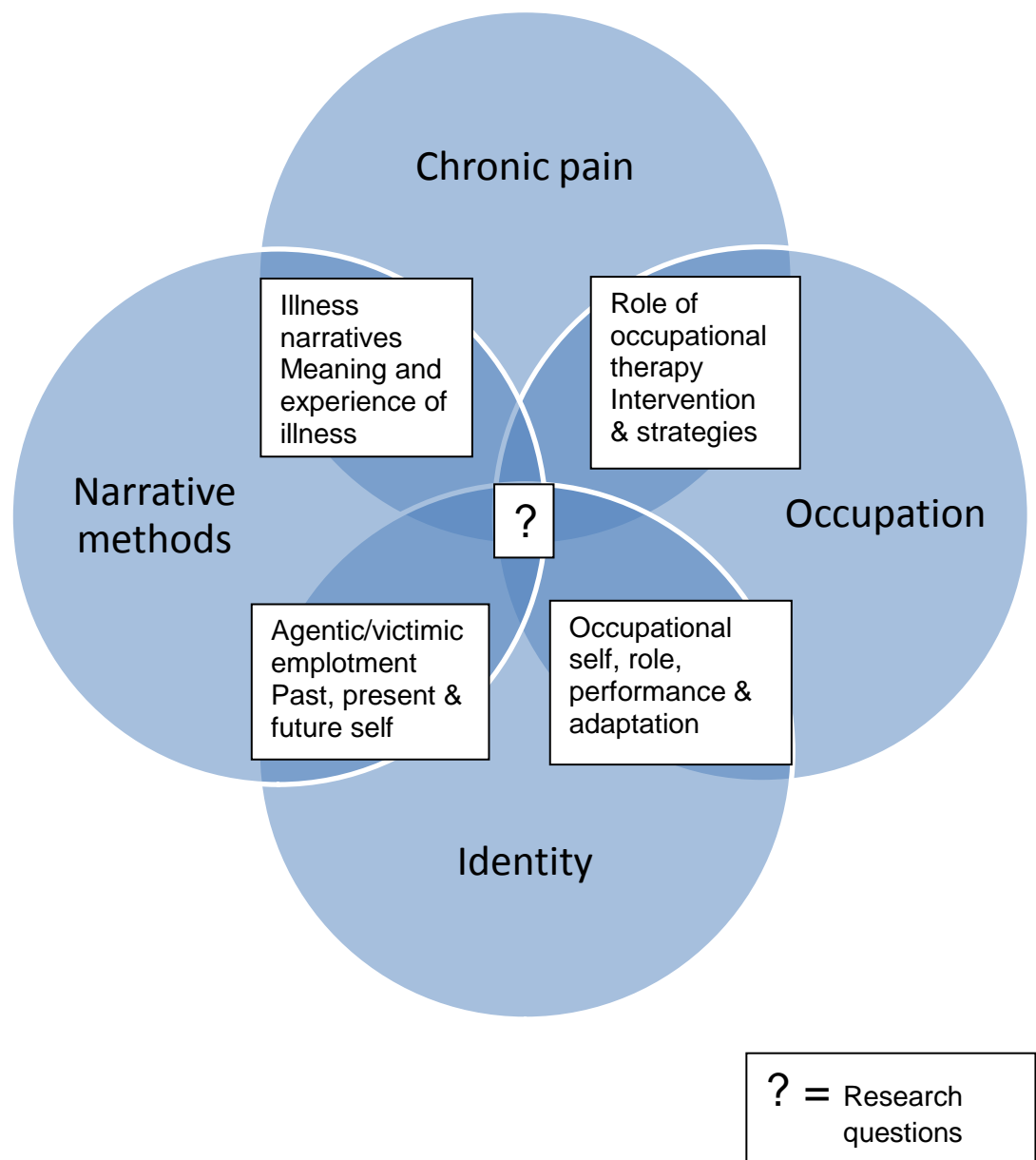


Figure 2.1: Conceptual framework related to research questions that informed and guided the design and conduct of the study.

The conceptual framework details the main areas considered relevant to this study. These are chronic pain, narrative methods, identity and occupation. These broad topics are further divided into specific sections related to the evolving and developmental nature of the literature reviewed within each area. The review and critique of the literature, combined with my practice experience and insights, contributed to the development of the conceptual framework for the design and conduct of this study. The framework helped to focus and shape the research process, and informed the methodological design and influenced the process of data collection (see Bloomberg & Volpe, 2008).

The next chapter addresses the research questions that arose from the literature. It also describes the methods used to implement and conduct the research as influenced by the literature considered in this chapter. The methods chapter additionally details the rationale for study design, recruitment of participants and the research process undertaken.

CHAPTER 3: METHODODOLOGY

3.1 Introduction

This chapter details the purpose of the research, the research approach taken, and the methods used to explore how people live and do with chronic pain every day. The research was conducted in two separate phases, referred to as Stage 1 and Stage 2. An explanation is provided of how the research questions that arose from the literature review guided the methodology used and the data collection procedure, and how the method influenced interpretation of the data and led to the research findings.

3.2 Purpose of the Research

The purpose of this study was to explore how people live with chronic pain in their everyday lives from two perspectives: (a) that of people with chronic pain and (b) that of occupational therapists working in this field of practice. Participants of a chronic pain management program (PMP), who had been part of a previous quantitative study in 2002-2003 (van Huet & Williams, 2007), were invited to participate 2-3 years post-PMP. This became Stage 1 of the research, to see how these people lived with pain at that time (as discussed in the background of Chapter 1).

I was interested to understand the impact of chronic pain on the roles and activities that people did every day, how they engaged in everyday activity and what strategies they used to manage their pain in the long term. For Stage 2, to understand therapists' perspectives, I investigated what factors therapists believed influenced successful pain management in the long term. Thus, the objectives of the research were to:

- Explore how people live and do (perform) everyday activities with chronic pain post attendance at a chronic PMP
- Investigate PMP participants' perspectives as to what influences long-term successful pain management

- Ascertain occupational therapists' perspectives of what predicts long-term successful pain management.

3.3 Research Questions

The following questions for Stage 1 and Stage 2 participants arose out of a previous study exploring self-efficacy and occupational performance and satisfaction for people who had been part of a PMP (van Huet & Williams, 2007). The principal questions that guided the research in the current study were:

How do people live and do with chronic pain in their everyday lives?

What factors do participants perceive influences successful long-term pain management?

Specific questions related to these principal questions emerged from the conceptual framework discussed in the Literature Review chapter (see Section 2.4). The questions in Table 3.1 relate to the areas of research interest that arose from the literature review, these being: (a) chronic pain (meaning and experience of illness), (b) identity (how people see themselves with pain and the effect on role enactment), (c) occupation (effect on occupational engagement and the role of occupational therapy in pain management) and (d) narrative methods (as a way to explore the pain experience). The tabular format in Table 3.1 aligns each question to the areas of research interest.

3.4 Research Approach

The research approach was guided by the exploratory nature of the research questions. A previous study of PMP participants (van Huet & Williams, 2007) used quantitative methods and measures, but I believed that the questions arising from that study and the nature of the pain experience itself were beyond reductionist methods of measurement.

Table 3.1: Questions That Arose From the Conceptual Framework of the Literature Review

Questions that arose from literature review areas of interest	Chronic Pain	Identity	Occupation	Narrative Methods
1. What predicts successful ongoing pain management after attendance at a PMP?	✓	✓	✓	✓
2. What do PMP participants think influences long-term management?	✓	✓	✓	✓
3. What do therapists think influences long-term management?	✓	✓	✓	✓
4. How does chronic pain affect a person's sense of identity/self?	✓	✓	✓	✓
5. How do people perform their daily roles/occupations with chronic pain and what do they find meaningful?	✓	✓	✓	✓
6. What are the pain stories of people who have been through a chronic PMP and what meaning does pain have for them?	✓	✓	✓	✓
7. What are PMP participants' and therapists' views of the benefits and limitations of using behavioural methods and practical strategies in chronic pain programs?	✓	✓	✓	✓
8. What strategies do people continue to use after returning to the community?	✓	✓	✓	✓
9. How do people live and do over a longer term with chronic pain after attending a PMP?	✓	✓	✓	✓

The questions that arose as a result of the previous study conducted in 2002-2003 (van Huet & Williams, 2007) were complex and multidimensional. To capture this complexity, people's beliefs, thoughts and feelings about pain, as well as the actions they took to manage pain required exploration. Also, an understanding of the impact of chronic pain on individuals and others within their social world was required. The quality of this lived experience and the subjectivity of personal views about chronic pain could not be reduced to items of measurement within a quantitative framework; nor, I believed, could quantitative methods encapsulate the complexity of a person's pain story. Therefore a qualitative approach was selected for Stage 1 and again applied in Stage

2. The following section discusses the qualitative research paradigm and the narrative methods used in this research.

3.4.1 Qualitative Research Paradigm

Qualitative researchers “seek answers to questions that stress how social experience is created and given meaning” (Denzin & Lincoln, 2003, p. 13). The interpretive framework of qualitative research contains epistemological, ontological and methodological research assumptions. These assumptions include that the researcher will find new knowledge in the area of inquiry, that the research will have a relationship to existing theory about the area being studied through methods of naturalistic inquiry, and that the researcher will bring a set of personal beliefs and feelings about the area being researched, based on life experience (Denzin & Lincoln, 2005). Qualitative research is focused on “the socially constructed nature of reality, the intimate relationship between the researcher and what is studied and situational constraints that shape inquiry” (Denzin & Lincoln, 2003, p. 13). The qualitative research paradigm does not seek absolutes of truth as outcomes, but recognises a “reality” as is perceived by the individual and as is interpreted by the researcher. As the researcher in this instance I brought to the research a view shaped by life experience and professional practice experience as an occupational therapist (see Section 3.9). The ontology (what is real) and epistemology (ways of knowing) of qualitative methods remain subjects of discussion and interpretation, but as an approach qualitative methods continue to gain credence within health care research due to their ability to capture the socially constructed elements of an experience and the meaning attached to it (Blackburn, 1996).

Within qualitative research, epistemology is based on a research process that considers:

- The researcher, ethics and politics of research, and perception of self and others
- Theoretical paradigms and perspectives

- Research strategies, such as study design and selection of qualitative research method
 - Methods of collection and analysis of data (e.g., interviewing, textual analysis)
 - Interpretation and presentation of findings (i.e., evaluation, writing as interpretation).
- (Denzin & Lincoln, 2005).

A description of this process as applied to this research study is detailed later in this chapter.

Qualitative approaches were indicated for this study as they have an interpretive framework, which was best suited to the exploration of the recognised subjective elements of the research question: “How do people live and do (perform) their everyday roles and activities with chronic pain”. The ontological nature of the research question (living and doing) therefore drove the research approach.

Within the qualitative paradigm, narrative inquiry and narrative analysis provided interpretive methods to study the research question. These were deemed by the researcher to be appropriate methods when the research questions were considered. These methods have been applied in chronic pain research that identified the narrative nature of the chronic pain story (Charmaz, 1991, 1999; Corbett, 2007; Lysack & Seipke, 2002).

3.4.2 Narrative Ways of Knowing

DePoy and Gitlin (2005) noted many approaches to narrative inquiry; all of those, however, centred around storytelling. Narrative inquiry uses people’s stories about a particular experience as data. Chase (2005, p. 652) described narrative inquiry as “revolving around an interest in biographical particulars as narrated by the one who lives them”. A central concern of narrative research is the consideration of voice, namely how the person’s (participant’s) story is represented and interpreted.

To facilitate representation, narrative researchers are required to consider the stories they collect through a number of analytical lenses (Chase, 2005). People tell stories in a particular way in a particular situation; they order the action of the narrative to make sense to themselves and the listener of the meaning of the whole. This is often not chronological. The story related may include the storyteller's emotions and feelings retrospective to the particular situation; but this may not be the result of concerted reflective effort. Ricoeur (1984) stated that narratives are based on actions and emplotment (i.e., the relationship between events and those who act within them). The plot is grounded in its meaning structures (environments), its symbolic resources (social symbols), and its temporal characteristics (past, present and future). In this research, the plot for Stage 1 participants centred on their lived experience of chronic pain, attendance at the PMP, and about their lives before, during and after the program. For Stage 2 participants, their plot centred on working with people who had chronic pain and what they perceived assisted ongoing pain management.

Reissman (1993) stated that narrative methods resist "realist assumptions" (p. 64) of validity within empirical paradigms. People's stories are both bound and enabled by social circumstances and are thus open to interpretation. However, as stated by Polkinghorne (1995, p. 300), "although self-stories are interpretive constructions, no-one is free to impose just any storyline on their lives". Frank (1995) noted that the social world pushes back in various ways to keep the story grounded in actuality.

Within stories, significant events or "turning points" (McAdams & Bowman, 2001, p. 3) can be identified that are indicative of important incidents or changes in people's lives. The turning points for individuals within Stage 1 are highlighted in the findings for that stage (see Section 4.2) as being cathartic, leading in some instances to long-term change.

Depending on situational aspects of stories being told, narratives can contain common elements. These elements may be identified as patterns within stories related to the subjectivities or realities as seen by the person

or group of people sharing that common experience. In this case, the shared experience was chronic pain and participation in the PMP for Stage 1 participants and working in chronic pain settings for Stage 2 participants. From a personal perspective, participants in both Stages 1 and 2 of the research appeared to welcome the opportunity to share their viewpoints. Several remarked that they enjoyed telling their story to me.

3.4.3 Illness Narratives

Narrative methods are “frequently used to illuminate the voices and experiences of marginalised or excluded individuals” (DePoy & Gitlin, 2005, p. 118). Kleinman (1988) introduced the term illness narrative to explore how illness affects the person and the family, and how perceptions of illness or disability are lived and responded to. The concept of illness narratives has gained credence in health care, initially through the work of people such as Kleinman (1988) and Frank (1995), who wrote about perceptions of illness as a lived experience and the relationship of illness to psychological states. Frank saw the process of telling one’s story of illness as redemptive in that by telling the story the person could begin to make sense of his/her experience within a “wounded” body (p. xi).

Polkinghorne (1995), in his research of chronic illness, described victimic and agentic life plots, with life plots defined as the “narrative operation that organises events into a unified flow from beginning to end” (p. 301). Agentic life plots were seen as stories that detailed optimism and hope, whereas victimic narratives had the tone of mistrust of health professionals and resignation about the chronic nature of illness. The use of this classification is particularly relevant to this study of chronic pain and is discussed in reference to the findings in Chapter 5 and 6.

3.4.4 Justification for Use of the Method

The legitimacy of the use of narrative approaches to the study of occupation has been discussed and supported by Clark, Carlson and Polkinghorne (1997). Exploration of pain and illness narratives as a means of understanding the individual pain experience and its impact on daily life

has been utilised in a number of studies by occupational therapists including Charmaz (1999, 2002), Bravemen and Helfrich (2001), Bullington, Nordemar, Nordemar and Sjöström-Flanagan (2003) and Reynolds (2003), and in social science research (Corbett, 2007).

Frank (2000) explained that people tell stories about their lives in an attempt to make sense of illness and disability and their impact on the things they do every day. Charmaz (1991) described her participants' fluctuating ability to engage in life endeavours of meaning and purpose, and the impact this had on them. Narrative methods were used in her study as the most opportune way to elicit in-depth information. When a person's "meaning, experience and function of occupation" (Wicks & Whiteford, 2003, p. 87) are considered, it appeared imperative to understand that person's chronic pain story, in the interest of broadening occupational therapy knowledge about living with chronic pain, when pain is a significant presenting problem throughout occupational therapy practice settings. This imperative guided the use of a narrative approach that adds to existing knowledge specific to chronic pain and occupational therapy practice narratives.

3.5 Study Design

3.5.1 Stages 1 and 2

The study design was qualitative. Questions that arose out of the review of the literature took into account people's stories, life experiences and impacts of living with chronic pain, and determined the approach used. Thus narrative inquiry was deemed appropriate to examine the above, before, during and after participation in the PMP for Stage 1 participants. Semi-structured interviews with a narrative focus were the data gathering method for Stage 1. The interview process utilised is described in Section 3.6.5. Stage 2 followed a similar format, but the questions differed. The questions were aimed at gaining narrative accounts that focused on the therapist-participants' area of chronic pain practice, philosophy behind practice, and considered opinion as to what influenced successful chronic

pain management. This was illustrated by recalling practice case scenarios that were seen as significant.

3.5.2 Study Settings

3.5.2.1 Stage 1 participants

Participants for Stage 1 were sourced from those who had previously attended the Wodonga Regional Health Service (WRHS) PMP based in north-east Victoria. This program is a 3 week in-patient multidisciplinary program based on a biopsychosocial model of chronic pain management. As this service is based near the border between Victoria and New South Wales, referrals are taken from a broad catchment area within those two states. Past participants completed the PMP in 2002-2003, and were also involved in previous research (van Huet & Williams, 2007) prior to being recruited to this study in 2005.

The majority of interviews were conducted in participants' homes. One participant chose to attend the university where I was based for her interviews. Two participants were interviewed by telephone exclusively due to the impracticality of distance from the research site and/or their work and travel commitments. During these interviews there was an awareness of how "the technology mediates the physical space between interviewee and interviewer" (Minichiello, Aroni, & Hays, 2008, p. 55). However these participants appeared to be comfortable using this technology, and the interviews were not significantly different in length from those conducted face-to-face.

The home setting was chosen to provide an environment that allowed exploration of participants' stories within the context of the familiar. The perceived power relationship between the researcher and participants could be expected to be different if, for example, the interview occurred in a clinical or university setting familiar to the researcher. Interviewing in the participant's home also meant that the home environment could be structured to suit individual chronic pain needs. Having a previous background working in chronic pain settings, I was aware that participants

used adapted seating, footrests and various back supports as methods of managing their pain, equipment that would be difficult to transfer to another setting. Also, as participants lived in the communities of regional north-east Victoria and southern New South Wales, travel to an interview venue could be difficult because of fuel and transport costs and the lack of a regular reliable public transport system. Participants chose the date and time of interview, and were made aware that the initial interview and subsequent interviews could last from 1 to 3 hours.

3.5.2.2 Stage 2 participants

Participants for Stage 2 were recruited from Victoria, Queensland, South Australia and New Zealand. Nine occupational therapists who worked within pain management programs in private practice, community or hospital settings were interviewed. Two of the therapist-participants worked on the WRHS PMP and would have had some Stage 1 participants on their program. The researcher travelled to those therapists located within the nearest capital cities or regional areas to conduct interviews. Therapist-participants nominated a venue that would contribute to their level of comfort during interviewing. As a result, one therapist chose to be interviewed at home and two others chose to be interviewed at a community-based venue. Four therapists were interviewed at their places of work. Two therapists were interviewed by telephone due to distance and time constraints. Of the above, five participants were located in capital cities, three worked in rural/regional settings, and one was located overseas.

3.5.3 Study Sequence and Rationale

Table 3.1 details the study sequence, indicating the timelines taken to prepare the research, gain ethics approval, and gather the data. Two research proposals were required to expand the study from Stage 1 to Stage 2 and thus two ethics proposals were submitted. The time taken to gather the data was dependent on the researcher's time availability, funding availability, distances travelled to interview Stage 1 and Stage 2 participants, and participants' availability.

Table 3.2: Study sequence and timelines

SEQUENCE	TIMELINES	STRATEGY
Prepare Stage 1 research proposal	August 2004	Proposal submitted
Stage 1 ethics application	November 2004 – January 2005	Ethics approved
Prepare Stage 2 research proposal	February 2005	Proposal submitted
Stage 1 PMP participant interviews	March 2005 – December 2005	Individual in-depth interviews <i>N</i> =15
Stage 2 ethics application	July 2006	Ethics approved
Stage 2 therapist-participant interviews	October 2006 – June 2007	Individual in-depth interviews <i>N</i> =9

3.6 Research Processes

Undertaking this research involved a series of processes in order to protect the rights of participants of Stage 1 and Stage 2. This included informed consent, confidentiality and right of withdrawal. The research process is detailed as follows and the responsibilities of the researcher are stated.

3.6.1 Ethical Approval

Ethics approval for this project was gained from both the University of Sydney's Human Ethics Committee (November 2004) and the Joint Hospitals' Ethics Committee – Albury-Wodonga (January 2005) for Stage 1 (PMP participants) interviews. Ethics approval for Stage 2 therapist-participant interviews was granted on July 2006 by the University of Sydney (Appendix C).

Participants were informed that they could withdraw at any stage of the project. This provision was included in the participant information sheet and consent form (Appendices A & B).

3.6.2 Recruitment

3.6.2.1 Stage 1

Participants were recruited from the Wodonga Regional Health Service Pain Management Program (WRHS PMP). The reason these particular participants were targeted is that they had all completed the PMP in 2002-2003 and had been provided with consistent information about pain management both during the PMP and post-program in the form of newsletters. Also, they were located within the region where the researcher lived, so were an accessible group. As they were previously involved in a research project (see Background to the Research, Section 1.2) they had some exposure to a research process and were conversant with what informed consent entailed. Although Stage 1 participants were recruited from the previous research project, results from that research were not applied here. As the research questions focused on how people managed their pain in relation to everyday activities in the long term, it was important that interviews were carried out at least 1-2 years after program completion.

Previous participants of the PMP were approached to participate in this research and it was hoped that to allow for maximum variation in sampling, that representatives from the following two groups would be recruited:

1. Persons who had improved on both perceived self-efficacy and occupational performance and satisfaction measures during the PMP and at review.
2. Persons who had deteriorated or stayed at the same level on both measures over the course of the PMP and at review.

(van Huet & Williams, 2007).

People were approached to participate in the first instance by the WRHS PMP, which had contact details stored in secure computer systems. Thus the researcher was not required to directly contact potential participants until consent had been granted to participate. Opportunely for the researcher, representatives from both groups consented to be included in the research.

3.6.2.2 Stage 2

Expressions of interest from occupational therapists working in the area of chronic pain were gained in the following ways. The researcher presented a paper at the 10th World Federation of Occupational Therapists' Congress (WFOT July, 2006) in Sydney and provided an information sheet to attendees. The researcher also presented a paper at a state meeting of the OT Australia (Victoria) Pain Special Interest Group (November, 2006) and provided information sheets. Following these presentations nine therapists provided informed consent to participate.

The reason for this particular method of sampling for Stage 1 and Stage 2 is discussed in the Section 3.6.4.

3.6.3 Consent/Revocation of Consent and Ensuring Confidentiality

Informed consent has been defined as the "voluntary and revocable agreement of a competent individual to participate in a therapeutic or research procedure, based on an adequate understanding of its nature, purpose and implications" (Sim, 1986, p. 584). Potential PMP participants were sent a research project information sheet and a consent form (Appendix A) with revocation attachment, which had been approved by the University of Sydney Human Ethics Committee. These forms were forwarded by the WRHS PMP with the program newsletter by mail to past PMP participants.

Potential therapist-participants were sent a therapist-specific information sheet and consent form (Appendix B) that had also received ethics approval from the University of Sydney Human Ethics Committee. This material was mailed to therapists' places of work by the researcher. In providing consent, all participants were additionally asked to agree to subsequent interviews being audio-taped.

Confidentiality regarding the identity of individuals involved in Stages 1 and 2 was addressed by asking participants to nominate a pseudonym as their participant name. This was of particular importance because, as

noted above, two of the Stage 2 participants worked within the PMP and were aware that Stage 1 participants were drawn from the same program. Further, within transcripts, identifying details such as place of residence, family name, and business name were altered to protect participants' identities. Data arising from interviews, including participants' contact details, were stored in a locked filing cabinet in the researcher's university office.

3.6.4 Sampling

3.6.4.1 Stage 1

Purposive sampling (Liamputtong & Ezzy, 2005) was used, targeting the two specific groups of participants described in the recruitment section (3.6.2.1). Maximum variation sampling (Liamputtong & Ezzy, 2005) was also used, as this typified the wide variations in perceived improvement or deterioration in self-efficacy and occupational performance of participants from the previous study (van Huet & Williams, 2007). This method does not require large numbers of participants but it does require representation from both the targeted groups (improved versus deteriorated). It was the intention of the researcher to include between three to six participants from each of the target groups, making a composite of 12 people in total. Following responses from 15 people consenting to participate, it was decided to include all respondents. Of these respondents, seven had improved on both measures, three had deteriorated on both measures and five had deteriorated on one measure as described in Section 3.6.2.1 above.

Characteristics such as age, gender and/or pain site were not specific criteria for inclusion. This also reflected the maximum variation sampling method. It was intended that by including all respondents, the diversity of participants' backgrounds, gender, age and chronic pain conditions would be represented. This needed to be tempered with practical considerations in terms of time available for data collection and physical access to participants (Llewellyn, Sullivan, & Minichiello, 1999).

3.6.4.2 Stage 2

Purposive sampling was also used as the recruitment procedure for therapists. Therapists were required to be working in chronic pain management programs within Australia. However, as the number of occupational therapists who worked in specific chronic pain programs was perceived to be limited, therapists who worked with people with chronic pain in their general practice were also invited to participate.

As an outcome of these invitations (at the WFOT Congress and OT Australia (Victoria) Pain Special Interest Group), five therapists who worked in hospital-based designated PMPs were recruited. Three therapists were recruited who worked in private practice with people who had chronic pain and had worked in pain programs previously. One therapist was recruited who worked in a community-based PMP. Although Australian-based therapists were sought, one therapist from New Zealand expressed interest in participating. As the therapist worked within a hospital-based designated pain program she was also included.

The demographics of Stage 1 and Stage 2 participants are shown in Tables 3.3 and 3.4 respectively.

Table 3.3: Demographics of Stage 1 participants at time of PMP attendance

Name*	Age (yrs)	Pain Location	Compensation (at time of PMP)	MIP	Marital Status	Highest Education (Years)	Work
Sarah	58	LL	No	84	Married	11	No
Maree	51	LBP	No	18	De facto	Tertiary	P/T
Will	61	LL	No	22	Married	11	No
Alexandra	59	LBP	No	300	Married	11	No
Dawn	55	LBP	Yes	153	Married	11	No
Stacey	31	LBP	Yes	72	Single	12	F/T
Julia	42	LBP	No	288	Married	10	No
Rachel	40	Perineal	No	60	Single	10	Student
Willie	64	LBP	Yes	49	Married	Tertiary	No
Margaret	60	LBP	No	24	Married	Tertiary	No
Alice	58	LBP	No	18	Married	Tertiary	P/T
Bill	62	Cervical	Yes	28	Divorced	Tertiary	No
Rosie	57	LL	No	38	Married	10	No
Ian	51	LBP	No	105	Married	10	No
Sara	43	Thoracic	Yes	26	Divorced	10	F/T

Pain location LL – lower limb, LBP – low back pain **MIP**: Months in pain at time of program attendance **Work (at time of interview)**: P/T= part-time, F/T= full time

Table 3.4: Demographics of Stage 2 therapist-participants at time of interview

Name*	Place of work	Location	Years working in chronic pain	Group (G) or (I) Individual	Work
Marie	H	R	3½	G	P/T
Alison	H	R	2½	G	P/T
Patricia	P	M	15	I	F/T
Elizabeth	H	M	20+	G & I	F/T
Kristine	P	M	20+	I	P/T
Leah	P	M	20+	G & I	F/T
Liz	C	R	9	I	F/T
Louise	H	M	15	G & I	F/T
Matt	H	M	3	G	F/T

Place of work: P= private practice, C= community, H= hospital setting

Location: R= Rural/regional centre, M= metropolitan

Group or Individual: Type of program offered

Work (at time of interview): P/T= part-time, F/T= full time

***Pseudonyms were nominated by all participants or changed to maintain anonymity.**

3.6.5 Method of Collecting Data

Data were collected in the form of a semi-structured, in-depth interview conducted exclusively by the researcher for each of the Stage 1 and Stage 2 participants. For the purpose of this study, an extended story of a significant event (e.g., living with chronic pain for Stage 1 participants) was collected as data. Stories were elicited from participants by the use of a semi-structured format. As stated by Minichiello, Aroni and Hays (2008), a semi-structured interview is dependent on the “social interaction between the interviewer and informant, to elicit interpretation” (p. 53) and is not bound by set interview schedules or a set order of questions. Use of this interview style can provide a greater breadth of data, particularly if undertaken using open-ended, in-depth questioning (Fontana & Frey, 2005). As the nature of the interviews was in-depth, aspects of the life story for Stage 1 participants became apparent due to discussing chronic pain with reference to what they had done before, during and after the PMP. A subtext to the questions was how people saw themselves now, compared to before undertaking the PMP, and what had transpired in the intervening years that had influenced their pain management or otherwise. For Stage 2 participants, questions centred on the methods they used in

practice and what they believed influenced successful pain management in the long term for their clients.

Semi-structured interviewing methods have been utilised in qualitative research for many years and have also been prominent in occupational therapy practice. The use of semi-structured interviews allowed for a more collaborative, inductive method of data gathering (Laliberte-Rudman & Moll, 2001). A recursive mode of questioning was used. This form of questioning “relies on the process of conversational interaction itself, that is, the relationship between the current remark and the next one” (Minichiello et al., 2008, p. 88). This allowed me, as researcher, to determine questions based on the previous response of the informant, dependent on the conversational material provided. Additionally, it allowed me to determine the structure and content of questions at subsequent interviews with a participant, based on the first interview with that participant, to ensure that all areas of research interest were covered. Of particular significance to me were participants’ points of transition or “turning points” (McAdams & Bowman, 2001, p. 3) that they identified as significant to life change.

3.6.5.1 Pilot Interview: Stage 1

An initial pilot interview was conducted to gauge whether probe questions were appropriate for gathering information about participants living with chronic pain. The participant was an 80 year old woman with long-standing chronic pain. The pilot interview was tape recorded and then transcribed. The transcript was then subjected to scrutiny by the researcher and principal supervisor to determine whether modifications to the method of interview needed to be made. Some minor modifications were made to the wording of probe questions for clarity, but the semi-structured interview was deemed appropriate for data collection with the participants in Stage 1.

3.7 Data Collection

3.7.1 Data Collection Stage 1

Interviews were recorded and conducted within participants' homes in most cases. In the initial interview I aimed to establish rapport with the participant. Participants were encouraged to move around if they wished during the interview process. I noted that people with chronic pain "may have difficulty maintaining static postures for extended periods of time and that the maintenance of these may be detrimental to posture and promote pain" (Strong, 2002, pp. 292-293). Again, this was a factor in the home setting being selected as it aimed to promote participant comfort, particularly if modified seating or back supports were used.

The use of a semi-structured interview format was familiar to participants, as this had been used during the PMP to gather information. As participants were encouraged to share personal information, it was deemed important to remind them that they were not required to answer any question if they so wished, to ensure that they were comfortable with the questions presented. I monitored this aspect using observation of nonverbal body language, pauses and participant hesitation. Participants were additionally informed that they could conclude the interview at any time. These points were also stated on the information sheet and consent form given to the participants (see Appendix A).

It was anticipated that two interviews would be conducted with Stage 1 participants. The aim of the first interview was to establish rapport and gather descriptive information about current occupations/roles, role importance and chronic pain background. The aim of the second interview was in-depth examination of the participant's experience on the PMP and how/if it had influenced current engagement in occupations/roles. The opportunity for corroboration of previous interview material at this time was also provided. However, due to the nature of the semi-structured interview process and the storytelling approach participants used, topics covered were not exclusive to either interview.

A range of stimulus questions were used to elicit information and then qualifying questions (see Section 3.7.2) were utilised within the areas of occupational role performance; how the participant saw him/herself within the context of living with chronic pain; and how the PMP had influenced his/her pain management. Additional probe questions were used during individual interviews or in follow-up interviews to gain further in-depth information and clarification.

3.7.2 Research Questions Stage 1

To gather the data, specific questions for Stage 1 (PMP) participants included questions arising from the conceptual framework which guided the study (Figure 2.1, p. 54). Questions were centred about the person (self and roles), occupation (activities and tasks performed) and the impact of the social, physical and cultural environment. Moreover, as the dominant treatment paradigm in chronic pain programs in Australia focuses on cognitive behavioural methods, there were also questions relating to the methods and strategies participants were given by program staff about how to manage their pain (see Appendix D, p. 363).

The questions were aimed at gaining descriptive narrative information across the participant's life course and how chronic pain had impacted on it. An underlying subtext to the questions was the impact of chronic pain on the participants' daily occupations and how they perceived themselves years after completion of the PMP. Often this information arose during interview without the need for specific questioning, due to participants' expectation of what the interview was about (via the information sheet) and being given permission to talk about their life when living with chronic pain.

3.7.2.1 *Role description*

The initial question asked related to identifying the roles the participant had in his/her life (see Appendix D). The process used here reflected aspects of the method of data collection performed by Hillman and Chapparo (1995, 2002) in their studies of role performance in men following stroke. Participants were asked the "grand tour" (Spradley, 1979)

question: “Can you tell me about the roles in your life right now?”. It was proposed that if this question was confusing to participants or did not receive an answer, the researcher would then use a clarifying question such as “Tell me what you do in a typical day?” This initial probe question aimed to provide a structure for participants to begin to explain their daily life. Contrary to my belief that this question could be misconstrued (e.g., role related to work; lack of awareness of what a role was), participants described a range of social roles related to self, family, leisure and productivity.

Further qualifying questions throughout the interviews were “used to elicit information more fully than the original questions that introduced the topic” (Minichiello, Aroni, & Hays, 2008, p. 100). Questions were aimed at gaining descriptive information (e.g., “Can you tell me about what you do related to [particular activity]?”), structural information related to role significance (“What roles are most important in your life?”), and contrast information (“Do you have things you would like to do in your life that you can’t do?”) (Hillman & Chapparo, 1995, p. 91).

3.7.2.2 *Role sorting and rating*

I listed roles as Stage 1 participants described them across the course of the interview (e.g., painter, homemaker). Once this information was gathered, I wrote the various roles on post-it notes. These were then displayed on a portable A5 sized whiteboard. The participant was asked to verify whether these were the roles in which he/she currently engaged. If the response was affirmative, I then asked participants to rate these roles in order of importance, by placing them in order vertically, with the uppermost being most important, and the lowest being least important. Some participants could not separate the importance of particular roles (e.g., mother, wife) and so placed them side by side, as the nature of those roles were either enfolded or they were seen as of equal importance. Additionally, I gained information from participants as to the frequency with which these roles were performed (i.e., daily, weekly) and the choice and satisfaction related to performing the roles (e.g., choosing to be in that role, being satisfied/dissatisfied with performance in that role). On completion I recorded this information diagrammatically in my journal

immediately after the interview, in addition to general observations and impressions (adapted from Hillman & Chapparo, 1995, pp. 91-92).

It was anticipated that the initial interview would take between 1-1½ hours to complete. For the majority of participants this was the case, although some initial interviews took up to 2 hours to complete. As each initial interview was concluded an appointment was made for a subsequent interview.

The second interview began by reviewing the participant's role sorting and rating from the first interview. This provided a foundation for revisiting information covered in the previous interview. This allowed for member checking by participants to ensure that information from the previous interview had been recorded correctly. By the time the second interviews were conducted, I had reviewed the initial interview recordings and had prepared additional qualifying and probe questions related to finding out more on specific issues of interest raised. Due to the nature of semi-structured interviewing, and by the strategy of allowing participants to have some direction in what was discussed, additional questions were compiled on an individual basis.

Typical questions asked in the second interview included clarifying questions related to the domains of the conceptual framework that arose from the literature review. For example, questions related to the meaning and experience of illness included:

- Do you think people in the general community understand chronic pain? (social/cultural environment)
- What is your advice for other people who live with chronic pain? (person as expert)
- How do you see yourself now? (person, self)

These second interviews took between 1-2 hours to complete. At the conclusion of each interview I informed participants again about the nature of the study and that each participant would be provided with a summary of both interviews to gauge whether it was an accurate representation of

what had been discussed. Participants were also informed that they could delete any details that they did not want included in the transcripts (see p. 88).

As stated previously, all interviews were audio-taped (using two tape recorders) with the written permission of the participant. Notes were also taken during the interviews to act as a backup to the audiotapes in case of problems with the technology. Interviews were transcribed verbatim as soon as practicable after completion of each participant interview (see Section 3.7.5).

I was available to debrief with PMP participants following interviews either face-to-face or by telephone if required. I went through my own debriefing with the principal supervisor after each interview. Additional debriefing with the principal and associate supervisors was carried out when material discussed was of a particularly sensitive nature. Participants were made aware that if required they could contact the psychologist on the PMP for counselling regarding sensitive information, and were also made aware of community support services available. There were no reports of adverse effects arising from interviews for participants who took part in the study.

3.7.3 Data Collection Stage 2

Data collection for Stage 2 interviews also utilised a semi-structured interview format. Some therapist-participants requested an outline of questions that would be asked, so they could consider their responses prior to interview. Proposed questions centred on the following areas: therapists' role within chronic pain practice; theory behind practice; methods of practice; factors influencing successful pain management. Therapists were also asked to detail a memorable "case" with whom they had worked in detail. Interviews lasted 2-3½ hours.

For the majority of therapist-participants only one interview was conducted. An opening was made at the conclusion of each interview for a follow-up interview to take place if necessary. Four follow-up interviews

were conducted, two face-to-face and two by telephone after data from the first interview were reviewed. The two face-to-face follow-up interviews were with therapist-participants who worked on the PMP to gain a deeper insight into the program that Stage 1 participants undertook. Two follow-up telephone interviews were also conducted with two therapist-participants who were identified in their first interviews as expert or key informants (Minichiello et al., 2008). These two therapist-participants had worked in chronic pain for over 20 years and had worked in pain programs of a similar structure to the PMP for over 15 and 10 years respectively. Their expertise was sought as both had researched as well as worked in this field of practice. They were able to provide detailed insights into the questions posed and provided specialist knowledge about the key question; “What factors do you believe influence successful chronic pain management?”

3.7.4 Research Questions: Stage 2

Stage 2 of the study addressed this research question:

- *What factors do you believe influence successful long-term pain management?*

As this question was considered complex, especially within the therapist-participants' given context, background information was gained prior to this question being asked. This included detailed information about the type of program in which the therapist-participant worked and their role and practice methods. Stage 2 questions are presented in Table 3.5, which is related to the conceptual framework that arose from the literature review. Questions related to: a) chronic pain (chronic pain practice and methods), b) identity (role within the program), c) occupation (how programs and strategies enable occupational engagement) and d) narrative methods (exploring pain practice through practice and case narratives).

Table 3.5: Therapist-participant questions that arose from the conceptual framework of the literature review

Questions that arose from literature review domains of interest	Chronic Pain	Identity	Occupation	Narrative Methods
1. Could you tell me about the chronic pain program/practice you are involved with?	✓		✓	✓
2. Could you tell me about your role within the program?	✓	✓	✓	✓
3. What do therapists think influences long-term management?	✓			✓
4. What is the theoretical perspective behind the methods used in the program/practice?	✓		✓	✓
5. Could you describe the overarching message that the program provides to clients about pain management?	✓		✓	✓
6. What is your opinion about the methods used in the program/practice?	✓	✓	✓	✓
7. In your opinion what factors influence successful chronic pain management?	✓		✓	
8. In your opinion what factors limit successful pain management?	✓		✓	
9. Could you provide an example of a case that made a significant impact on your thoughts about pain or your practice?	✓	✓	✓	✓

The final question was aimed at providing a client-based context to what had been discussed previously and was also of interest in teasing out positive and negative aspects of particular cases that might not have been articulated up to that point. Again, all interviews were recorded and transcribed as soon as possible following the interview.

3.7.5 Transcription: Stages 1 and 2

I performed the transcription of the pilot interview and some interviews where sound quality was affected. Most other Stage 1 and Stage 2 interviews were transcribed verbatim by an experienced transcriber. This person was mature aged, understood the nature of confidential information and had been involved in a number of research projects. I then reviewed the transcripts while listening to the interview audio tapes to ensure that they were accurate. A summary of the interview transcripts was forwarded by mail to all participants for verification and member checking of interview

contents. Participants were made aware that a full transcript of the interviews could be provided on request.

3.7.6 Rigour

Ensuring that the data were representative of the participants' stories in Stage 1 and Stage 2 was of paramount importance in the research process. Prior to selection of the research method of narrative inquiry, I undertook detailed study to examine which methods would best suit the research questions based on my experience and established research in the field of interest.

To ensure that the data were deemed trustworthy prior to analysis the following methods were applied:

- Theoretical rigour, which means that the theory and concepts behind the research were appropriate so that the research strategy used was consistent with the research purpose (Liamputtong & Ezzy, 2005). This has been considered in Section 3.4.4., justifying the research.
- Interpretive rigour, which involves a clear demonstration of how the interpretation of themes was achieved, and involves an accurate representation of events within the selected methodology and the lived experience of participants (Liamputtong & Ezzy, 2005). This is discussed in Section 3.8 under Data Analysis
- Methodological rigour, which indicates detailed and careful documentation of the process used to arrive at research findings by having a maintained and reported audit trail that considers how participants were accessed, how trust was developed with participants and how data were collected and recorded (Liamputtong & Ezzy, 2005). This has been explored in Research Processes (Section 3.6), Data Collection (Section 3.7), and is discussed in Data Analysis (Section 3.8).

Although there are differing views among qualitative researchers on the value of various forms of establishing and maintaining authenticity,

member checking, data saturation and triangulation were used in this research.

3.7.7 Member Checking

Participants were provided with a summary of both interview transcripts (for Stage 1) and single/multiple interview(s) (Stage 2). These summaries contained participant's quotes of significance on various topic areas. Additionally, participants were invited to comment or amend any part of the summaries. This process of member checking (checking back with participants) has been suggested by Cohn and Lyons (2003) as a useful method of presenting researcher interpretations of the data and asking for feedback. One purpose of member checking can be "to realign the balance of power in the research relationship as the researcher is making a deliberate attempt to avoid misinterpretation" (Cohn & Lyons, 2003, p. 45) (see Section 3.8.4). Member checking in this context did not involve corroboration of the findings from the research with participants.

3.7.8 Saturation

Saturation has been defined as reaching a point of "data accuracy and operationalised as collecting data until no new information is obtained" (Morse, 1995, p. 147). This is more likely to be achieved if a cohesive sample with similar characteristics is used, such as in the purposive sampling of Stage 1 and 2 participants. Although the sampling of participants used within Stage 1 and Stage 2 had some common characteristics, there were exceptions. Stage 1 participants' stories, while sharing the diagnosis of chronic pain and the experience of participation on the PMP, contained individual characteristics and nuances reflective of the personal stories. Although most Stage 1 participants enjoyed the PMP and found it effective, one participant viewed the whole program negatively, and some were equivocal about its benefits. Improvement post-program also varied, with two participants having deteriorated significantly. These negative case examples are included in the research to "sample all variations appearing in the data" (Morse, 1995, p. 149). Because negative stories of participants' experiences of the PMP and

living with chronic pain were taken into account, any hypothesis as to what facilitates pain management in the long term could consider and account for all Stage 1 participants (Lincoln & Guba, 1985). Using positive and negative case examples strengthens the theory generated from the research by making sense of erroneous data in relation to understanding living with chronic pain for past PMP participants.

Stage 2 participants, while sharing the experience of working with people with chronic pain, had a broad range of personal and professional experiences that influenced their perceptions. Thus, although due to the numbers involved some generalisations became apparent, there were also individual experiences which made working with people with pain unique.

3.7.9 Triangulation

Triangulation of research information has also been advocated as a useful method for ensuring the rigour of analysis. Researcher triangulation (Rice & Ezzy, 1999, p. 38) was carried out during the analysis of information to gain different perspectives. For the purpose of this research the following perspectives were used:

- Researcher – competent in the administration of semi-structured interviews and having worked in chronic pain practice
- Supervisor(s) – skilled in qualitative data analysis across a range of qualitative methods (i.e., phenomenology, discourse analysis)
- Supervisor – skilled in chronic pain practice and the use of mixed methods.

The use of these different lenses of analysis brought out subtleties in the data missed by the researcher and alternative views of the data interpretation as presented in the transcripts (see Section 3.8.2). I believe that this provided a more inclusive view of participants' stories and balanced any researcher bias that might have influenced the findings.

3.7.10 Reflective Journal

Before each section of the research process, I gave careful consideration to, and discussed with research supervisors, methods of recruitment, selection, ethical concerns and methods of data collection. During the process I kept a detailed reflective journal that recorded thoughts and feelings about each interview, problems and issues that arose and decisions made which influenced subsequent interviews. Meetings with supervisors were minuted in the journal to provide a developmental pathway of collaborative research ideas and problem-solving scenarios, as well as debriefings that occurred after interviews. Conceptual maps based on emergent themes were also diagrammatically represented. Excerpts from this journal are included in Appendix E.

3.8 Data Analysis

The methods used to analyse the information gathered in Stage 1 and Stage 2 consisted of:

1. Sequencing the events
2. Discovering the themes
3. Interpreting the stories
4. Reflexivity.

3.8.1 Sequencing the Events

Transcripts were read and re-read to gain an initial impression of the narrative plot relating to the participant's pain story of living and doing with chronic pain. As stated by Kielhofner et al. (2008, p. 111), the "plot is the intersection between the progression of time and direction (for better or worse) that life events take". Narrative shaping (Larson, 1995) was used to put the story into a developmental chronological framework. During this phase, significant life events or turning points were identified as described by participants. These significant events were depicted as progressive, stable, or regressive points within the narrative and are displayed for each Stage 1 participant within Chapter 4, Section 4.2. These were represented pictorially with the midline point representing a stable period in the person's life, and agentic (progressive) and victimic (regressive) events

placed above and below the midline respectively (see Chapter 4, Section 4.2). This method of plot depiction has been used previously within narrative research in occupational therapy (Jonsson, Josephsson, & Keilhofner, 1999). I judged the significance of the event based on descriptive information provided by participants as to its importance and meaning.

3.8.2 Discovering the Themes

Initial analysis of the text using open coding was undertaken systematically for the first and second interviews of each participant in Stage 1 and Stage 2. This was carried out by reading the transcript and writing down general impressions of ideas presented (Lincoln & Guba, 1985).

Following initial analysis, I coded key themes, words or phrases that appeared in the transcriptions on the side margins of the transcripts. These were recorded in the participant's own words to retain the language or voice of participants.

A comparison of these key themes, words and phrases was made between both first and second participant interviews within each stage. At this time copies of transcripts were provided for peer review by supervisors for triangulation purposes. Once this was completed for all interviews the initial analysis of findings resulted in the creation of a number of key overarching themes to guide further deeper analysis.

3.8.3 Interpreting the Stories

3.8.3.1 *Preliminary theme development – Stage 1*

The themes were categorised under the following headings and defined for Stage 1 as:

- Self/identity – how participants perceived themselves, their sense of self, and how their roles informed others about who they were
- Meaning ascriptions – affective beliefs and thoughts about chronic pain and chronic pain management

- Strategies used to do everyday things – discussing daily occupations and how these had been adapted to suit the participant, describing occupations of meaning and importance, learning ways to live with pain
- External world influences – including the physical environment and the socio-cultural influences of family, workplace, friends, health professionals and the PMP.

These themes were developed and refined in conjunction with both supervisors' input. They are displayed diagrammatically in Figure 3.1.



Figure 3.1: Schematic diagram of the relationship between developmental theme categories

Each interview transcript was then reanalysed and categorised according to the above headings. These detailed themes were sorted into common groupings and compared across participants. Common and recurring themes were identified across transcripts. Any themes that were not

common or recurring were also noted. These themes formed the categories for findings from the Stage 1 data which are presented in Chapter 5 “Stage 1 PMP Participants’ Findings” (Section 5.2).

A similar process was undertaken with the Stage 2 transcripts; however, events were not sequenced chronologically as the stories provided related to the semi-structured interview questions about their chronic pain practice. Each transcript was read and reread allowing me to immerse myself in the therapist-participant’s story. Words and phrases that arose from the transcripts were detailed in the side margins of the transcripts using the participants’ words. These words and phrases were then analysed for common themes across and within transcripts. Any data outlying the main themes were also noted.

3.8.3.2 Preliminary theme development – Stage 2

The themes were categorised under the following headings for Stage 2:

- About the “person” – how therapist-participants saw clients give importance to life roles, how they saw clients view themselves and how depression and compensation affected their clients’ view of self
- Meaning ascriptions – how therapist-participants interpreted the meanings ascribed to pain by their clients and how these affected self-management
- Adopting and using strategies – strategies and methods that therapist-participants saw as useful for clients, such as educating, pacing, goal setting, and enabling occupation
- External/social world influences – impact of family, of the pain intervention or program used, and the ongoing social support available to the person.

As themes arose from each transcript they were grouped under these headings, which were similar to those used in Stage 1. Some unique themes emerged related to individual features of programs and therapist-participants’ approach to clients, and they are noted under “unique features of pain programs” (Chapter 6, Section “Therapist-participant

Findings” [client related themes]). Therapist-participants perspectives were their interpretations of clients’ approaches to pain self-management or otherwise based on their practice experience. The focus was on the subjective view of clients they worked with, rather than what constituted best available evidence in practice. This was seen as important to maintain consistency in the method of analysis used for Stage 1 and 2. Using case stories of clients therapist-participants had worked with gave credence to the method, as clients’ characteristics were highlighted. These are detailed in Findings Part C (Section 4.9).

3.8.4 Reflexivity

Reflexivity refers to a process of reflecting critically on the self as researcher, as one way of acknowledging the subjectivity of the research process (Lincoln & Guba, 2000). Being reflexive is critical to the research process. I aimed to be reflexive by continually evaluating thinking and reasoning regarding the data, the emergence of headings and themes, and the subsequent development of conceptual models. Reflexivity for me as researcher involved:

- Maintaining and revisiting a reflective journal of feelings, thoughts and impressions following interviews
- Thinking about why participants responded to questions in the way they did and how I might have influenced this process
- Clarifying previous information in subsequent interviews to ensure the meaning was clear to both the participant and me. This often involved repetition and elaboration of questions asked previously.

Reflexivity also involved being critical of the research process and reviewing my possible agenda (what the findings from the research might be) and being aware of biases I brought to the research. As I had a background in chronic pain practice, there were definite established ideas about theoretical and practice methods and their efficacy which could have influenced the research. I was also aware that I had personally challenged and changed my view about the use of those methods over time

(discussed below). This created a tension of which I was aware during the research process.

Within any research, the importance of power in the process of collecting and interpreting data also needs to be considered (Foucault, 1980). My perceived power as the researcher (being in that position) might have influenced the information provided by participants. Participants in Stage 1 might have seen me as a representative of the WRHS PMP, and therapist-participants in Stage 2 might have viewed me as having an agenda separate from the research purpose. I made a conscious effort to address the issue of power by being open and honest about the research process and stating that I was not affiliated with the WRHS PMP.

Respect for the participants and their ownership of the information provided was demonstrated by providing member checking and by reviewing sensitive information at subsequent interviews. By revisiting this information, I could review anomalies in interpretation. Interviews were conducted at venues of the participants' choosing and at times designated by the participants. Participants were provided with information about probe questions (if requested) and informed that they were not required to answer any questions if they wished. Transcript summaries were provided to all participants, with instructions that any part of the transcript could be amended or deleted on their direction. Some participants did provide amendments, mostly related to dates and times or place/person names. Only one participant requested that material of a sensitive nature discussed at interview not be included, but other sensitive material within the same interview was approved for inclusion. Although these strategies cannot resolve all ethical and pragmatic issues they were considered to be the most equitable way of addressing issues of power in this particular study.

3.9 About the Researcher

This section introduces me, the researcher. Due to the interpretive nature of the study an understanding of my background can inform the reader

about the life experiences that might have influenced the research. I was born in 1963 and completed an undergraduate degree in occupational therapy in 1984. I currently live in a small rural town and have a partner and three children aged between 8 and 15 years. I have worked in metropolitan and regional occupational therapy practice, including the areas of mental health, physical rehabilitation and occupational rehabilitation. I have worked in structured in-house and community-based chronic pain programs for over 10 years while in practice. This was exclusively in metropolitan practice settings and therefore completely separate from and prior to any involvement with WRHS PMP. Since 1998 I have been a lecturer in the undergraduate occupational therapy program at Charles Sturt University, Albury, New South Wales.

In my experience working within pain management programs, I observed that the participants of the programs often did not have their pain story heard, nor was an attempt made to understand it in the context of its impact on their life course. The programs I worked within operated under a biopsychosocial model that involved cognitive behavioural methods. I felt at times that for certain clients the imposition of a set of beliefs about pain (as adhered to by the program) was counter to those that they had formed for themselves. This, in my experience, created a tension between what the therapists' goals were (i.e., a decrease in pain, and outcomes related to return to work), and what the person wanted to achieve (i.e., an understanding about why he/she had the pain he/she had and how he/she could manage it realistically in daily life). Moreover, I completed a quantitative study looking at outcome measures from the WRHS PMP that indicated a positive relationship between self-efficacy, occupational performance and satisfaction with performance. This quantitative study, however, left questions in my mind about how people managed in the long term with a chronic condition. The participants sampled here also included some of the subsequent Stage 1 participants. This therefore piqued my interest in ongoing research into chronic pain management.

3.10 Summary

A qualitative research paradigm, using narrative methods of inquiry and analysis, was considered the most suitable method to collect and analyse the data in this research. Central to the research questions was a consideration of the theoretical underpinnings of occupation, role and identity. The two main questions that guided the study for both Stage 1 and Stage 2 participants were:

- *How do people live and do (perform) their everyday roles and activities when they have chronic pain?*
- *What factors influence successful long-term pain management?*

A subtext to these questions was the Stage 1 participants' involvement in the PMP and the methods used within that program; while for Stage 2 therapist-participants it included the factors that influenced successful pain management for their clients and a consideration of the methods they used in practice:

- *What factors do you believe influence successful chronic pain management?*
- *What theoretical framework guides the methods you use in your pain management practice?*

This chapter has discussed the rationale for the methodology chosen and the procedures that were undertaken to conduct the research. It has demonstrated how the conceptual framework related to the questions raised in the literature review influenced the questions posed to Stage 1 and 2 participants and influenced the method of data gathering and interpretation of data. It has also detailed the processes used to ensure that the research findings were an accurate representation of participant and therapist-participant stories and the themes elicited from those stories.

The findings from the research are contained in Chapters 4, 5 and 6. Chapter 4 introduces the participants from Stage 1 and 2 and includes the narrative slopes of Stage 1 PMP participants. Chapter 5 consists of themes that arose from PMP participant narratives presented under the

categories from Section 3.8.3, using their own words to retain their authenticity. Many of the stories contain messages of powerful emotion related to a life lived with chronic illness and pain. The stories are compelling in that the issues faced are multi-factorial and affect all aspects of their lives. The reality is that so many people live with pain in our communities, yet their stories are rarely heard and shared.

The stories of Stage 2 therapist-participants centred on their professional practice and the clients they worked with. Their stories, and the opportunity to reflect on practice and the methods used, provided insight that the therapists valued as they rarely had time to consider those questions when working in busy health care settings. Through this process, therapist-participants were able to articulate their reasoning as to why some people are better able to manage their chronic pain. These findings are presented in Chapter 6. Within the context of this research the findings often resonated between the PMP- and therapist-participants.

CHAPTER 4: FINDINGS – INTRODUCING THE PARTICIPANTS

4.1 Introduction

This chapter introduces the stories of the participants of Stage 1 (pain management program PMP) and Stage 2 (therapist-participants). It provides a summarised account of participants' pain and practice narratives. It also provides a sequence of events for Stage 1 participants prior to and post-injury, including details of their chronic pain condition. This précis provides a basis for understanding why participants were referred to the PMP and notes the diversity of chronic pain conditions with which Stage 1 participants presented. After each summary, a rating of the importance of life roles discussed in interviews is presented. Role rating is noted in the order of reported importance of each role in the Stage 1 participant's life. Thus 1 equals most important/significant role and so on, as self-rated by the participant. Roles with the same importance rating are placed on the same line.

Kielhofner et al. (2008, p. 125) stated that "the plot of a narrative reveals the overall meaning because it sums up where life has been and is going". Plots link life events together to make "sense of life as a whole" (p. 125). I interpreted life plots of Stage 1 participants as "narrative slopes" based on their stories. These slopes illustrate significant incidents or turning points in Stage 1 participants' lives that emerged and were discussed in the interviews. The narrative slopes and turning points are presented after each Stage 1 participant summary. Narrative slopes for Stage 1 participants were considered on a continuum from pre-PMP, post-PMP, to the time of interview and projected future based on current trajectory. This was interpreted from the information provided by participants at interview. Life incidents/turning points were noted as "progressive" (agentic) or "regressive" (victimic). An upward slope denotes a progressive (agentic) change over time, whereas a downward slope shows a regressive (victimic) change, with a flat slope implying no change. Wavy lines indicate an unstable period fluctuating between progression and regression. These

concepts of role importance and turning points were discussed in the Literature Review and Methodology chapters. Similar methods of displaying and describing roles and narrative slopes have been utilised in occupational therapy research by Hillman and Chapparo (1995), Kielhofner et al. (2008) and Jonsson, Josephsson and Kielhofner (1999).

Stage 2 therapist-participant narratives detail the therapist's place of work, practice history (i.e., novice or experienced practitioner), and the therapist's role of working with people with chronic pain. Elite therapist-participants are the key informants identified in the first interview and described in the Methods chapter (Section 3.7.3).

Chapter 4 sets the scene for the themes that unfolded from the stories. With this background the themes that emerged in Chapter 5 and 6 can be applied contextually to the Discussion (Chapter 7) that follows the findings.

4.2 Introducing Stage 1 PMP Participants

4.2.1 Sarah

Sarah is a 58 year old housewife, wife, mother and grandmother who lives in a large rural town. Her father was 20 years older than her mother and she had four brothers. She saw herself as the "boss" of the family (second oldest) and able to do the work of a man. Her father was crippled by arthritis in his 60s, which she vividly remembers; she also remembers how he became depressed following this. She has three children and one adopted child. She acts as a sitter for her daughter's son, who lives nearby. She has long-standing diabetes and had lengthy medical investigations prior to being diagnosed with psoriatic arthritis. She had a total knee replacement prior to the first interview and a second total knee replacement scheduled, which delayed the second interview until after it was completed. She currently sees a physiotherapist twice a week for rehabilitation and has a "fantastic" general practitioner. She mobilises with a wheeled frame. Her interests are sewing, reading, writing, and learning how to operate a computer laptop. She is involved in meal preparation, ironing, loading the washing machine, and light cleaning. Her husband

Fred is her full-time carer. Her general practitioner has called her “Superwoman” for the life she has spent supporting her husband and brother in their bakery business while raising young children, and her voluntary community work, which has included Meals on Wheels, catering for the Catholic school, and church. She says, “One day I collapsed and got carted to the surgery and this doctor came in and he went ‘Bloody hell, superwoman hit the dust’”. She attended the PMP in 2002. She enjoyed the program and was told to go home and “keep on striving”, which she did, until her knees “gave out”. She takes ongoing medication for pain related to her arthritis and diabetes. Her motto is “keep on striving”, and she sees focusing on pain as “self-indulgent”.

Life role rating: Sarah

- Wife (1)
- Mother, grandmother (2)
- Friend (3)
- Housewife (4)
- Sewer (5)
- Letter writer (6)
- Computer user (7)

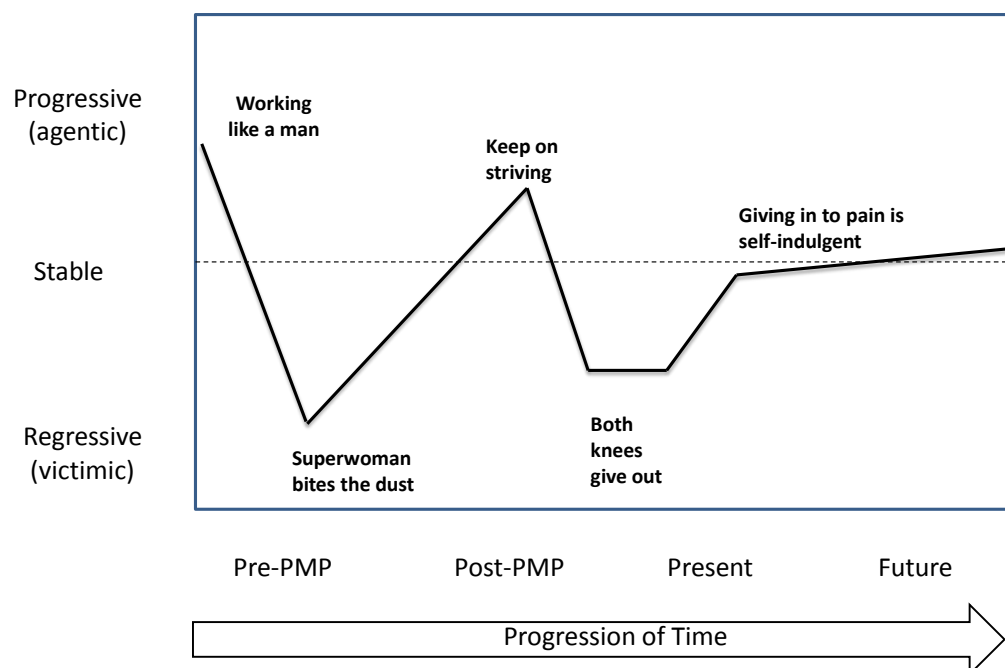


Figure 4.1: Sarah’s narrative slope

4.2.2 Maree

Maree is a 51 year old mental health nurse who lives with her de-facto in a small rural town. She has worked for the same organisation for 27 years. She has been with her partner for 10 years and has two step-daughters. She was the eldest child and the “bossy boots” of her family. She enjoys her work, although she finds working in the area of mental health “testing” and “difficult” at times. She does, however, say that she sees the residents with whom she works as an extension of her family. She had 3 years off work due to a low back injury, when she was severely restricted in what she could do and had no income. During this time she became depressed and suicidal. As well, she and her partner moved away from a larger town (they were renting and could not afford this on one wage), and she became isolated.

She was on the waiting list for the PMP for 6 months and was “so ready” to do the PMP, that when she arrived she “just burst into tears” to be finally there. When speaking about the PMP she says “yeah millions of things come from the program”. She went off all medication after the PMP but could not manage without it as she also returned to work at that time. She now chooses to have pain all the time so she can remain on a smaller amount of pain medication. She volunteers for the local Country Fire Authority and does volunteer craft work at the local school. She enjoys various crafts and knitting and organises craft activities for the residents where she works. She says she has to remain “vigilant” with regard to her pain, so she does not “slip back” into depression. She uses the metaphor of “side-stepping” around the pain as a strategy she uses in her pain management.

Life role rating: Maree

- Wife (1)
- Nurse (2)
- Friend (3)
- Craft worker (4)
- Volunteer (5)
- Stepmother (6)

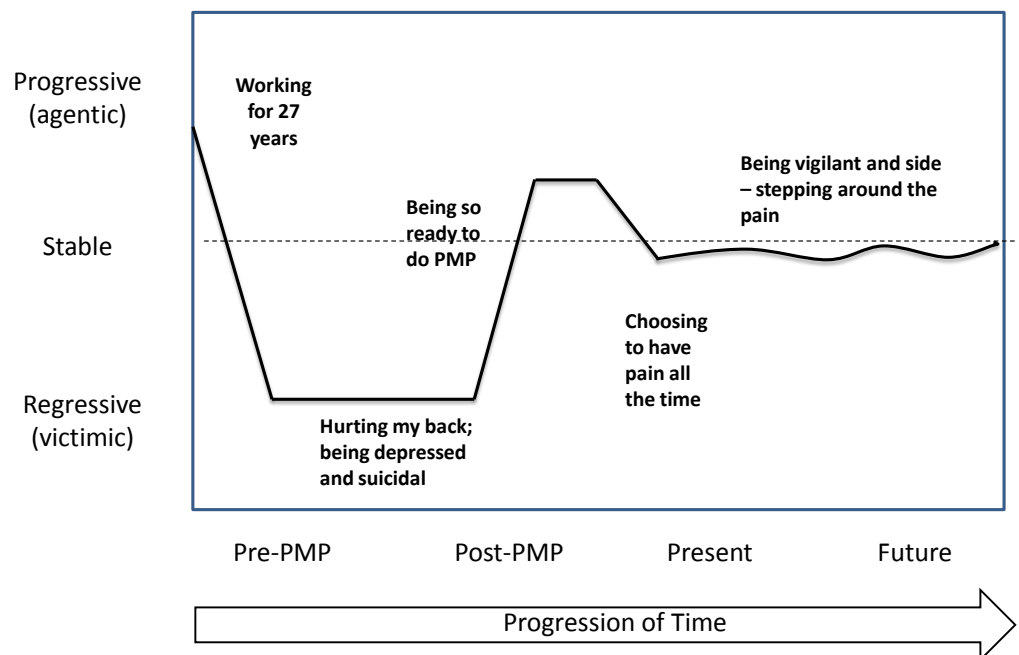


Figure 4.2: Maree's narrative slope

4.2.3 Will

Will is a 61 year old diesel mechanic, who is closing down his business after 32 years to retire. He is married, has a son and a daughter and three grandchildren; two of whom have cystic fibrosis. His interests include coin collecting, rebuilding old engines and volunteering for the local Lions Club. His daughter lives nearby and she and her husband have run the business for the past few years, but financial concerns, Will's health and the pressure of continuing working resulted in Will's decision to close the business. He injured his right knee on the first day of a caravanning holiday. There was no apparent cause for the injury. He has had multiple operative procedures.

I had an arthroscopy to see what was wrong, they [specialists] said the knee was crooked and they decided to cut the tibia in half and straighten the knee and then I kept complaining because the tibia had split right up into the knee knuckle. So, another operation, that replaced the knee and I still wasn't happy with it, and so they operated again and removed some of the scar tissue. And that gave me a bit of movement, but I still had the pain and they said it will come good, give it 12 months. So I gave it 12 months. And in the

meantime pain and depression set in. In the end I went back to them again and he lined the kneecap or refurbished the kneecap. And that was the last operation and I still wasn't having any good pain relief and they said "Righto, pain management for you."

Will enjoyed the PMP, which he completed 3 years ago, and was actively trying to put strategies such as pacing and relaxation into his daily routine.

He has ongoing depression resulting from his injury and has been on anti-depressant medication for several years. He has been told by a leading specialist in the last 12 months that nothing more could be done for his knee. At the time of initial interview he reported feeling depressed and having difficulty controlling his pain (while still taking medication for both). Ideally he and his wife would like to go travelling around Australia, but he is still sure that "somewhere, something can be done to help" his ongoing knee pain.

Life role rating: Will

Husband (1a), father (1b)
Grandfather (2)
Businessman (3a), Friend (3b)
Diesel mechanic (4)
Lions Club member (5a), Volunteer fire-truck driver (5b)
Gardener (6)
Caravanner/Camper (7)
Coin collector (8)

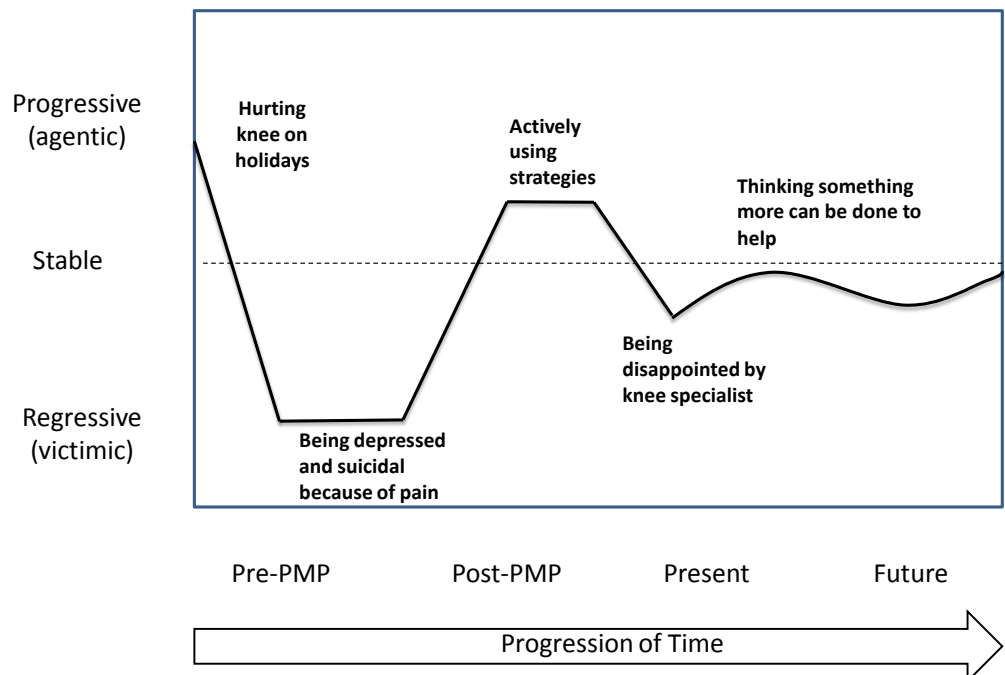


Figure 4.3: Will's narrative slope

4.2.4 Alexandra

Alexandra is a 59 year old married woman who has two adult children from a previous marriage. She has been married three times. Her current husband is a businessman, and she assists in running the business and also travels with her husband for up to 3 months of the year to the United States. She lives in a small rural town and often babysits her 8-year old granddaughter when she is at home. Her son, who lives in a capital city, has two boys, so Alexandra is a grandmother of three. She is the eldest of four siblings and states that she had a lot of responsibility growing up. She says that she was brought up to be very stoic and self-reliant, including taking herself to the dentist at age five. Her parents were not demonstrative with affection, and she says she has made amends for that with her own children. She enjoys life drawing, reading, cooking, entertaining and crosswords. She has worked as a personal assistant, a model, in publishing, and now with her husband's company. She developed back problems after the birth of her last child and subsequently

injured her back horse riding and in a skiing accident (early in the 1980s). For her back problems she has had multiple invasive procedures. She says:

I had a Harrington rod for a while and I had L4 ,L5, S1 fused and then a year later I started getting shocking pain down there, and one of the rods unhooked. He [surgeon] had to go in and remove the rod, so that was '88, '89, sort of a year apart and then I was having trouble with my cervical spine, cause I'd had a car accident and initially I thought I was OK but then, shortly after I was getting pain in my neck and I ended up having my cervical spine fused, which has been very good.

Alexandra has been taking methadone since 1994 when nothing further could be done surgically and she takes Valium to help her sleep. She has participated in the PMP and another pain program in South Australia. Regarding the PMP she says, "Yeah, I thought all that was great. I did enjoy it".

She continues to have maintenance therapy with a physiotherapist and masseuse as well as cortisone injections for spinal adhesions. She manages pain in her daily life by "just doing what I can cope with". She does not want "to give in to pain" and wants "to be in charge" of her pain.

Life role rating: Alexandra

Mother (1a), Grandmother (1b), Wife (1c)
Friend (2)
Traveller (3)
Home maintainer (4)
Chef (5)
Reader (6)
Artist (7)

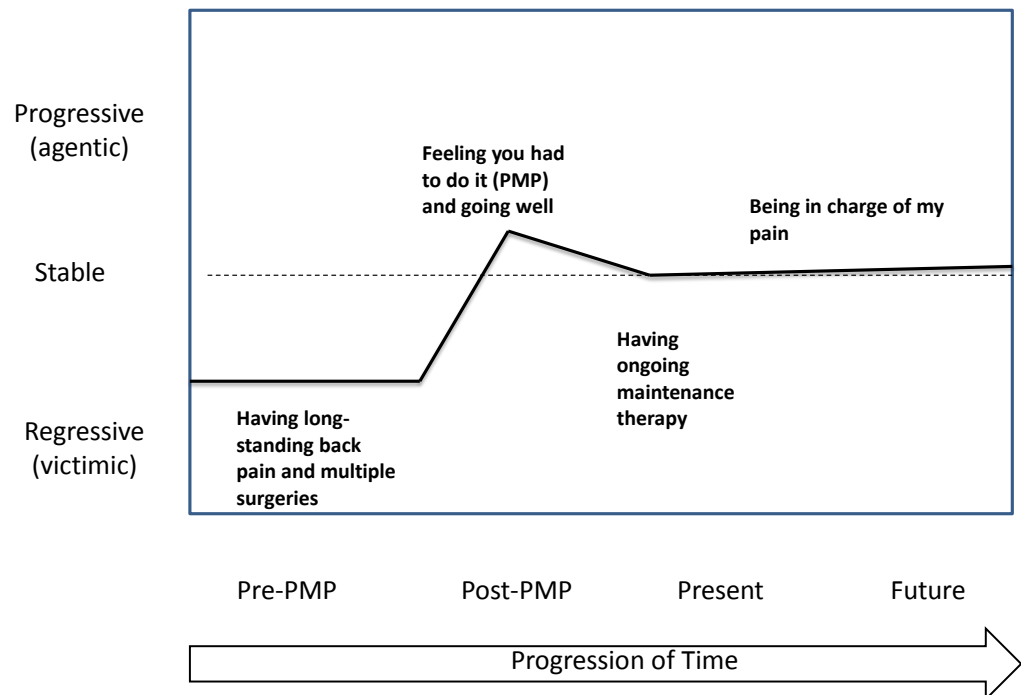


Figure 4.4: Alexandra's narrative slope

4.2.5 Dawn

Dawn is a 58 year old wife, mother, grandmother, keen golfer and gardener. She lives in a small rural town with her husband and has 127 rose bushes in the garden as well as a vegetable patch. She has two sons and a daughter and four grandchildren. About growing up she says, "My dad always made sure that we were self-sufficient like, if in an emergency, I'm not relying on someone else to do it, I know how to do it for myself".

She injured herself while working in a warehouse when trying to stop a loaded trolley from running into another woman. She refers to her subsequent low back injury as a "bruise" that she is waiting on to appear. Within 6 months the business she worked for "went bust", but she continued to be on workers' compensation benefits.

She did the PMP about 3 years ago, 14 years after her injury, due to difficulty managing her ongoing pain. By this stage her workers' compensation case had been settled but she was still entitled to ongoing

cover for her medical costs, as such there was no expectation of her returning to work. She says that over time she has adjusted to her pain and she has learned “patience and tolerance” and not to be as judgemental with herself. She thinks that the PMP “is the last resort” for people who are never going to be free of pain and that the program showed her a way of living with pain. Her personal philosophy on living with chronic pain is based on “using it, or losing it”.

Life role rating: Dawn

- Wife (1a), Mother (1b), Domestic engineer (1c)
- Grandmother (2)
- Volunteer (3a), Gardener (3b)
- Friend (4)
- Golfer (5)

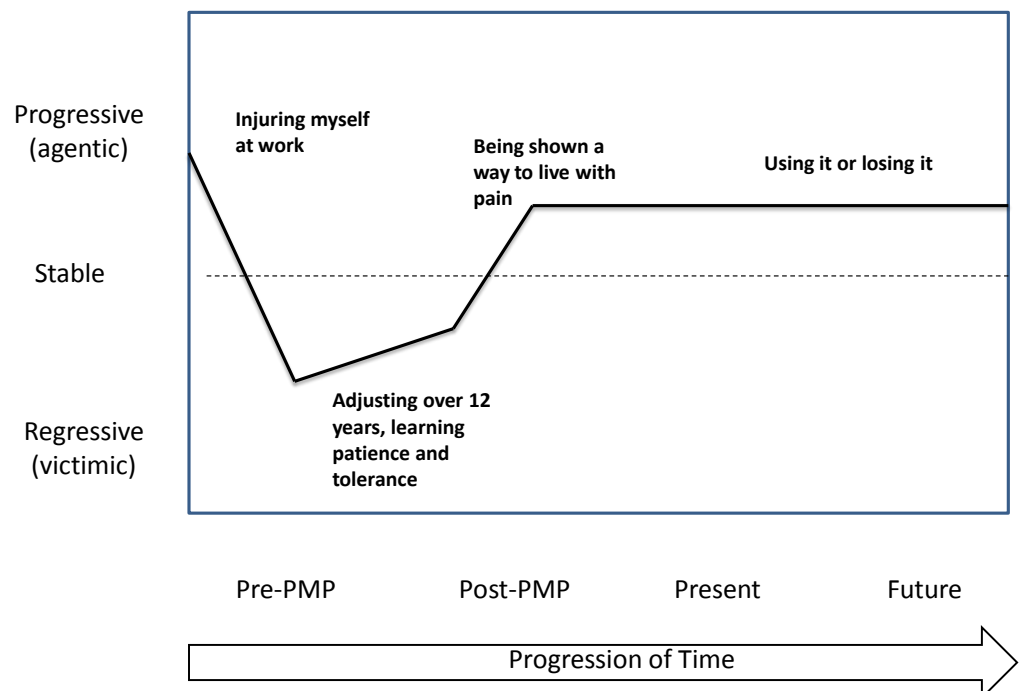


Figure 4.5: Dawn’s narrative slope

4.2.6 Stacey

At age 33, Stacey was the youngest PMP participant in the Stage 1 study. She lives in an apartment in a large regional town. She works full-time for the public service. She is “classified as an administrative person”, which

involves mainly working on a computer. She also travels to other regional centres with work.

She grew up in Melbourne with her mother, “four dads” and two half-sisters. She says her mother remarried three times. She had a lot of responsibility growing up as the oldest child as her mother worked. By age nine she was responsible for getting dinner ready and looking after her younger siblings.

As a teenager she wanted to work for the police force. “That’s all I ever wanted to do”, but she was devastated when she failed the exam. A friend suggested she try out for the army, “so I went and tried out and got straight in”. Once in the army Stacey underwent rigorous basic training. While undergoing this she sustained her injury, as she explains:

I had a groin strain and treated it with relaxation and whatever else, it didn't go away and I attended a tri-service, army, navy, air force athletics carnival and I landed in the long-jump pit and something went snap-crackle-pop and it happened to be my pelvis.

After seven years of various treatments she was medically discharged from the army, although she fought against this decision. She became depressed and was on medication when she heard about the PMP after seeing a pain consultant on the program. She told the pain consultant, “Please let me in, this is perfect, this is what I need”.

Stacey enjoyed the program as she knew “I could improve myself; I just needed a bit of a hand”. She now has the attitude of “I live with it and not let it affect anything that I do”. She says that “work has just been the godsend. If I didn’t have work I’d probably be backwards. And that’s why I’m enjoying it so much”.

Life role rating: Stacey

Daughter (1)
Friend (2)
Worker (3)
Socialiser (4)
Swimmer (5)
Step-sister (6)

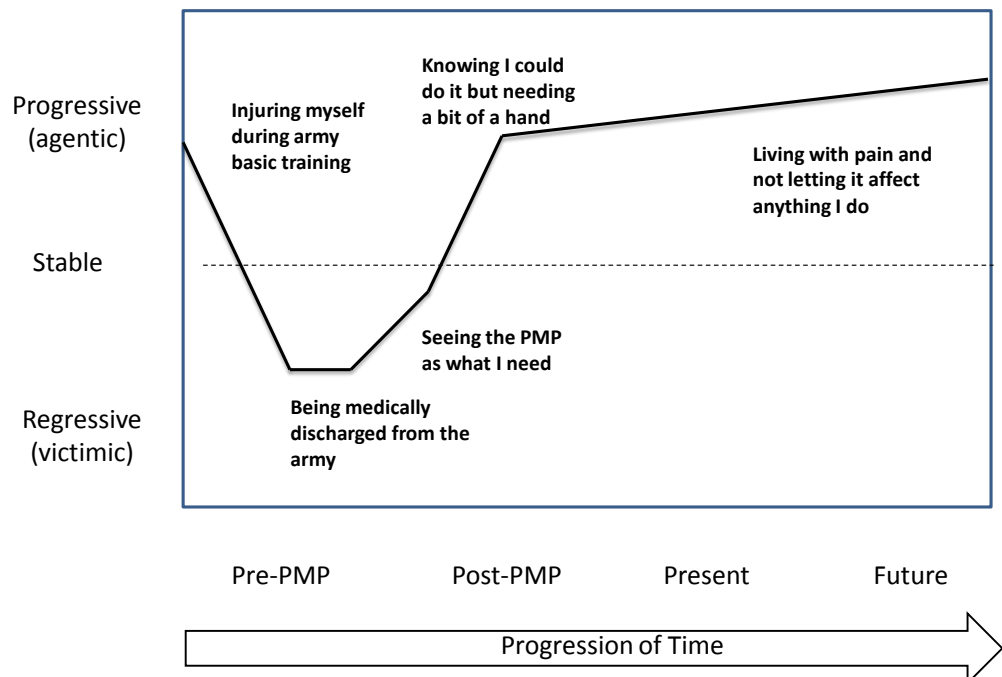


Figure 4.6: Stacey’s narrative slope

4.2.7 Julia

Julia is a 42 year old mother of six children. She also has six grandchildren. She lives on the outskirts of a small town with four of her children and her partner. Their large block of land is full of car bodies, old machinery, a large shed and a couple of caravans. She says, thinking “back to my childhood life, it wasn’t a happy one”. She had six siblings, but only talked about one of them during the interviews. She grew up in a metropolitan area. When Julia was five her father wore a back brace after being in a fight, and around that time he started to be violent to her mother. Her parents fought a lot and she says “he [father] would take to her with a knife or a gun”. She believes that because of this, sleep has always been a problem for her. She does not know a lot about her father, but describes her mother as a “runner” who she has not seen for 20 years. Julia was run over by a car at age nine and thinks she was unconscious for 6 weeks. Her mother came and saw her every day in hospital. Julia left hospital in a back brace. She went to live with her mother, but her mother

“up and left”; she went to live with her father for a short time but he “punched me up because he reckoned I wasn’t his”. She then lived with her older sister who had a young baby of her own and did not know what to do with her. She says she started having bad back pain around this time which was diagnosed as rheumatism. Julia ended up in a children’s home and then was one of the first girls to attend a boy’s home (around the age of 13), where she stayed until about 16-17. She reunited with her mother at that time and went to the country to live with her. Her mother would have several men over to her house and Julia would go out and “wander at night until it was all over”. She met her first partner and had two daughters with him. She “finally got rid of him” when her daughters were seven and four years of age. He had thrown methylated spirits on her and she sustained burns to her arms, trunk and neck. She “swore off men after that” until about the age of 25 when she was picking fruit and she met the aunt of her current partner. She says she was drinking a lot at the time and she and her partner used to fight a lot. She stopped drinking so that people could see that she was not the cause of the fights. She stayed with him and had four children who are now aged 17, 14, 8 and 7. Her pain has become progressively worse over the past 10 years. She takes morphine, anti-depressant medication (she has had depression for years) and other pain relieving medication, in increasing doses. She receives a disability support pension and her partner has assumed the role of carer.

She did the PMP a few years ago. She enjoyed being away from her partner and children. She thought the staff were excellent but found not talking about pain (a cognitive behavioural strategy used in the program) as “pretty hard days”. She has tried to use some of the strategies used in the program such as pacing, using correct body mechanics, but says it is “all right if you can use it”, but she cannot. She tries to walk every day, but she describes a routine where she is mostly housebound and doing the chores in the morning and going to bed in the afternoon. Her partner “tinkers” out in the shed for most of the day. She describes verbal and some physical abuse to both herself and older daughters but feels she is locked in the relationship. She sees herself as a loner and is happy being this way. She continues to take high doses of morphine and other

medications. Before the second interview she was hospitalised for a bad pain reaction following a radio-frequency invasive procedure, which her partner and doctor convinced her to have. She says about pain, “It’s me best friend, well it’s always there”.

Life role rating: Julia

- Mother (1)
- Grandmother (2)
- Housekeeper (3)
- Cricket ‘nut’ (4)
- Shopper (5)
- Poker machine/bingo player (6)
- Partner [de facto] (7)

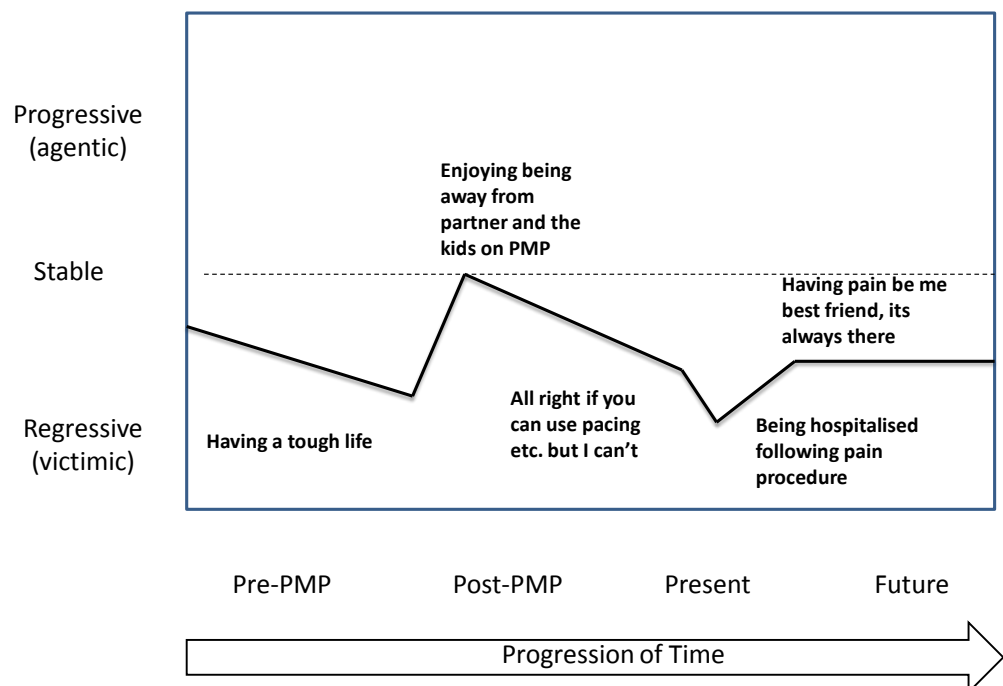


Figure 4.7: Julia’s narrative slope

4.2.8 Rachel

Rachel is a 42 year old student. She has a rare medical condition present from birth which caused paralysis of facial muscles and difficulty with speech, eating and drinking. It also causes a lack of blinking, inability to cry and a flat expressionless appearance. Although Rachel was difficult to understand verbally at first, using gestures, repetition and written

comments, the interviews proceeded. She was born in a large town and was one of a multiple birth. She was and remains very close to her sisters but also has three other sisters and two brothers. Her mother passed away 4 years ago and she had been much supported by her. She says, "I'm not close to my dad, we don't have that relationship" and she is disappointed that he cannot understand her when she speaks. She describes being abused between the ages of four and nine and as a result has lost her trust in people. She says her family did not believe her and describes a time when she lost contact with all her family.

She was the youngest person on the PMP she attended. She wanted to be seen as "equal not different" in her group, but thought that the staff "didn't know how to deal with people with multiple conditions". She acknowledges that the PMP did give her some motivation to work with the pain. Since finishing the program, however, she is finding it "hard to keep active", as she has lost motivation and interest.

One of her sisters (who is married with two children) lives close by and Rachel gets her brother-in-law to help with things she cannot do around the home. In return she does some cooking for her sister's family, which she enjoys.

As a young woman she was asked to run a group for women with disabilities. Having the organiser of the group believe that she could do this is described as a major turning point in her life. It also fostered a keen interest in working with people with disabilities. She tried to do a cooking apprenticeship, but could not cope with the physical demands required, as she says that her condition also affects her neck, shoulders, arms and chest. She has been doing a Certificate in Disability Studies at Technical and Further Education (TAFE) and is interested in doing advocacy training as well. She says that it was difficult for her to get into TAFE, as the admissions officer did not think she would be able to do it. She says that all her life she has had "to fight for my rights". She believes her pain is slowly getting worse because of her condition.

Life role rating: Rachel

- Sister (1)
- Home maintainer (2)
- Friend (3)
- Student (4a), Volunteer (4b)
- Ceramics maker (5a), Cook (5b)

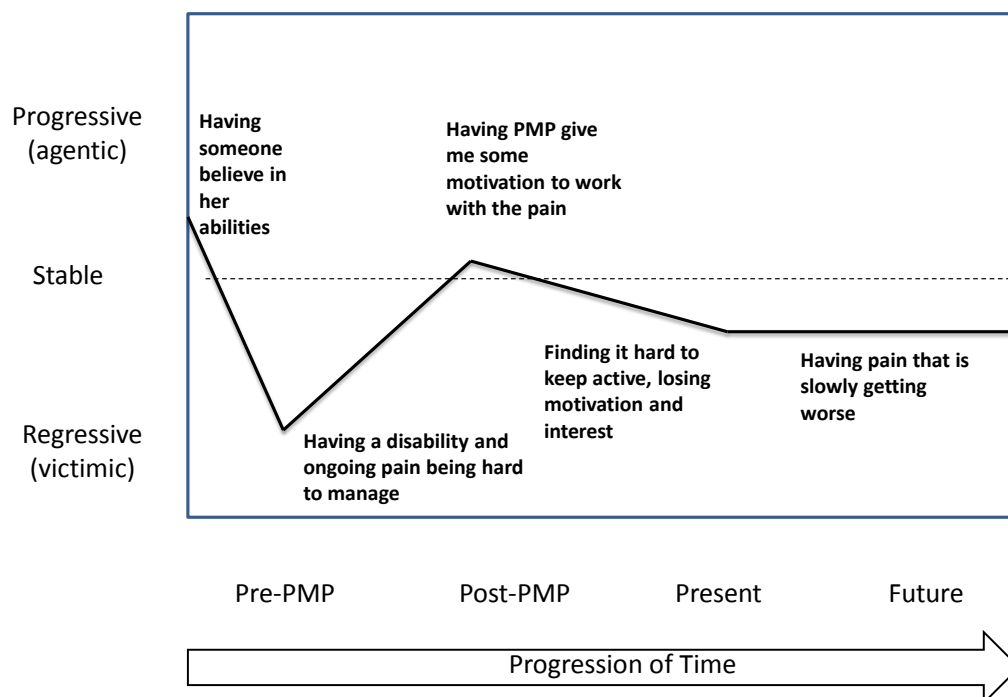


Figure 4.8. Rachel's narrative slope

4.2.9 Willie

Willie is a 67 year old horse breeder and semi-retired farmer. He lives with his wife in a small town. He has a son and two daughters and seven grandchildren. He grew up on the family farm, the eldest of four brothers and three sisters. He says he “copped all the muck jobs” growing up, looking after his younger siblings. He was always taught to be stoic about pain but he tells this story:

When I was about eight I came down with a very severe case of appendicitis. More dangerous thing to have than what it is today. We used to ride horses 6 miles to school. So for 3 days I was sent to school with a septic appendix.

He was hospitalised for some time, which he says made his parents a “bit more sympathetic”. Of more recent events he says that he handed over his dairy farm to his son-in-law and daughter. He also sold his own farm before buying in town. He retains some land out of town where he keeps his horses.

He talks about the accident that led to his injury in detail:

I was helping out my daughter and son-in-law on his dairy farm. He asked me if I had any spare time if I could give him a hand because it's a pretty big property. There was a lot of timber on the river on the place and a problem with erosion, so we went down to the river and my son-in-law was on the tractor doing scarfing¹ and he asked me if I could drop those branches or trees or limbs that were on the edge of the river and we will push them in and tie them back. A lot of them were high up. I had sawn through the dozen or 20 limbs from the bottom of the tree while he put scarfing in on the top, but I remember every one of them splitting, straight up the centre. And none of them had virtually fallen to the ground when the dog cutter reached the scarf¹. Then there was a horrible noise and it just seemed as if it was never going to end and then it stopped and there was a big bang just after it stopped. It dragged me down and I was left on the ground And me son-in-law who was still on the tractor at the time, just saw that I was sitting up and the limb was on my leg and I couldn't pull it out and he from memory, he lifted it [branch] which would have taken superhuman strength and I pulled my leg out and it seemed like I was there for a long time.

Willie had sustained a traction injury to L1-2 and the injury also affected his bowel, bladder and sexual function.

He was covered by workers' compensation for his injury, but only for a proportion of a part-time wage. His pain continued for several years, and although he tried physiotherapy and transcutaneous nerve stimulation (TENS) he had no relief. He was referred to the PMP and was surprised “to find out it was all lectures and brainwashing”. Although he enjoyed the social and exercise aspects of the program he continues to have pain and seek relief. He has tried nerve blocks and he continues to see a

¹¹The following description details the process of scarfing: Trees with unusual shapes or poor stump quality are felled higher up the trunk. This makes the tree easier to transport. A scarf (wedge) is cut in the front of the tree using an axe and this ensures the tree falls in the required direction. A saw is used to back cut through to the scarf from the other side of the tree using wedges to keep the tree off the saw. If wind catches the tree prior to it being cut through to the scarf, or the back cut is above the lower level of the scarf, the tree can split-up vertically, causing it to whip back (Blair, 2000; Kestel, 2005).

chiropractor and a myotherapist. He also had to adjust to the loss of sexual function, which he describes now as “just pleasant memories”. He sees himself as “a prematurely retired person, you know, who is trying to keep busy doing things”.

Life role rating: Willie

- Grandfather (1)
- Father (2)
- Husband (3)
- Gardener (4)
- Friend (5)
- Semi-retired farmer (6a), Lawn bowler (6b), Stock market trader (6c), Chairman of the racecourse (6d).

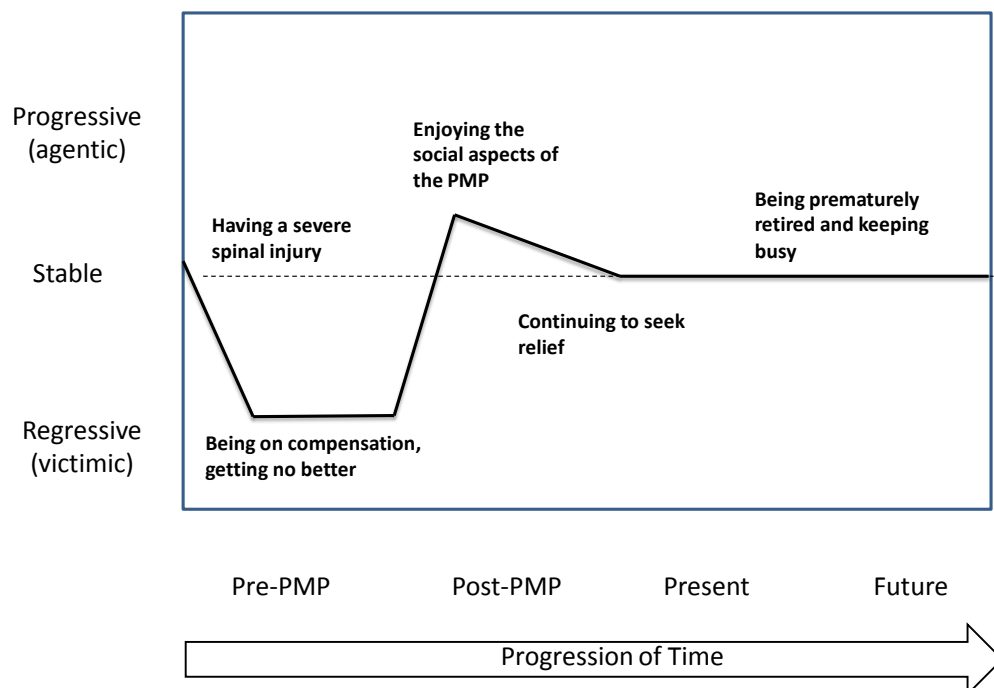


Figure 4.9: Willie's narrative slope

4.2.10 Margaret

Margaret is a 62 year old woman who assists her husband in running the family farm. She was an only child and grew up in a small town. She trained as a nurse in Sydney in the 1960s and returned to her home town to work. She married in 1976, when she was in her 30s, gave up work and had her first child in 1977. She noted that low back pain started with her

first pregnancy, and states that she has had pain for 28 years. She subsequently had another boy and describes both boys as “sick” babies who required “a lot of care”. Around the time of her first son’s birth, her husband and she relocated to a large farm out of town. She describes the transition as “just so different”. She describes herself as always being “organised” and being a “supermum”; even when bringing up her sons she always had a fresh-baked slice ready for the farm workers’ morning and afternoon teas. She took over the bookkeeping for the farm as well as being the “gofer” to get things from town. She also fed the animals and did the gardening. Her back pain settled down once her boys were walking, but in the past 8-10 years it has become progressively worse. In 2000 she had an L 4-5, S 1 spinal fusion; she had a subsequent operation that year to insert steel rods in her spine. In 2001 the rods and screws were removed, but her back pain continued. Before going on the PMP she managed her pain by “doing nothing, to cope with it”. She also tried everything to relieve her pain, including chiropractors and acupuncturists. She now does a lot of things differently and has learned “to delegate”. She continues to do an occasional session of Tai Chi and does exercises from the PMP. She also sees a physiotherapist from time to time. She says “you have to try and put it [pain] in the background”, which is what she has been doing. Her mother had died 10 days before the first interview and her father had died at the end of the previous year. She was their primary caregiver and nursed her mother for 4 1/2 months, living with her at home, prior to her mother’s death.

Life role rating: Margaret

Wife (1a), Mother (1b).
Bookkeeper (2)
Friend (3)
Housekeeper (4a), Cook (4b)
Daughter (not rated, as parents deceased).

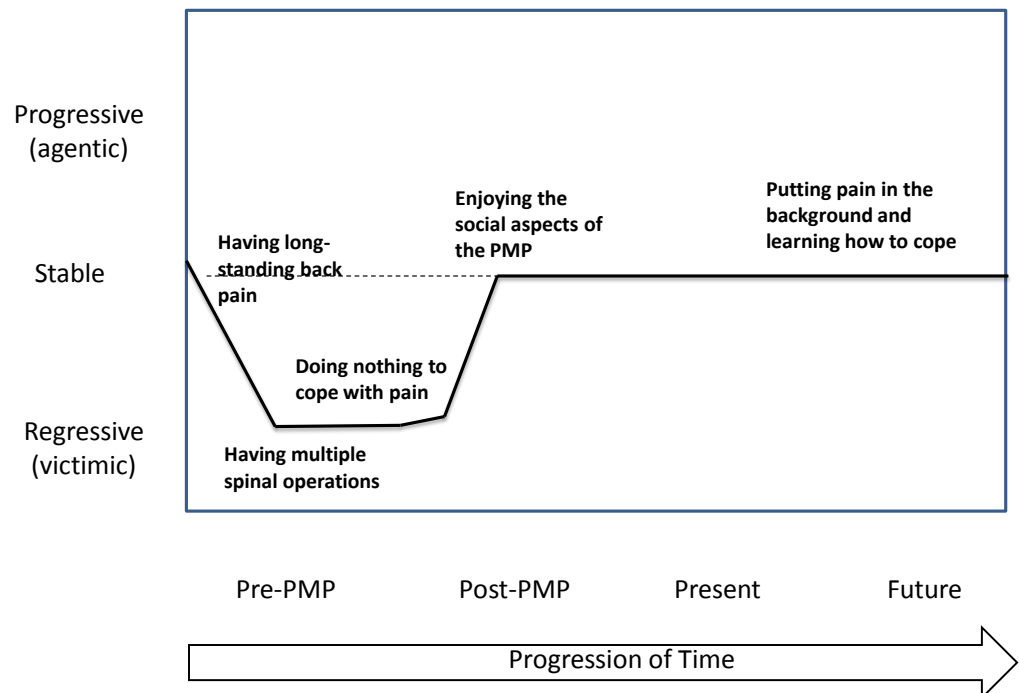


Figure 4.10: Margaret’s narrative slope

4.2.11 Alice

Alice is in her late 50s. She has two daughters in their 30s and lives with her husband on a “15-acre farm”. She lives approximately 50 minutes from the nearest large town. She grew up on a farm with both parents and five siblings. She did not elaborate on her siblings but described her mother as “domineering, still to this day”. At the age of 17 she moved into town to train as a secretary. She became “independent” very quickly at that time. Her first daughter was born in 1975 and she subsequently had two other daughters. One lives nearby and the others live interstate. She worked as a secretary for 40 years, and prior to the PMP had been a legal secretary with the same firm for 16 years. Early in her marriage she was the sole breadwinner as her husband was studying.

In 2001 she was getting a lot of abdominal and low back pain. She consulted doctors and specialists who could not find the cause of her pain. She was eventually diagnosed with a “growth” that was affecting vital

organs. As a result she had a total hysterectomy. She was also fired from her job of 16 years at the same time. After the hysterectomy she was “at a very low edge, [I’d] lost a lot of weight and was extremely weak and a bit vulnerable”. She worried about how the operation would affect her relationship with her husband and she missed her previous job and felt devastated at the “major adjustment” she had to make. She described the difficulty she had with allowing her husband to help her with things and adjusting to the “role reversal”. Her doctor referred her to the PMP as she continued to have post-operative pain and difficulty coping with it. She states that the program allowed her “to learn the tools to get out of that hole” and “positive self-talk”. She and her husband had counselling after the PMP and this helped them both come to terms with her pain and limitations. She recently joined a meditation group and continues to use strategies from the PMP such as “visualisation”, “cognitive therapy” and “stretching”. She is working part-time on a property planting and looking after olive trees, but is hoping to get into different work in the future. She is awaiting surgery for bilateral carpal tunnel syndrome, but thinks she will cope better with these surgeries due to her past experience. She says “I am pretty happy with where I am; who would have thought that I could manage as well as this”.

Life role rating: Alice

Wife (1a), Friend (1b)
Mother (2a), Gardener (2b)
Part-time worker (3a), Painter (3b)
Housekeeping (4)
Exerciser (5)

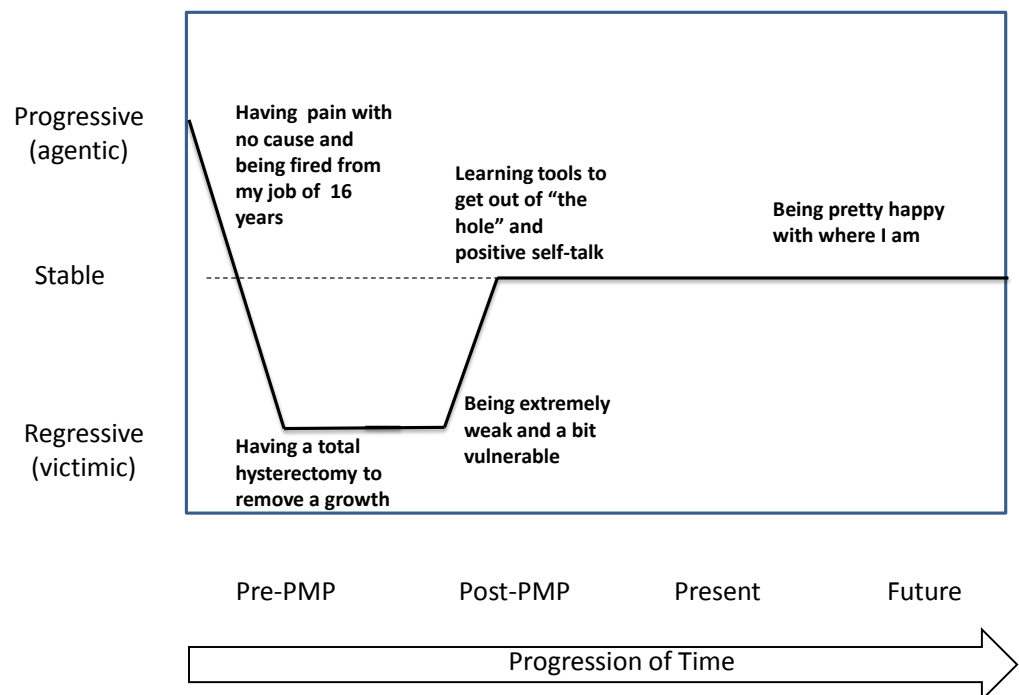


Figure 4.11: Alice’s narrative slope

4.2.12 Bill

Bill is a 64 year old single man who has had a variety of work roles both in Australia and overseas. He is currently enrolled with Technical and Further Education (TAFE) studying engineering. He also occasionally conducts audits on commercial boats and has built several boats of his own. He enjoys hunting and fishing, although he does not do as much of this as he did previously.

Prior to going on the PMP he had a cervical laminectomy and a number of nerve blocks for work-related neck pain, but he says “nothing is fixed”. He describes the times when pain “catches up” with him and “you’re ineffective in everything”.

He said early in the first interview: “I don’t know which causes it, whether the pain causes the psychological shutdown, or the psychological shutdown causes pain. I don’t know which”.

He describes a recent dinner party he hosted where “because they were enjoying themselves, nobody even knew that I’d gone and had a lie down for half an hour”. This is one of the ways that he deals with his pain. He does not take sleeping pills because “none of them will leave tomorrow untouched. They all have an effect”. He describes his experience of being on the PMP as unpleasant: “It’s a very unpleasant place to be, and why was I there? Because I asked to go there”. He was receiving workers’ compensation for his neck pain and he said that the staff on the PMP would remind him about who “was paying the bills and that I should cooperate”. He describes the program as “the world’s best fitness regime” and focuses on the negative aspects that he experienced. These aspects included group members who were not “the full quid” and how his medication was increased. He also saw the PMP staff as unhelpful.

Bill married at the age of 30, but the marriage lasted only 18 months. He spent 15 years before the courts and spent \$1.5 million, in what he describes as “just 15 years of waste”. Part of this was gaining custody of his son who he looked after from six weeks of age. His son has since completed university and is living in a capital city.

He sold real estate for 15-20 years and he used to “come home from work and I’d drink a bottle of whisky every night. And I would smoke one and a half packets of cigarettes for the day”. He was able to give this up as he saw it as just a bad “habit”. He is writing a book that he believes to be “the best Australian novel ever written”. He finds his ongoing pain to be “a hell of a nuisance because it doesn’t always let me do what I want to do”.

Life role sorting: Bill

- Father (1)
- Friend (2)
- Casual worker (3)
- Student (4)
- Writer (5)
- Domestic housekeeper (6)
- Fisherman (7a), Hunter (7b)
- Pet owner (8)

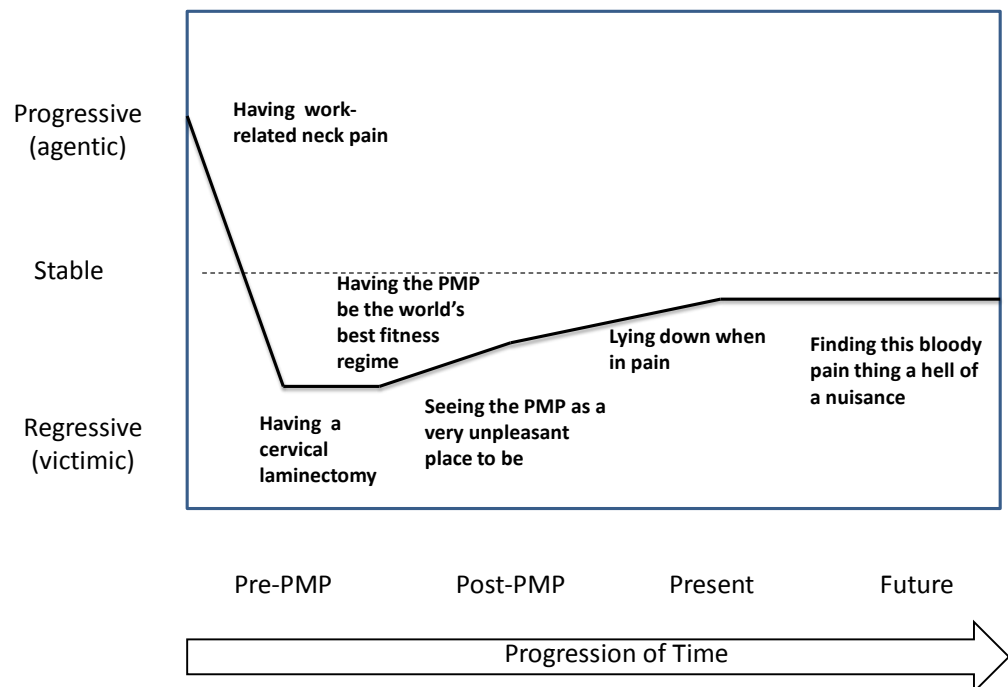


Figure 4.12: Bill's narrative slope

4.2.13 Rosie

Rosie is a 59 year old homemaker, who is married, has two daughters, three grandchildren and five step-grandchildren. Her main passion is sewing, which she does "day in to day out".

About growing up, she says:

Well, my mum and dad divorced when I was about 14. I had a yucky life. Mum and Dad both drank. I'd been a very sick little girl when I was eight. I had appendicitis and it burst. And I had three operations as well, to get me up and going. And I guess this has a lot of bearing on my life. Apparently I stopped breathing on the operation theatre on the table, and they brought me back. I had 12 months off school. I don't remember, Mum was around, but then my grandmother was there as well.

As the oldest in the family she "was in charge of my younger brother and sister". Thus she had a lot of responsibility growing up. She married at twenty-one. Three years later her husband died in a car accident, leaving Rosie to raise two young daughters on her own. She says that "I must

have grieved that 12 months, then picked myself up, and I have a good habit of picking myself up". She remarried several years later.

In 1977 she saw a specialist due to severe pain in the back of her knees, and he removed both her patellae. She says that "it didn't fix any of it". In 1999 she had a total knee replacement, but she feels she is "worse off than 30 years ago". She saw the doctor on the PMP after having three orthopaedic surgeons say her other knee needed replacing, which she is "just not prepared" to do.

About the PMP she says, "I don't know what I really expected". She did not enjoy the group she was in, which influenced what she saw as "a wasted three weeks" about which she is still disappointed. She now has a daily routine that she enjoys, which gives her time for sewing and embroidery, and she notes that she has a great capacity to "bounce back" from most things. She says she has not had an easy life, but in regard to pain she states, "You have to do what you have to do, but don't dwell on it, I suppose".

Life role rating: Rosie

- Mother (1)
- Grandmother (2)
- Wife (3)
- Sewer of patchwork (4)
- Friend (5)
- Housekeeper (6)
- Grocery shopper (7)

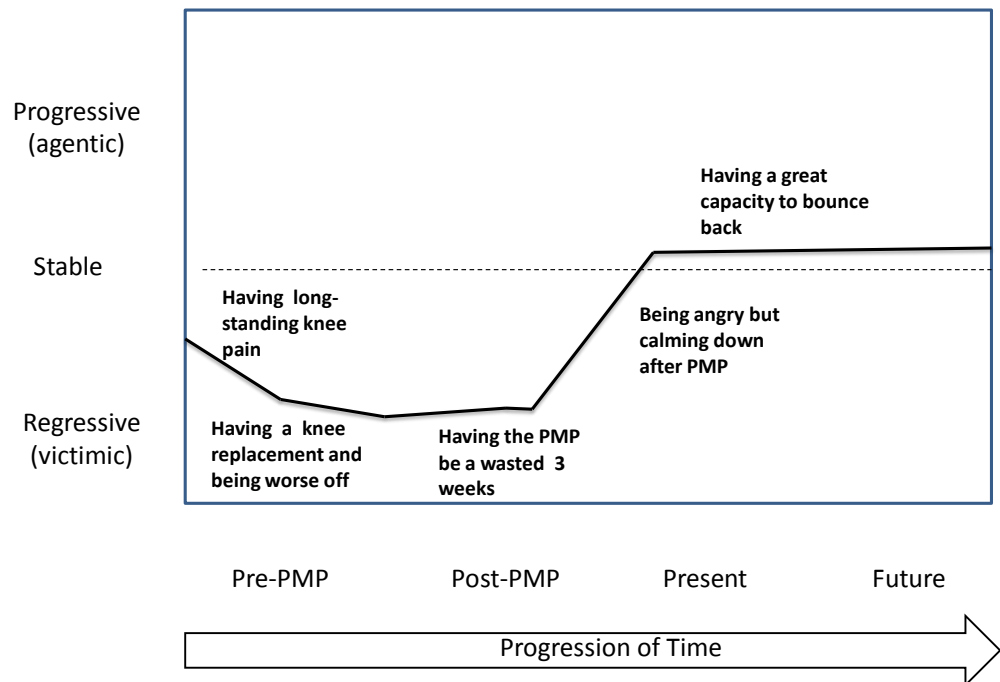


Figure 4.13: Rosie's narrative slope

4.2.14 Ian

Ian is a 53 year old volunteer fire-fighter. He has been a volunteer fire-fighter for 37 years and is currently second in-charge of his brigade. He describes a fire that went through his property when he was aged five, "I can still remember how I felt that day. The fear and all that, to see this thing roaring towards us". This influenced his decision at age 13 to join the volunteer fire brigade. He is also a husband, father and new grandfather of a 4 month old granddaughter. Among his roles he includes being a brother (with two brothers and a sister) and dog-owner, saying "she [the dog] has been one of my best mates actually".

At the age of 24 he joined the police force after working as a carpenter.

About joining up he says:

I wanted to join the army and Vietnam was on at the time and Dad wouldn't sign the papers. So I did the building, and then the police force or the army was always something that I wanted to do and so I ended up going into the police force.

About his work he stresses “I loved it. But who knows if I hadn’t have had my accident I would still be in it”.

He describes the accident that occurred in 1986 as follows:

I was standing on the edge of the swimming pool talking to one of my mates and I heard from my two sons saying let’s play a trick on dad and push him into the pool. Unfortunately it was in the shallow end and I hit my head on the bottom and I don’t know whether I actually blacked out at the time.

He talks about the impact of this on his job and his eldest son in particular, who was seven at the time:

And it ended up costing me my job and the kids at school used to give him [son] a hard time. “Look what you did to your old man” and all this sort of stuff. You know and it played up on him. I still think he blames himself.

He had three cervical fractures that were not detected until 7 weeks after the injury. As a result of this he had multiple procedures which he describes as follows:

They operated on me on the Friday and did a fusion and they operated again on the following Tuesday and did another fusion and they sent me home. I was home for 6 weeks and I was taken back down and they operated again and did a discectomy and I think it was about 4 months later they opened me up again and they all opened me up in the same spot and I thought they were going to put a zip in there at one stage. They did another fusion and I was in there for a while.

However, this did not relieve his pain. It was at this time that he was given an ultimatum by his superiors: “You are not being fair to your workmates here, because they are carrying your workload. The best thing for you is to probably leave”. Ian says he felt “terrible” and describes his subsequent depression: “Days where you can’t do anything and there might be days and days at a time. There were days where I contemplated suicide”. His wife went back to work and Ian “stayed home with the kids”. He admires how his wife coped with everything over that time. He was also diagnosed with post-traumatic stress disorder due, he believes, to what he witnessed working as a policeman and fire-fighter. He saw a psychologist for post-traumatic stress, who referred him to the PMP. He had attended a pain program in Melbourne previously but gained little from it. He says the PMP

staff “couldn’t do enough to help you” and that he had been ready and open to find out about what the program offered. He says “You just have to weigh up everything and be ready for the course. I can’t speak too highly for it because I know what it did for me”. Ian continues to have pain and depression and also now has Type II diabetes. He finds it difficult to motivate himself to go walking for exercise.

Life role rating: Ian

- Husband (1)
- Father (2a), Friend (2b)
- New grandfather (3)
- Volunteer fire-fighter (4)
- Dog owner (5)
- Brother (6)

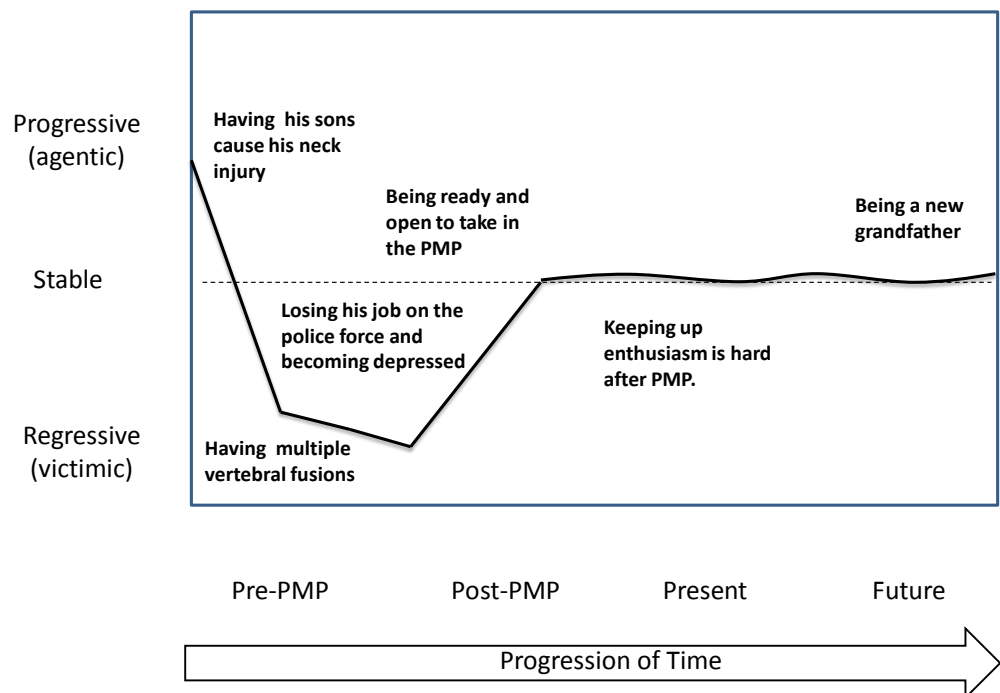


Figure 4.14: Ian’s narrative slope

4.2.15 Sara

Sara is a 45-year old supermarket checkout operator who relocated from her home town after attending the PMP. As she was now living a considerable distance away, interviews were conducted by telephone.

Sara was responsible for looking after her siblings when she was growing up; “Basically, I took the role of mother while my mother was at work. So it was sort of my responsibility to feed and bath and get washing off lines and put washing on lines”. She describes her father as an “aggressive angry type man” who also subjected her to mental and physical abuse; so at the age of 15 she left home.

She injured her back in November 1999, lifting a box of celery from a trolley. She re-injured her back in November 2000. She tried a number of different medications for her pain and was also diagnosed with depression. She was not surprised by having depression which she saw as “because of my injury”. She says “it was nearly 3 years from my first injury, before I got into the program”. She found that the set routine of the PMP suited her and she “really enjoyed being there”. She returned home and tried to keep up the exercises and stretches but her marriage was failing. She spoke about her marriage breakdown about 6 months after the PMP: “He wasn’t a great deal of support at all. He wasn’t dealing with my pain, and I wasn’t dealing with my pain”. Sara also did not retain custody of her two children. She describes her subsequent move away from her home town for a fresh start which she describes as “the way of me trying just to get on with my life”.

Her injury was covered by workers’ compensation. She found this especially difficult when it came to applying for jobs with the same supermarket chain after she re-located. She says her employment options became limited because of her injury.

Sara’s brother had died for no apparent reason a few weeks prior to the first interview. As she says “It’s the not knowing [what happened] that’s the hardest”. She is now living with a new partner, who does not really know about her pain and past. She has taken up ballroom dancing and wants to return to walking and exercise, as well as give up smoking. As she says, “I can’t change the past and I can’t change the damage so it’s just get on with it and take it day by day, hour by hour”.

Life role sorting: Sara

- Daughter (1a), Sister (1b), Mother (1c)
- Partner (2)
- Worker (3)
- Friend (4)
- Housekeeper (5)
- Walker (6a), Dancer (6b)

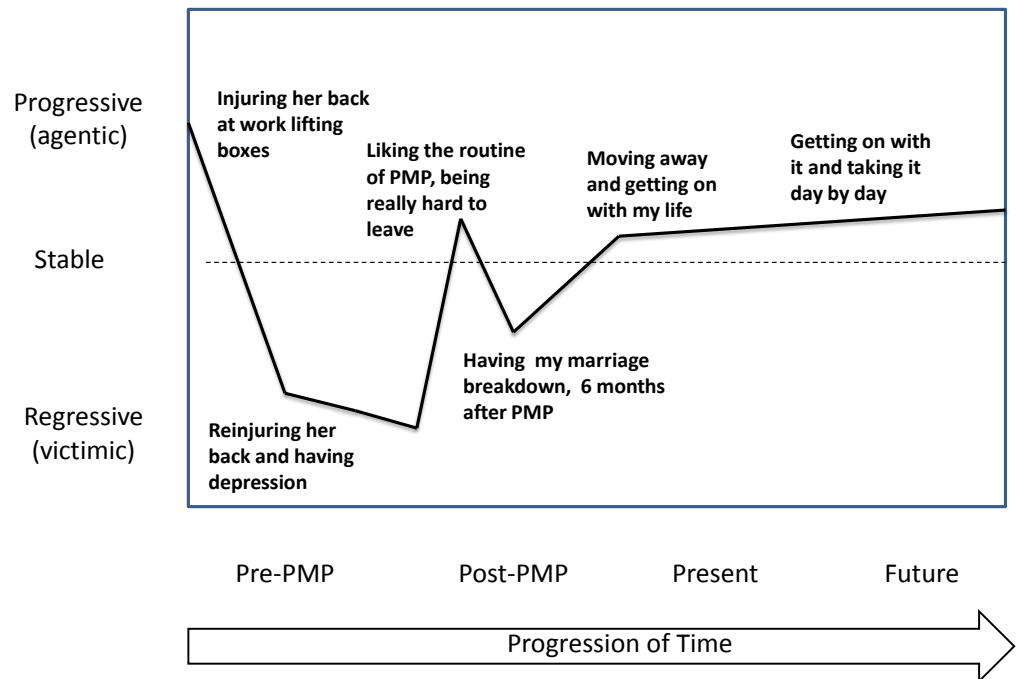


Figure 4.15: Sara's narrative slope

A précis of the importance of including Stage 1 participant's stories and narrative slopes is provided in this chapter's summary (see Section 4.4).

4.3 Introducing Stage 2 Therapist-Participants

Occupational therapists (OT) or therapist-participants are grouped according to their place of work: private practice, community- or hospital-based. This allows comparison and contrast between similar settings.

Private Practice

4.3.1 Patricia (elite therapist-participant)

Patricia works in private practice in a capital city. Patricia was regarded as an elite therapist-participant due to her years working in chronic pain and her involvement in both group-based and individual programs. She works in a multidisciplinary pain program in a team of “two doctors, three psychologists, two physiotherapists and myself”. She sees clients individually in her rooms at the private practice. She describes her involvement, indicating “this would usually take the process of seeing clients for several sessions in my room for education followed with possible home and/or work visits”. She usually sees clients for about 10 sessions. “Predominantly the clients we see are either through the workers’ compensation system – WorkCover – or through the Motor Accident Commission (transport accidents)”. The insurance companies, she states, “have certainly, in the past, had unreal expectations of a pain management program and the outcomes as such”. She describes her approach as an OT working with clients as having an awareness of “psychological issues” working within a “CBT [cognitive behavioural therapy] framework” with an emphasis on “activity-based issues”. She uses cognitive behavioural methods and states, “Why I like it is I think I can make a difference”.

Her program is educative and practical and includes teaching pacing, goal setting, relaxation strategies and increasing activity tolerances and engagement in daily activities. She has found that being able to visit clients’ homes is “on reflection, probably the thing I’m really finding useful at this stage, is that the problem solving in the home environment is much more effective”.

As for OT-specific outcome measures used on the program, Patricia states, “I’m using the COPM [Canadian Occupational Performance Measure, Law et al. 1994] to evaluate pre- and post- my involvement, which seems to be a useful tool because it works very nicely to help set up treatment goals with the client”. Formal reviews of clients occur every 6 to 8 weeks with the multidisciplinary team. Patricia’s practice had previously run a “4-week intensive multidisciplinary” group program. This ceased operating 2 years ago due to financial constraints. She states that she enjoyed the group format of the program offered.

She describes the key message of the program she offers as “teaching strategies to be able to manage their [clients’] pain more effectively and to improve their [clients’] quality of life despite their pain”. She talks about doing things differently over her years in practice and how she initially saw her role as “pushing people hard for change”. She has now learned that “it’s usually better to use a shared goal setting approach of looking at what’s important to them [the person]”. She notes how chronic pain affects “every part of a person’s life, and pain has both physical and psychological aspects to it and cognitive and emotional, and the whole bit needs to be looked at”.

4.3.2 Kristine

Kristine works at a private hospital in a capital city as a consultant OT and is referred both in-patients and out-patients. Her expertise is in the areas of stress and sleep management and she uses cognitive behavioural methods. Of the clients she sees she says, “I get the really difficult ones, the ones the younger OTs go ‘Oh, my God’ and they’re often people who are very resistant to change”. She talks about her previous experience of working on a PMP using cognitive behavioural methods. “When I worked for community health that’s probably where I first started using CBT. So that’s probably where my CBT skills got refined. I always use CBT”.

She describes other aspects of her current OT role which include using goal setting and distraction away from pain. She also teaches clients

different relaxation methods including “visualisation, I’ll teach things that might have a muscular component to it. I’ll do some meditative stuff. Often I do quite a lot of breathing stuff. And sometimes that’s all that people need”. She enjoys her current consultative role “because I don’t do a lot of treatment stuff, because the rest of the stuff I do is primarily assessment and review, it gives me a nice balance”. She describes the “challenging” nature of the clients she sees but notes that she only sees them two to three times on average.

Kristine gives the message to the people she sees “that pain is manageable” and “... with the right skills... [you] can manage... independently”. She talks about her previous group involvement, “I mean with groups there is that nice dynamic thing that can happen”. She currently sees many people who have English as a second language and because of this thinks “for [city] populations, individual stuff is probably the best”.

She sees the OT role as unique in pain management:

Who else has that ability to pick eyes out of things, and like sure some purely practical stuff they can give the nurses to do, but I don’t believe that there’s anybody else who has that whole kind of grab-bag again. You know, “the physio taught you about posture, psych taught you how to do that breathing, how can you use those things at work?”. Who else does that?

4.3.3 Leah

Leah works in private practice, as a sole practitioner. She describes herself as tending “to tailor to each person. So I don’t work in a program with a set protocol”. She sees programs that work to a set structure as limited by lack of flexibility: “They don’t have the time, they work within a structure that isn’t client focused because it is based on time fractions and limited manpower”.

She predominantly sees people who receive compensation payments and obtains referrals from general practitioners, physiotherapists and psychologists. She notes the difficulty in getting referrals for clients who

have had pain for a long time. “So by the time we see people, there are entrenched patterns of thinking usually and behaviour that are all based around grief and fear”.

Leah describes her assessment process and the assessment tools she utilises:

I use predominantly a physical series of assessments. And I also listen very carefully for the psychological profile. I'm looking for holding patterns, I'm looking for guarding, I'm looking for repetitive patterns that I see in movement, or in language. I use SUDS [Subjective Unit of Discomfort Scale] all the time. Long before the COPM came about I had my own COPM. So I think it's quite useful, but it's not always useful.

She describes having a number of skills that she uses within practice. These skills included being a qualified family therapist and a Feldenkrais practitioner. This method facilitates learning about posture, movement and breathing to increase the range and awareness of movement (Feldenkrais Guild of Australia, 2010). She sees it as important that “I've got lots of hats. I think if I didn't have all of those hats, and constructs, I wouldn't be confident that I could make a difference”.

She started working with people with pain after graduating as a Feldenkrais practitioner in 1990. She states that “Feldenkrais is all about kinaesthetic sense. It's trying to build a map for people to make sense in their bodies of what has happened and a pathway out of this”. She prefers to see people individually to decide on strategies to use “because for many people, going straight into a group is not a useful process for people with pain”.

Leah also uses CBT but considers it “flawed” as a sole approach. She does, however, address “catastrophising” about pain and how this can trigger people's stress responses. She sees identifying these as important “because in those triggers is often the key to pain management”. At the conclusion of individual therapy Leah encourages clients to attend ongoing Feldenkrais classes, “because WorkCover doesn't mind paying for classes

and then they [clients] can self-monitor, and learn a lot more about things they can do for themselves that's really the goal".

Leah talks about the importance of retaining her OT focus in therapy and how this complements her other skills:

OT has been the basis for everything, and it remains the basis for everything. OT is like my substrate and Feldenkrais is my umbrella. Now Feldenkrais and family therapy have very similar understandings of the way things work, because they've both come out of systems thinking. So those two things all meld with OT magnificently, the whole thing's a package as far as I'm concerned.

She makes the interesting observation that "all people move on and they have a relapse. I very often see people who've been through pain programs. They can't sustain it on their own".

Community-Based Practice

4.3.4 Liz

Liz works in a regional community-based health centre. "I've been working as an occupational therapist since 1998". She now works as a sole pain therapist, although the community centre ran a multidisciplinary group-based pain program for several years. She offers a 10-week individual program based around aspects of the group program model she used previously. This includes both assessment and review sessions.

The people she sees are "members of the community who have problems with persistent pain. Some people are compensable". She is aware that there might be "cross motivation" for clients receiving compensation to attend, particularly if referred by workers' compensation insurance. She accepts self-referrals but these must be substantiated by a medical referral. She says that "most people come with a history of pathology".

Although she found the previous group program "quite successful" and thought it had a lot to offer, it was unsustainable due to the staffing required. She notes the difficulty of country areas getting health resources. She finds the benefits of the individual program being "that I can tailor it to

meet people's needs, and it's working well for people". She also finds that "working as a single practitioner I can actually achieve more for my time".

She holds individual hour-long sessions once a fortnight with each client, that include relaxation strategies, education about chronic pain and current physiology, goal setting and pacing. She also uses CBT within her practice. As she states, "we're not developing splinter skills, but we're developing basic skills for daily living". She sees the aim of the 10-week program being to develop "a tool kit of strategies that they can use to help them with managing the pain". She sees herself as a "coach" to help people understand their problems and how best to apply strategies. In addition to her OT role she is also a Feldenkrais practitioner. Like Leah, Liz finds this "really valuable in teaching people about their bodies and how to help themselves relax, move with more ease, and reduce their muscle tension". She sees Feldenkrais "as a tool" that is "really just embodying OT".

Liz also uses the COPM as well as other pain outcome measures such as "the Oswestry [Disability Questionnaire], the Brief Pain Inventory, and one called the POP, which is the Pain Outcome Performance Measure". At the conclusion of her clients' 10 sessions she completes a report based on these measures. She has noted "quite big changes with regard to the COPM, and their [clients'] goals". She also encourages people to return for a refresher program if they wish.

Hospital-based Practice

4.3.5 Marie

Marie works at a large regional hospital in a 3-week inpatient multidisciplinary chronic pain management program. This group program has a biopsychosocial focus and uses cognitive behavioural methods. The cognitive behavioural methods used include constructive thinking "so challenging beliefs, thought processes and behaviour". All participants sign a contract prior to starting the program. The contract states, "You're going to do everything – you're just going to do it within your limits". She

describes that all staff use a consistent approach to pain and pain behaviour which is seen as important. Clients are given three warnings and if they do not commit to the program, they are asked to leave.

The program is staffed by an anaesthetist/pain specialist, doctor, nurse, social worker, physiotherapist, two occupational therapists (who job-share) and two psychologists. Marie has been working on the program for 3½ years. The program accepts groups of 10 people at a time with pain ranging from 5 months post-injury to over 50 years since pain onset.

Marie's role in the program is described as

... very much about activities for daily living, which are important to the clients. We do a session on activity planning; a session on stress and I do a session on relaxation. We've got four different sorts of relaxation that we do.

She is also responsible for taking a session on goal setting. "We call it SMART goals: Specific and Measurable Achievable, Reasonable and Timed". The program has the same long-term goal for everyone of being able to self-manage pain within 12 months. She sees Week 2 of the program as learning practical strategies and Week 3 as preparing for home. She describes relapse education as the "real concrete process for if things are going pear-shaped in terms of an activity, what they can do to solve that". Her role also involves addressing return to work in terms of "how are you going to apply what you've learnt here to your work situation"? The program also has a family day when family members attend and try out the various aspects of the program and also discuss ways of facilitating pain management for the person once home.

Clients are reviewed 10 weeks following program completion. "It's really just focusing on how things are going from an activity point of view". The main occupational therapy outcome measure used is the COPM. This is administered in the first week of the program and at review.

Marie enjoys working in chronic pain:

It's really rewarding in terms of seeing someone so disabled, and so miserable, so uncomfortable; to see that we can actually help them over 3 weeks get to the point where they can function. It's really rewarding to see someone go from being so disabled to being much more able.

4.3.6 Alison

Alison works in the same multidisciplinary pain program as Marie. She has worked in the area of chronic pain for 2½ years. “There’s a job-share situation with the two OTs in this program, but there is an OT here every day”. Although the program takes compensable and non-compensable clients they “need to be independent with their self-care before they come in, because we can’t provide nursing care in the [program] accommodation”.

Alison’s role on the program is similar to that described by Marie. Additionally, she does a session on “posture awareness, using correct body mechanics and adaptive equipment”. However, she stresses advocating the use of minimal adaptive equipment. Activities such as ironing and gardening are simulated to practise strategies taught. She also looks at return to work issues, but notes “if return to work isn’t an issue for them, then we look at how they’re filling their day with appropriate hobbies and leisure and things like that”.

Alison sees the main message of the program as:

We are a pain management program; our aim is not to take the pain away, so what we’re teaching them now is coping strategies. They’re encouraged to see pain as more of a nuisance really, rather than anything else. So distraction also is a big part of that.

Alison perceives the program to be a predominantly positive experience for her clients. She states enthusiastically, “That’s one reason I love working in this program because you really feel that you’ve made a difference”.

4.3.7 Elizabeth (elite therapist-participant)

Elizabeth is also regarded as an elite therapist participant due to her years of working within the one pain program and her interest in chronic pain research. Elizabeth works in a large metropolitan group-based pain management program that offers various individual therapy options and a

group program. As in other such programs a range of health professionals are involved. Additionally the program has access to a rheumatologist and an ear nose and throat surgeon. She is the only occupational therapist on the team

She describes the screening process for prospective participants as a “triple assessment”. This involves physical and psychosocial screening and a functional capacity evaluation. A team meeting follows that decides if the 3-week pain program is the most suitable option. Clients are then required to come in for an “application interview” which is “looking for motivation and acceptance really”. Elizabeth’s clients include both “compensable people and people through the health service”. She sees people who have had pain from 6 months to 50 years. The age range is 16 to 76 and includes a higher number of women. The hospital runs eight to nine programs a year; there being a 3-week break between programs. Elizabeth is involved in the program most days.

As in Marie and Alison’s program, prospective participants have to commit to come. “They’re allowed to miss 3 days – maximum. They have to be there on time, they have to give everything a go, and we’re quite strict about all of that”. The program has a philosophy of treating people equally, which includes not being able to opt out of activities. As the program is self-help and not intervention focused it uses a “psycho-educational, cognitive behavioural sort of mix really”.

Elizabeth’s role on the program is similar to that of other occupational therapists; her special interest, however, is “psychosocial assessment” and she performs this as part of the “triple assessment”. She also runs an art session that focuses on participants making a pictorial representation of their pain. At the end of the program there is a family day where “we have a session on family issues and pain”.

Elizabeth uses “a sort of pirated version” of the COPM as an OT-specific outcome measure. This is administered pre- and post- program. She notes that she does not “keep a record of that, it’s probably something I should

keep a record of but I don't". Clients are also reviewed at 1-, 6- and 12-month follow-up and staff participate in this on a roster basis.

Although Elizabeth has been a professional adviser and manager, she disliked those mainly administrative positions. She talks about her experience of working in pain management over many years in positive terms; "I'm just coming to the end of my 11th year (of working in pain), for me personally, I love being a clinician". She enjoys the mix of assessment, group and one-to-one work which she has created in her position. "So I still feel quite sort of grounded in occupational therapy. And I'm in a team that respects that".

4.3.8 Louise

Louise works in a hospital-based pain management unit in a capital city, which is part of a large rehabilitation centre. Her program is referred clients both from the rehabilitation centre and from an on-site interventional pain clinic. As in many other programs, clients are accepted from the ages of 18 to 60 plus. Length of time in pain is similar to other hospital-based programs. They accept people who receive compensation, but she states, "we're quite candid about whether they're ready, whether this is the right time for them to participate in the program. So if they're very depressed, it may not be the right time for them to be involved".

The assessment process is described as "quite rigorous", with a psychological assessment followed by physiotherapy and occupational therapy assessments on the same day. A team meeting is held to decide on the best course of intervention. Her program offers a structured outpatient group program or an individual program "based on the client's needs". Louise sees many people who have English as a second language; most are seen individually although some aspects of the group program may be suitable with the use of interpreters. In general the program runs for 8 -12 weeks but this is also flexible depending on need. Louise describes the aim of both the group and individual programs as to "get someone to a point where they're using active self-management

strategies. So that gives them a greater sense of control". She notes that pain management is an "ongoing process" in terms of adherence to strategies, and she sees her program as "a starting point and it's about an on-going journey for that person".

The program uses a CBT approach, which includes challenging pain behaviours by making clear "that everyone has pain and that we're not wanting to speak about that, as that's not a useful strategy". Louise's role within the program is similar to that in other programs already described. She uses a lot of education into relaxation, pacing and simulation of tasks and practice strategies. Clients are then given homework to practise in the home environment and their progress is checked at the following session. The program previously used the COPM as an OT-specific outcome measure but has moved towards a goal attainment scaling measure (GAS). She says that when using the GAS "it's very clear whether you've achieved that goal or not, it's quite objective". She notes the need to be accountable for showing successful outcomes within pain programs.

Louise has been working in chronic pain for 15 years. She also works in other areas of the hospital and, like Elizabeth, thinks "that balance has been really important; working with some conditions that get better, that's very important for me". As with Patricia, Louise's approach to working with clients is very different now from when she first worked in the area. She also finds "that on-going learning and just staying in touch with what is recent in terms of research and application is very important".

4.3.9 Matt

Matt works in a large tertiary teaching hospital in a capital city. He describes his somewhat unique current and past roles in the pain program:

At the moment, I'm in a non-clinical role, but for the last 3 years I've been in an in-patient pain program. It's a 2- or 3-year rotational position; it's a critical research position, so you're allocated a full-time position within the pain clinic, as the pain clinic OT. And you also have to complete a research master's degree.

He describes the model the program operates under as the “medical model” with clients having medical procedures while on the program. He recognises the tension of trying to promote self-management of pain when clients are having invasive interventions as well.

Staffing on the program is similar to that in other hospital-based programs. A difference with his program is that it is a “rolling” 2-week inpatient group program “so every week you would get new patients coming in, and every week we’d have patients leaving at the end of that week”. The program sees over 180 people a year, which Matt describes as “hugely demanding on the therapists”. The average age “is 45 and the average pain duration is 10 years”. As the program services the whole of the state they serve mainly “public patients” because of the long waiting list. The clients he sees are “really disabled” by pain and he believes they would not cope with a standard type of pain program. He also notes his frustration at being unable to follow clients up after program completion due to the high client turnover and large catchment area.

When working in the in-patient pain program Matt’s main aim was to “look at people’s function”; however, he tried to make the role more “occupational” than “functional”. He achieved this by establishing activity-based programs for clients in the program’s gym. Otherwise his role includes education on strategies similar to other programs. He recognises that “imparting information is probably okay in a group setting, but then I think it really needs to be applied to the individual and conceptualised”.

Matt aspires to use occupational therapy practice models in the pain program. He sees that “MOHO [Model of Human Occupation (Kielhofner, 2002)] is probably a model that I see has a lot of application, especially in chronic disease”. He uses this as a basis to explore people’s interests and life roles, and develops activities that have purpose and meaning from this. The program also applies cognitive behavioural methods to chronic pain. He finds that “challenging people and correcting cognitions... in the moment they happen”, is useful. He concedes that “everyone says they do

CBT” and that “it’s just a buzz word around pain” but “it’s certainly the best approach we’ve got”.

Matt has been an OT for 4 years. He finds that working in chronic pain “there’s no black or white, and it’s all grey. And I think the grey is quite enjoyable, but it can be really quite frustrating and exhausting, as well”. He sees his new non-clinical role as being “my job to look at how we can improve things”.

4.4 Summary

This chapter introduced the participants for Stages 1 and 2 of the research. It provided detailed précis of participants’ stories and, in the case of Stage 1 PMP participants, life trajectories of living with pain. These trajectories are taken in the context of the overall pain story for Stage 1 PMP participants that accounts for their life before, during and after the PMP. Seeing the turning points in the narrative over time is important for understanding their perspective of being progressive, regressive or stable in their life plot. For Stage 2 therapist-participants, their précis detailed working with people who have chronic pain, the aim of the practice or program, and the unique role that the OTs brought to their work. This chapter sets the scene for the findings that emerged from both stages (Chapter 5 and 6).

CHAPTER 5: FINDINGS – PMP PARTICIPANTS’ PERSPECTIVES

5.1 Introduction

This chapter follows on from Chapter 4 “Introducing the participants”, where the roles and narrative slopes for Stage 1 participants were explored and descriptions of Stage 2 therapist-participants were presented. The following findings are divided into two chapters. In Chapter 5, the findings from Stage 1 participants are presented in terms of the categories used in the analysis of “Interpreting the stories” (Chapter 3, Section 3.8.3). These categories of themes relate to:

- Self/person
- Meaning ascriptions
- Strategies used
- External/social world factors.

Themes identified under each of these categories are tabled and discussed for Stage 1 PMP participants in Chapter 5. The same categories are used to structure the findings from Stage 2 therapist-participants in Chapter 6. The tables detail findings as either agentic or victimic. This concept was previously introduced in the Chapter 2 (Section 2.3.9) and Chapter 3 (Section 3.4.3.). Whether the theme was considered agentic or victimic was dependent on participants’ reports as interpreted by them (Stage 1) or perceived by therapist-participants (Stage 2) in practice. Some themes were interpreted as having both positive and negative aspects depending on the particular context, as illustrated in the tables. Themes were largely derived from the actual language used by participants to describe their experience of living or working with chronic pain. This provided authenticity by reducing the possibility of misunderstanding when considered in the overall narrative context.

5.2 Stage 1 PMP Participant Findings

Table 5.1: *“Self” themes of PMP participants*

1. “Self” themes	A. Agentic	B. Victimic
Having family and home-based roles	Being a mother and grandmother; having home-based roles	Having one loss after another
Being a worker	Working is important	Losing worker role
Being a volunteer	Being community minded; helping others; passing on skills	Losing valued roles
Being responsible	Being the oldest; being the boss; being self-sufficient	Being abused
Having depression	Keeping out of the black hole	Having suicidal thoughts
Being me	Being selfish (giving time to myself); being in control; being independent; being positive; being determined; being strong; being how I see myself now	Being unable to do what I want to do

Table 5.2: *Meaning ascriptions of PMP participants*

2. Meaning Ascriptions	A. Agentic	B. Victimic
Being ready to do the PMP	Being the right time; being open; PMP being at the end of the line (having to make it work)	Not knowing what to expect; having different expectations
Acceptance of living with pain	Doing things in spite of pain; being able to move forward	Looking for a cure; getting angry because I can't do things
Seeing pain as a process	Moving through the process of pain self-management	Getting stuck in the process; feeling fearful of doing things
Comparing myself to others	Being better	Seeing others who get better than me
Pain being a battle	Fighting the pain; living day to day	Seeking sympathy; being told how to manage my pain by others

Table 5.3: Strategies of PMP participants

3. Strategies	A. Agentic	B. Victimic
Setting goals	Setting little goals; having future plans	Being unable to set goals
Having strategies that work	Having a number of strategies	Being unable to use strategies
Using medication	Being in control; having my own routine; taking medication regularly	Being taken off all medication; taking medication in response to pain; using alcohol and drugs
Using education about pain	Having the "bible"	Information not helping in the long term
Finding different ways	Making life easier by using equipment; doing things differently; using correct body mechanics; using pacing	Not getting tasks finished; pacing being non-existent; being unable to use techniques
Having a routine	Having a daily routine	Rushing to get things done
Keeping busy	Keeping going; using it or losing it; having a rest	Having difficulty finding motivation; finding sleeping difficult
Doing meaningful things	Having hobbies and interests; getting satisfaction out of doing things; getting others to help	Frustration at relying on others
Doing exercise	Trying to do things again; challenging myself; making exercise a habit	Falling off the wagon; having difficulty finding the motivation to exercise; doing more harm than good
Learning how to relax	Using a variety of different techniques	Being unable to relax
Using cognitive-behavioural strategies	Using positive self-talk; using mind over matter; side-stepping around the pain; using humour	Experiencing brainwashing; being unable to change my thinking

Table 5.4: Social world influences on PMP participants

4. Social World	A. Agentic	B. Victimic
Family and friends		
Parental influences	Being supportive; growing up tough; being stoic	Being in abusive/difficult relationships
Spousal influences	Having a shared pain experience; having good support; maintaining a sexual relationship	Having relationships break down; being in an abusive relationship; having difficulty with role reversal
Family influences	Being supported by family	Family being overprotective; having difficulty explaining pain to others
Friends' influences	Having supportive friends; re-evaluating who my friends are; having pets	Having limited friendships
Isolating myself	Isolating myself to cope with the pain	Being away from others; explaining isolation to others and being misunderstood
Institutional influences		
Being within the compensation system	Having my claim settled and my medical costs covered	Having to prove my pain
Seeing general practitioners (GPs) and specialists	Having a good GP; stopping doctor-shopping; considering GP a friend	Having pain seen as all in my head; seeing specialists as indifferent; having specialists miss something; being seen as a malingerer
Going to the PMP	The PMP being amazing	Having multiple conditions; the PMP being a negative experience
Interacting with PMP staff	Seeing staff as excellent	Seeing staff as off-putting
Being in a PMP group	Being in a supportive group; being a motivator; socialising out of hours	Having nothing in common with the group; being unable to socialise; lumping us all together
Being assessed	Using video to show what we achieved	Being frustrated by pain questionnaires
Having a family day on the PMP	Realising the impact of chronic pain on family	Partner not attending family day
Using CBT methods	Avoiding pain talk and pain behaviours	Having difficulty avoiding pain talk and pain behaviours; being pulled down by others' pain

Finishing the PMP	Having more control; being fitter; having a newsletter from the PMP	Going back to a realistic world; falling in a heap; doing it on your own; being cast off; having ongoing treatment; deteriorating since the PMP
Community Influences		
Using community support	Having buddies; joining a support group	Having economic constraints; distance being a problem
Having a refresher	Being a great idea	Funding being an issue
Dealing with people in the community	Being supported by others	Being judged; finding a lack of understanding; looking fine but not feeling fine; having the stigma of chronic pain

5.2.1 “Self” themes

Themes related to the concept of self/identity emerged from the narratives in many different ways, which reflected the uniqueness of each participant and his/her distinct pain narrative (see Table 5.1). Themes clustered around familial and work roles are reflective of the person’s sense of a social identity (i.e., as seen by and interacting with others). Individual personality traits that were identified by participants and informed their sense of “who I am” might have been learned when participants were children, experienced while growing up, or developed as a result of their chronic pain experience.

Having family and home-based roles

As evidenced by the role rating of importance in Chapter 4 (Introducing the Participants), familial roles were identified as very important to all participants. Roles related to the home were also prominent.

A. Agentic

PMP participants identified a number of familial and home-based roles important in their lives. Familial roles were often those rated most highly, but home-based roles were also prominent, particularly for women. Ian²

² All names used are pseudonyms

identified his new role as “grandfather” as significant when caring for his baby granddaughter. Dawn used the term “domestic engineer” to discuss the various activities she completed around the house.

Being a mother and grandmother

Alexandra described the various familial and home-based roles filling her busy life:

I'm a mother and grandmother. My husband is an international businessman so I travel extensively with him. I help him in the business. So I have a fairly active, busy life. I've got a few homes to maintain which keeps me busy. We have the house we live in and a farm and we've got a unit down in Melbourne and then a house over in the U.S. I do a lot of babysitting with my 8-year old granddaughter. So I'm sort of a hands-on grand-mum.

B. Victimic

Having one loss after another

For some participants, however, chronic pain involved a loss of valued roles due to the inability to continue performing them, or in some cases the role being removed. Maree spoke about the myriad of losses she experienced with chronic pain and depression:

Well it's not only the pain, it's the huge loss that the pain entails, I lost my job, I lost my income, I lost my independence. I just felt like I wasn't contributing to the house or anything like that and that was a huge loss and with the not going to work as well that was a great part. Not only the finances but my social life consisted of lots of people at work as well and even just that thing of going to work in B... [town] meant that you pick up the shopping or you pop in and see somebody and I wouldn't do it, just I wouldn't go into town to do it and that was a really, really big thing, it was huge.

Being a worker

Being a worker was identified by those who were employed as an important part of their lives. Only two participants had resumed full-time work, with other participants working part-time or working in alternative jobs as a means of returning to the workforce. Being a student was also included, as one participant was actively studying to gain a career.

A. Agentic

Working is important

Maree had resumed work as a psychiatric nurse. She identified the social aspects of working as “a huge part of my life”. Stacey described her work duties and the importance of work in her life. She found the challenge and the distraction of work something she looked forward to:

I am classified as an administrative person, so the majority of the time I'm actually sitting and working on a computer. If I didn't have work I'd probably be backwards, because it gives me something alternative to think about; it gives me a challenge pretty much every day and that's why I'm enjoying it so much. I have a distraction and it's something to look forward to every day.

For some participants, productive roles were related to living on the land, as the PMP was situated in a regional town and many of the participants came from rural locations. Alice took a job at an organic farm after working as an administrator for many years. She found the self-paced nature of her work suited her. Willie, despite being semi-retired largely due to his pain condition, maintained an interest in raising horses and cattle. He no longer lived on the land but continued to perceive himself as a farmer, as he had maintained his previous work-related interests:

One of my roles is semi-retired farmer; that's the horses and cattle; I've got 60 at the property. At first after we married we lived on a dairy farm for 23 years but I handed most of that over to my son and daughter-in-law. Then we moved to town and made the decision to sell. Now I'm deciding what to do, day to day, couldn't tell you. Because farming was the only thing that I'd ever known, but anyway, when I had this injury that put an end to that.

For some participants who were not working, being in the student role, which would hopefully lead to work, was seen as worthwhile. Rachel was pursuing welfare studies: “I'm doing a Certificate 4 in Disability Studies. From an earlier age, I've always liked to work in community service”.

B. Victimic

Losing worker role

Several PMP participants described losing their paid employment due to their ongoing pain. This was a negative experience to which some

participants were still adjusting. Ian described receiving the “ultimatum” to “get out of the job” after working as a policemen for many years. This was a “kick in the guts” as he had held out hope of returning to work after his injury. Alice was sacked from her job of 16 years because of chronic pain and described the adjustments now that she was working part-time elsewhere:

I'd lost the job that I'd been in for 16 years which was really, it was a really unpleasant experience. They just sacked me, and that's a bit hard for an older worker, being a loyal worker for so long... so yeah, that was a big adjustment. But I got used to it now. There are still days now when I would like to have a full-time job, which sounds silly. I enjoy the interaction with people and I like having a bit of responsibility and a bit of a challenge and those are the things that I miss.

Being a volunteer

A common theme among participants, both working and not, was the range of community-based and other volunteer roles undertaken. Several participants noted that providing service to the community was important in their lives.

A. Agentive

Being community minded

Ian described his role as a volunteer fire-fighter. He had become more involved in that since being stood down from his paid work:

Loyalty is very important, pride in your community, pride in your country, all that sort of stuff. Because I believe in the organisation I believe in what the organisation stands for and I am also a big believer in helping communities. It is just an important part of my life, it has helped me quite a lot. Because I was able to really throw myself in instead of feeling sorry for myself.

Helping others

Will spoke about his role with the Lions Club and how helping others was their core business. He had become more involved since winding up his business, making it a more prominent role in his life.

That's what I've been finding with the Lions Club, we were just saying that we've got to change our ideas and the way the club's involved because to me they're not doing enough to what they should be doing, you know. Getting out and helping other

people that are less fortunate. I know we're helping with finances and things like that, but doing the personal things that are making contact back to the people themselves.

B. Victimic

Losing valued roles

Dawn spoke about her valued role of being a netball umpire. She was unable to resume this role after her accident and it was one of her goals when on the PMP to return to this. Unfortunately, although she tried, she was unable to fulfil the role.

So I umpired. And then after the accident, I sort of lost it. I wasn't happy; I really wanted to get back the umpire certificate. I tried to get my umpire certificate back after pain management, but the turning; I couldn't keep the half the court. By the time I've turned around, the ball's gone back that way. It was just too hard.

Being responsible

Themes related to childhood upbringing emerged in the narratives as influencing how the participants saw themselves. Being responsible was something that was noted in several PMP participants' narratives. Many had assumed adult responsibilities at a young age, which at the time was culturally acceptable.

A. Agentic

Being the oldest

Six of the participants were the eldest child in their family (Maree, Alexandra, Stacey, Willie, Rosie & Sara). They described being responsible as an attribute they developed when looking after younger siblings. Stacey, the youngest participant, would have to be "home and get dinner ready" at age nine. This contributed to her early sense of maturity.

Similarly Alexandra discussed growing up in her family:

I'm the eldest of four siblings. I had a lot of responsibility as a child growing up in Queensland; my parents both worked and so I was always left in charge of my younger siblings. I was about 9 years old and to be left with my two younger siblings while they were out at night; well I used to get nervous at night by myself. I used to cook at a young age; I could run a household at the age of nine. But in those days it had to be done, there wasn't that many choices.

Being the boss

Sarah, although not the eldest in her family, was seen as the “boss” growing up with four brothers. She noted that she was a “tomboy” who was expected to do what boys did.

I was the boss. There's one older than me and three younger. I don't know how I actually saw myself, but I was the boss. I ruled the roost. And so I was very much a tomboy and I was very much expected to do what the boys did.

Being self-sufficient

Dawn, although not the eldest, was brought up to be independent early in life. She related this to the culture of the time when women had to become self-sufficient and how her father believed this to be a positive attribute. She adopted his philosophy:

I'm one of four girls. My dad always made sure that we were self-sufficient that we never had to rely on men. Like, if in an emergency, I'm not relying on someone else to do it, I know how to do it for myself. My dad sort of believed I suppose, being one of the war kids, – the women did a lot of things during that time and they did it well.

B. Victimic

Being abused

Four participants spoke frankly about experiencing abuse as children and the ongoing effect on their lives. Sara left home early because she “couldn't cope with being physically abused any more.” Rachel³ described her account of childhood abuse and the way it affected other personal and family relationships in her life:

I don't trust people anymore; I've been hurt in so many ways. At an earlier age I was abused. I have other relationship of living with this guy but he decided to not understand what the pain [is]. [I have been] 4 years and 2 years with two guys, two times I was engaged. The guys don't understand what the pain is all about; they do not understand when they see me aggressive, moody, [they] try to ignore it. It is difficult with the family [they] don't believe it.

³ As Rachel had a significant communication impairment some predictive text has been inserted in square parentheses.

Julia detailed a lifetime of abuse; firstly by her father, then from her first husband, through to her current relationship. The ongoing impact of this was significant in her life and how she saw herself:

I was living with my mum but she just packed up and left. So then I had to go to my dad's, which was hell. He punched me up because he reckoned that I wasn't his. And so he would bash me up and then I went to my elder sister's and she was 18 or 19 but she was having a baby so didn't know what to do with me so she put me into L... [girls' home].

Because I got burnt as well. All over my chest and arms. About 20 years ago, the two older girls, their father threw metho [methylated spirits] on me. Yeah I have been through a fair bit... See R [partner] just went and got me a brand new bed and he was going to leave me last Monday. He picked me up by the throat and was going to throw me around. But I'm not the one that is going to sit around and cringe when things like that are going to happen. I just look at him straight in the eye and say well if you are going to hit me then do it. Then two days later he goes out and buys me a \$1300 bed. Please help me. What is happening here?

Having depression

Having depression was also a prominent theme for several participants. A few participants experienced depression early in life, but the majority developed depression after their chronic pain condition. The debilitating effect of this was detailed, as well as the ongoing need to be “vigilant” for those who overcame it.

A. Agentive

Keeping out of the black hole

Sara used the metaphor of the “black hole”, a term applied to depression and pain on the PMP, and about the effort it took to keep out of it:

I think there's a lot of people like me... Do they want to get out of that black hole? Or, do they want to stay in it? And I've tried to get out of it. I mean it's easier said than done, but you've got to put your mind, your heart, and your soul into it, if you really want it.

B. Victimic

Having suicidal thoughts

Several participants experienced pain-related depression and spoke about having suicidal thoughts. Maree described how her “spark had gone” and

that she was “barely functioning”, spending most of the day in bed when her pain was severe. She eventually went onto anti-depressant medication. Will was hospitalised with depression when he became suicidal. He continued to battle depression and used the metaphor of the “black hole” from the PMP to illustrate this:

I had a bit of a breakdown and went in and spent a week in hospital, under the psychologist there. Because I got pretty down and I was sort of suicidal and it went right through my mind pretty well. I had it all planned out what I was going to do, but I didn't. It's stressful for M... [wife] but it gets that way. In the program they talk about... to keep out of the black hole and you fall back into the black hole, but it's just got so much lately, it's just been as M... [wife] will probably say that I haven't been real good.

Being me

“Being me” was how PMP participants saw themselves at the time of interviews. Who they perceived themselves to be was influenced by their past, their upbringing and characteristics they developed by having and living with chronic pain. As such, this was a diverse theme that was idiosyncratic to each participant.

A. Agentic

Giving time to myself

Some participants spoke about being selfish in making time to go and undertake the PMP. Stacey saw it as “something I want to do by myself” in the sense of providing herself with the space and time away from others to devote to her chronic pain management. For Rosie, it was about putting herself first for a change with regard to doing what she wanted to do:

I think that I've always put everyone else first, and put myself at the back burner. Whereas now I'm sort of thinking more along the line – well, if I don't look after me nobody else is. I love my partner to death, but I think, if I don't do something for myself nobody's going to do it for me. So, that's the way I'm thinking, and I sort of feel on top of the world at the moment.

Being in control

Participants spoke about being in control as a positive feature of managing pain. Maree described how previously “the pain was in control and the pain was all-consuming,” whereas now “I feel like I'm in control”. For

Alexandra, being in control and being positive in her outlook were important personal attributes:

So, I'm very fortunate that I'm an upbeat person so I tend to just get on with it. I mean, life's to live, and I don't want to sit in a corner and feel sorry for myself. It gets me down occasionally, if I've had real breakthrough pain and it's been going on for a few days, then I might get a bit tired and if something just sort of knocks me out of kilter or gets me upset, I just give myself a good talking to: "You could be in a wheelchair, just get on with it girl, you can't just live in misery". So, I just sort of put myself through it and out the other end and get on with it. You know, so I feel like I'm in control. I just try not to let it rule my life I guess.

Being independent

Alice found that wanting to be independent helped her get back to doing things she had thought she could not do:

I would call it stubbornness but it is probably that feeling that I am not going to rely on people to do things for me. It's probably helped me get back on my feet and do a lot of things that initially I just thought I wouldn't be able to do. The independent streak paid off.

Being positive

The recent event of her brother's untimely death made Sara reflect on her life and how she saw herself. She also noted how pain and depression influenced her life and how she saw life more positively now:

Well, at the moment I'm sort of pretty well happy with my life... there are days where I do feel sorry for myself, but I'm very positive at the moment, I just want everything to be right, sort of thing. Well, I think I've been in a black hole for so long and I just need to get out of that black hole. So, get on with it and let's live our life, because you know, it's there and I've got to live with it. It's taken a long time... it's not fair that it had to take my brother's death to open my eyes to a lot of things, but if that's what it was meant to be, that's the way it's meant to be.

Being determined

Rachel saw her past as impacting on her view of self and her chronic pain. She became determined to fight for what she believed in:

That's the hard part, because they [others] don't know that the physical pain has a lot to do with the past, where you start from, I know myself I have to be strong, I have to be determined to do what I want to, and if I hold back and say that I can't do it the pain will get worse, so in myself I have to be very strong and determined and fight everything for what I believe. I have my

days, [when I say] “Why, why has it happened to me?” So when they said that “you are a miracle”, I am a miracle because what I learn, what I am is me.

Being strong

Rosie also found that being “strong” shaped the person she became when dealing with a life of challenging events:

I’ve always been strong, very strong. I’ve had a strong resolve from when I can remember way back. You know, and I’ve had some ups and downs and... right throughout my life and I just haven’t let them beat me. And I just feel that I’d be weak if I did that, so I just don’t allow it.

Being how I see myself now

Alice described the process of time, having chronic pain and her past experiences as formative to how she saw herself from a more mature outlook:

It is amazing when you get into your late 50s and you think, “Well, this is who I am and where I’m at and if people don’t like it then it is bad luck”. But basically I am pretty happy with where I am. If I stop to think where I was 3 years ago I think “Well gee who would have thought that I could have managed as well as this” and if I have a bad pain day now as well I think there will be a better one shortly. I’m sure that the pain has been my major hurdle.

B. Victimic

Being unable to do what I want to do

Several participants noted with frustration their inability to participate in past role-related activities and how this impacted on their sense of self. Bill was candid about who he was and how his inability to do things affected this:

Whether it suits the answer profile or you’re uncomfortable with it or not, it doesn’t matter because that’s who I am [an extraordinary person]. That’s why I find this bloody pain thing a hell of a nuisance because it doesn’t always let me do what I want to do.

In summary, PMP participants recognised various aspects of themselves as influencing how they perceived their view of “self” and their ability to cope with chronic pain. While some aspects, such as being responsible

and being strong and determined, were viewed as positive, this could be mitigated by depression, role loss and other life circumstances.

5.2.2 Meaning ascription themes

Meaning ascriptions refer to the way participants thought about their pain, the process they went through to manage their pain and their way of interpreting what pain meant in their everyday lives. Past, present and future time appeared to be a significant factor in influencing meaning ascriptions as participants went through a process of acquiring pain, looking for a cure, participating in the PMP and then returning home to manage in the long term. Agentic meaning ascriptions, as interpreted by PMP participants, were related to those who were actively managing their pain. Victimic meaning ascriptions were those that, from a PMP participants' perspective, did not allow them to move forward in the pain management process.

Being ready to do the PMP

"Being ready" emerged as a common theme across PMP participant narratives. Being ready was related to thinking the pain program was going to offer some relief from chronic pain, especially for participants who had tried a number of other interventions.

A. Agentic

Being the right time

Being the right time for PMP participants to undertake the PMP was illustrated in several narratives. Stacey talked about having done "the doctor hunt" initially; but after 5 years she felt she was "ready to get better". Maree also epitomised being ready for change; she felt it was exactly the right time for her to do the program:

I was just so ready to be there, it was just the exact right time for me and I was sort of prepared for it a bit and everything you know. Somehow I knew that it was going to help and I needed to do it but I couldn't do it myself and I knew that.

Being open

Being ready was related to being open to the PMP message about pain management and that pain had both physical and psychological components. Ian saw this as entering the program with an open mind to what the program would offer:

So you've got to be, like it or not, prepared to accept it, maybe some of what you are going through is a little bit psychological, you know like in the mind and you've got to be ready to accept that and you've got to be ready and open to take in what they are saying and be prepared to try it instead of just saying "No; medication is the only way and everything that they say is a load of bull". You have got to be there for the right reasons.

PMP being at the end of the line

Metaphors were used by participants to signify where they were in the process of managing their pain. Being at the "end of the line" was seen as signifying an end to looking for a cure. It also meant that after the PMP, participants had tried everything and could now get on with life. Sara spoke about being on her "last leg" and that the PMP was "all or nothing". Margaret saw the PMP as the "end of the line" for her in terms of treatment options for her chronic pain, and this meant that she needed to give it her best:

I suppose when you have a terrible backache, you really just keep chasing everything you can to see if you can find some relief, or some way of living with it, or something. No, I went with the idea that I was going to stick it out, I told them right from the start. Because I felt I'd been everywhere else, this was about the end of the line. I thought I'd done everything else, like for the physios and to the acupuncturists and whatever else there is, the tablets you buy at the health food store, all the arthritis sort of things, and all that. Yes, so I did feel to give it all your best.

B. Victimic

Not knowing what to expect

Although many participants felt it was the right time to do the program, they also had limited knowledge about what to expect, or different ideas regarding what the program actually provided. This was seen by some participants as a negative factor when the PMP did not meet their expectations. Dawn, for example, read a brochure stating that PMP participants were staying at a hospital. She therefore expected to be a

patient wearing “slippers, dressing gown and pyjamas”. When she found it was “nothing like that”, she felt it would have been useful for the PMP to make “a small documentary” so that potential participants could be better informed.

Rosie’s perception of what the PMP was going to be like was based on reading a book based on a different PMP. She therefore went in with the expectation that the PMP would be the same and was subsequently disappointed:

I went there expecting something and I got this. I have to tell you, I came away very disappointed, I really don’t know what I expected. There was an awful, awful lot of paperwork and a lot to absorb. And at the time I was I suppose still angry about the knee. I don’t know what I expected to get out of it, but I came away thinking it was a wasted 3 weeks.

Acceptance of living with pain

One of the most common themes that emerged from the PMP participant narratives was acceptance of living with pain. Most narratives discussed acceptance as part of the process of chronic pain management.

Acceptance was seen as time contingent and occurred after all other avenues of treatment had been explored. For some participants acceptance was equivocal, while for others “looking for a cure” remained high on their personal agenda.

A. Agentic

Doing things in spite of pain

Margaret learned to accept her pain while on the PMP. She found that even though she had pain she could keep doing activity, and this was one of the biggest things she got out of the program:

I learnt that I was really stuck with it [pain] forever, and that I have to learn to live with it or learn to accept it. So I really found that was quite valuable. I think that’s the greatest thing I got out of the pain management, I think being taught that if you think you can’t do something, or you go somewhere and think “I can’t walk further” you really can a lot of the time. I’m not out on a big mission to find the next thing. Because acceptance is there, it’s “Move on”.

B. Victimic

Looking for a cure

A few participants were equivocal about living life with pain. While they acknowledged the nature of their chronic pain, they did not accept that this was final and hoped that something more could be done. Will continued to look for an answer by seeking treatment for his knee pain:

Yes, I'm still hoping, I have got my hopes up that one day maybe something's there that will help relieve it. I have got an appointment booked to see my doctor and I'll have to be referred back to the Pain Management doctor. I want to go back and see him, and see what he can offer me, some little bit of assistance, see if he can get some help through the pain management.

Getting angry because I can't do things

Sara noted that acceptance was not easily acquired. She still had days when she got angry about the nature of her chronic pain and what it prevented her from doing;

I get very frustrated about things because you hear other people my age, who don't have a little bit of a disability, being able to do this and do that, and that's when I get angry. And then I get over it, I think "Well, you've been like this for a long time – that's it. You have to accept it". And then I do. And I carry on again until it happens again.

Seeing pain as a process

Related to acceptance was the concept of coming to terms with chronic pain over a period of time. Coming to terms is referred to here as "pain as process" to indicate that acceptance was often a lengthy task involving much introspection and reflection on the part of the PMP participants. The temporal aspects are of particular significance as being individual to each participant.

A. Agentic

Moving through the process of pain self-management

Stacey noted: "It was a very slow process. Doctors and psychologists helped me to a degree, but most of it I had to do by myself".

Maree also described the hard work she put in to overcome pain and depression. The image of her struggle of moving forward in life is powerfully evoked in her narrative:

It used to frustrate me no end and I used to get bogged down, I used to have a huge long list of things that I can't do, I can't do, I can't do and I just was so depressed and so run down with it and so debilitated by the depression that it took a lot of time and a lot of work to just look at it all positively in terms of the things that I could do and the things that I could help other people to do. You know, that took a long time of getting your head into gear. It was sometimes just hour to hour, then it gradually got to day to day and then suddenly the weeks rolled together, you know. It just seems to be that there's a time frame and a process that you have to go through to get to the other end and if we can streamline it and make it easier for people, instead of the horrific times that I had, I think that would be great.

B. Victimic

Getting stuck in the process

For some participants, chronic pain and depression caused the life that they knew to cease. Participants like Ian were stuck in the process of trying to adjust to chronic pain and the associated life changes many years after his injury. He continued to dwell on what he had lost:

Yeah, things like that they all accumulate up and they upset you. So you didn't feel good. Because... in the end it just felt like the whole world stopped. Like it cost me my job. And as I said I played sport, anything and everything, I used to run. All that stopped and it all just stopped overnight sort of thing. So like my hobbies all stopped. And then to lose your friends on top of it. Yeah, is just another kick in the guts I suppose and I often think about it. The fact that we sit home here on Friday nights and Saturday nights unless we decide to go to the pictures by ourselves...

Feeling fearful of doing things

Fear avoidance of activity is a focus of current chronic pain literature and research. In terms of doing everyday things, some participants were fearful of going out because they might fall. For Rosie and Julia, going out was accompanied by a fear of falling in public. This resulted in a significant alteration to what they did, in order to avoid the fearful situation. Rosie described how she curtailed her outside activity if she had experienced a recent fall:

Yeah, and when I have a real bad day with the knee, I sort of have a few falls because I don't have much muscle there – because I've got to be careful. And if that happens somewhere, I won't go out for a while, until I get the confidence back up again. I'm very wary of walking on ground that's not level... you know, dirt footpaths, and I don't go out at night at all, because I don't like to walk where I can't see. So those sorts of things are real limitations.

Comparing myself to others

A. Agentic

Being better

Participants found that the PMP helped them to realise their chronic pain was not as severe as that of other participants. Comparing themselves to others in pain changed their thinking about their own pain condition, which in turn had a positive effect in their own pain management.

Stacey saw herself as much further down the track than others in her PMP group. She felt she had already overcome most of her chronic pain issues prior to commencing the program: “They were really chronic pain-wise, whereas I'd already overcome that barrier by myself and I just wanted some more guidance in how to channel it better, or how to maintain myself”.

B. Victimic

Seeing others who get better than me

Comparing themselves to others was not useful for all participants. Will met others with a similar pain problem who progressed beyond what he had achieved:

Because I compare it to other people who have had the same operation done. I feel envious of them, because every time you talk to someone about a knee operation, people say “Oh, look at me, look at what I've done, look at what I'm doing” and what I can't do, you know.

Pain being a battle

Most PMP participants saw managing pain as an ongoing battle. Finding the energy to continue fighting pain was influenced by how participants felt

from day to day. PMP participants acknowledged there was “no other option” if they did not want to deteriorate.

A. Agentic

Fighting the pain

Participants acknowledged there was no easy way to deal with ongoing pain, and dealing with pain was a constant battle. Sarah saw chronic pain as something you had to keep fighting against “day to day”. She felt being “indulgent to the pain” meant “letting the pain win”. Rosie similarly saw fighting the pain as something you had to do, and felt that giving in was not an option:

You do not give in! And I get very passionate about it, because I think it's too easy to give in and go with it; it's just too easy to do that. Take in every bit that you can, I suppose – health-wise, but just don't lie down and let it take your life over. Life's too short. Fight it, in other words.

Living day to day

The temporal aspects of living with chronic pain were again apparent as a number of participants stated they lived life “day-to-day”. This was either their previous personal philosophy about life or was attributed to trying to fight against the ongoing pain. Dawn approached each day as “putting one foot in front of the other” and worrying “about it as it comes” as her personal philosophy on life. For Sara, each day was influenced by being unable to change past events and the nature of her pain:

I can't change the past and I can't change the damage so it's just...you know, get on with it and take it day by day, hour by hour. So that's sort of the way it is... like the days that I wake up with no pain, I just wish that that day was like every day. It's not meant to be, so... just take it day by day.

B. Victimic

Seeking sympathy

Bill saw spending time with others with pain as counterproductive to pain management. He thought there was no benefit from attending a chronic pain support group. For example:

The first thing I would say [to others] is to keep away from like-minded people because what I have seen, they seem to form themselves in groups or whatever and seek each other's

sympathy. That goes contrary to everything we have talked about, we are supposed to have support groups and this, that and the other thing.

Being told how to manage my pain by others

Sarah was sick of others giving her advice on how to think about and manage her pain. Family members and friends advised her on what she should do to cure it, although she was aware her chronic pain was not curable:

Everyone has something to tell me that will improve my life... And I have to admit it pisses me right off. But someone always has someone you should see, and "I've got a naturopath this"... I couldn't afford it. I don't believe half of this shit that goes on... I just don't. But everyone has something that will cure me.

In summary, how PMP participants thought about and ascribed meaning to their pain varied from individual to individual. What PMP participants perceived as positive or negative meaning ascriptions also varied according to the individual.

5.2.3 Themes of strategies to manage pain

Strategies were approaches PMP participants used to manage pain from day to day. Strategies included practical skills such as doing things differently, using equipment or using correct body mechanics. They also included changing thinking, such as thinking positively. The use of strategies were inherently related to occupations or "doing" in everyday life. Many participants adopted strategies learned during the PMP or applied their own ways of getting around things they could not do. These agentic measures enabled many participants to resume familial, household and hobby activities to an acceptable level. Yet not all participants were able to use strategies in their daily lives. Some returned to previous ways of doing things, which ultimately led to increasing and reinforcing their chronic pain and/or depression.

Setting goals

One of the strategies used throughout the 3 weeks of the PMP was goal setting. Before, during and after the program, participants were advised to set short-term achievable goals and to aim for a valued long-term goal.

A. Agentic

Setting little goals

For some participants, setting goals was a way of moving forward in their pain management. Ian described how he set “little goals” for himself, such as going down the street to get out of the house. He found although this might not seem much to others, it was “big steps” for him as it was something he struggled to do. Maree described how getting up and getting dressed was at one time a major challenge. This then led to her getting out of the house after a protracted period of being in bed all day:

I had just got up and got dressed and had a shower, that started off as being a fairly big achievement, and then sort of it was to get up before lunchtime which I kept challenging myself, but they were only very minute things, a lot of things I didn't tell anybody about, because they would think that I was an idiot. You know what – be up before lunch and be dressed and showered? That's nothing. It was huge! It would just start off with D [partner] saying “Oh let's go into town for a cuppa” so I would have to get up, get showered, get dressed put a bit of makeup on put shoes on and it was like a little date. And I think that carries in with that sort of outlook on life that you need nice things to look forward to.

Having future plans

Some participants had long-term goals they wanted to see achieved. These goals related to travelling, work and leisure pursuits they wanted to undertake. Stacey challenged herself throughout the PMP and realised her long-term goal of overseas travel. This propelled her into future goal setting:

I had set myself a challenge and I wanted to better myself. I didn't know if I'd make it, but I did. And now I just don't look back, because I've done what I wanted to do, I went to Africa and I did bushwalking and I did this and I did that and 6 months before, or 12 months before I would never have thought of it. Every day is a challenge, so it's up and looking forward to work, and I'm planning things in the future.

Rachel's goals related to her studies and working with people with disabilities, which was a long-term valued goal:

My heart and my soul is to get the certificate and hope to work with people with disability, to lead a normal life; they have a right to do what they can in life. If I got my Certificate 4 in Disabilities, I would be an advocate, working in camps with people with disabilities.

B. Victimic

Being unable to set goals

Participants such as Julia were taught about goal setting on the PMP. On return home, however, she found this difficult to implement due to a lack of interest in previously valued activities:

Goal planning, I mean I come away with it but I haven't done anything about it yet. Yeah and I used to love the pokies and they don't do nothing for me no more. You know it doesn't interest me... Takes a lot to get me interested these days.

Having strategies that work

Participants spoke about the overall strategies they found useful after the PMP. Participants often used a number of different strategies that suited their personal lifestyle and thinking about chronic pain. Although they found strategies useful, some participants were no longer using them for a variety of reasons. These reasons are discussed under individual strategies in the following sections.

A. Agentic

Having a number of strategies

Stacey found psychological and physical strategies useful overall: "The cognitive distraction, thought distraction, the visualisation and the relaxation and definitely flexibility, like stretching... Pacing is another one that's huge". Dawn used a variety of strategies she had utilised previously or had acquired from the PMP, and rationalised the ones she used dependent on her finances:

The names of the things that they [PMP] gave them, like they used pacing which is something I'd been doing before. Everything was done in moderation. I liked their relaxation. That I still use regularly. Their exercises – a daily part of life still. They tried to teach us a little bit of Tai Chi. I took that further. I'd been doing Tai Chi in town. I just dropped out of it now. My funds

don't allow me to play golf, do Tai Chi, whatever else. So the Tai Chi – I bought all the videos and I do the Tai Chi here.

B. Victimic

Being unable to use strategies

Rosie learned strategies on the PMP and used them while on the program. She did not continue to use them on returning home and noticed her pain was subsequently getting worse. She felt that if there had been more emphasis on this within the program she might have continued to use strategies such as exercise and walking:

I mean I didn't keep it going, okay. I know that and I probably should have, but I didn't. That's all right for me to say in hindsight, but I didn't do it, and maybe I should have. But I'm not. If they'd have written a little list out and said, "You have to keep this going and going" then maybe I would.

Using medication

Taking medication was discussed by all participants. Most participants had been on some form of medication prior to the PMP and some were on high doses of opiates and other strong medications. The PMP encouraged taking medication regularly as a pain management strategy. If participants wanted to work on reducing medication that was also related to their goal setting. As part of the program protocol, medication was removed on the first day and placed into a Dosette box (partitioned container with days and times to be taken, into which medication was sorted). This was handed back to participants so they could regulate how much and when they took their medication. Over time participants either continued to take medication regularly, reverted to taking medication in response to pain, or used other individual methods.

A. Agentic

Being in control

Several participants who had been on medication for a considerable time preferred to be in control of when and how much medication they took. Sarah wanted to be in control of her medication, but accepted having her medication taken away during the PMP. She saw this as a special circumstance:

Anyway on the Monday morning you have to give Pain Management every drug you've got. You're not even allowed to keep your Panadol... which is fair enough. And then they give them back to you measured out – Monday to Friday. I like to be in control, but them taking it, that was in a controlled circumstance. I'm not sure I would have felt the same if they took it, and I came home and I'd have nothing here to adjust to, I might feel differently.

Having my own routine

For some participants, however, having their medication taken from them by the PMP was not expected or welcomed. Alexandra developed her own regimen of taking minimal medication and felt like a “drug addict” during the PMP once the medication was taken out of her control:

Immediately you went in there they took all your medication away and they just issued it out. I didn't realise that we would have to hand in our medication and then they would issue medication, so that sort of got me a bit upset because I'm in such a routine and I had it down to such a minimum dose anyhow and I felt like they were treating me like I was a real drug addict, and I had no right to have them in my possession. And I feel you shouldn't do that. It's our problem and we're the ones who feel pain.

Taking medication regularly

The aim of the PMP was to reduce or promote regular medication taking rather than taking it in response to pain. Participants reported varying success in their ability to achieve this. Margaret made a decision while on the PMP to keep taking medication regularly:

I also discovered that I had to make a little bit of a choice; I had to think about it towards the end of it [the PMP], because they've given me pain killers, slow release, twice a day, 12 hourly. I said “I don't know whether to take these forever or?” and the nurse said to me, “You might have to make a decision, is it better that you take something, and they're not the strongest things there are, and lead a reasonable sort of a life? Or, do you take nothing and go back to your lying down on the bed, the life that you've had?” I really didn't want to take it... Well I still am.

B. Victimic

Being taken off all medication

A few participants stopped taking medication after the PMP, as that was their goal. Most participants, however, returned to taking medication. Will talked about being “off it for a while”, but was now taking increasing

amounts of pain tablets, which he was not happy about. Maree found although she was medication free after the PMP, she could not sustain this on returning to work. The demands of working and managing her pain were overwhelming. She made a choice of taking medication regularly and accepted that she now needed to do that in the long term:

I'm in pain all the time and I choose to have that because I'm only on a small amount of medication. I still take anti-depressants because I still think that I need them and when I went off it was a huge, huge facet of my life in going off medication because the side effects and withdrawal symptoms and stuff were just horrific sometimes and extremely debilitating. When I went back to work I found that I just needed to take something because it was just too much, because I couldn't concentrate at work, I just couldn't cope. I used to look at the medication as a weakness. It's not a weakness, it's helping me. So I probably have to be on that forever and I've just accepted that.

Taking medication in response to pain

Alice was on a limited amount of medication prior to the PMP and struggled to keep up with taking medication regularly after the program. She reverted to taking medication in response to pain:

I was taking just mainly Panadeine Forte. I was trying to take it regularly and I am really bad at that because I would just take it if I needed it and then go the rest of the day without it. So I did find that a bit difficult and I still tend to take them only when I need them.

Using alcohol and drugs

The PMP strongly discouraged participants from using alcohol and other recreational drugs as a way to manage pain. Participants who were found to be actively under the influence of either were sent away from the program for counselling and alcohol and drug education. Some participants, however, continued to use these post-program to manage pain. Rachel resorted to taking alcohol and drugs when conventional methods were no longer of benefit: "I still do it sometimes now, alcohol and drugs, I'm in so much pain that I take alcohol and drugs and I actually told that to my doctor and she didn't like that so much".

Using education about pain

A large amount of pain education information was delivered by various health professionals on the PMP. After each education session handouts were given to participants, which they were encouraged to keep in a folder. By the end of the program this constituted a considerable resource they could take home.

A. Agentic

Having the “bible”

Some participants continued to refer back to resource information years after attending the PMP. Stacey and Dawn referred to the information as the “bible,” a metaphor that signified its perceived importance in their lives. Stacey found that having “that bible” was important to help her out if she was having a “bad day”. Dawn also continued to refer back to the information:

Like I said – I don’t throw anything away. Sometimes exercises you think you’ve missed a couple and you can go back and check, because we had all the instructions with that. And you charge back and go through the book. It’s a bible.

B. Victimic

Information not helping in the long term

Rosie found although the information given was good, it did not help her practically in the long term, especially where sleeping was concerned: “A lot of good information came out of it, about medication, but nothing helped me to sleep any better, even though we talked about lots of things like that”.

Finding different ways

An important theme that arose from PMP participant narratives related to how strategies were practically applied to daily occupations. The theme of “finding different ways” encompassed the many unique methods and idiosyncratic techniques PMP participants used to make daily activities easier to perform with chronic pain. Some of these aspects were taught in practical sessions during the PMP by the occupational therapist and physiotherapist. However, participants adapted these methods to match their particular lifestyles.

A. Agentic

Making life easier by using equipment

Several participants used a variety of equipment to make life easier, both at home and at work. Maree used a wheelbarrow to transport linen bags at work. She described her laundry trolley at home as “one of my biggest assets”, which she used to transport shopping from the car and buckets of water to her plants. She adapted to being unable to use the vacuum cleaner (a difficulty common to several participants) and used a carpet sweeper instead. Long-handled kitchen tools were included in “all those different bits and pieces that make life easier”.

The PMP did not endorse the prescription of equipment in general, but a few participants were prescribed specific equipment by occupational therapists. Bill was provided with a long-handled reacher by his workers’ compensation rehabilitation provider. He found this “wonderful” as it meant he could “keep away from bending down or bending over”. Stacey was prescribed with “my own ergonomic chair, specially sized and fitted to me” that she used at work. Two taller PMP participants (Alexandra and Margaret) renovated their kitchens to include higher benches and sinks so that they did not need to bend. Dawn had come up with unique equipment ideas for years due to the necessity of finding easier ways of doing household tasks with chronic pain:

The boys made me up a skate-board thing that you can sit on and you can actually do the garden with it. It’s just got lawnmower wheels and you just pushed yourself along so you didn’t have to get up and down. And I’d been doing that, I’d been making things up like that for years. I like polished floors; you will find polished floors seem to make the house cooler. But yeah, I just sit on my bum on a foam thing and go round and round in circles. Necessity, the mother of the inventions.

Doing things differently

Participants had to adjust to doing things differently. For several participants this meant slowing down their activity rate, which was something they had not done in the past. Sarah needed to adopt a slower pace for activity. Although acknowledging the necessity of this, she also noted that it was a “major bugbear in my life” when previously she could

always keep going. Sara modified home duties by doing things over longer periods of time. She found that doing housework over days meant that she could maintain her home, continue to work and manage her pain:

Yes, I do household things, but over days. Over periods of time, I can't just do a full housework in one day. So I sort of just set myself a task each day, this is actually when I'm home, if I'm not at work. You know, "Today I'm going to just do the dusting, tomorrow I'll do the vacuuming, the next day I'll change the sheets and change the towels". And just things like that.

Using correct body mechanics

Doing things differently also referred to the use of correct body mechanics as taught during the PMP. Correct body mechanics included not bending from the waist to pick things up and avoiding twisting the spine during activities. Stacey talked about the "body technique" taught on the program and how being told that she was "doing the right thing" reinforced the changes she had already made.

Using pacing

Pacing was mentioned by all participants. Some participants had adopted the technique prior to attending the PMP. The PMP taught pacing by performing activities to time increments and by alternating tasks. The use of time increments enabled some participants to monitor how much continuous activity they did. Years after the program, participants recalled the way they individualised pacing to suit their needs. Alice found that pacing on the PMP proved her "biggest learning curve". She found she had to "undo" her previous way of "doing six things in a big rush" and "relearn just that you do part of it and you then go back to it later". Bill applied time increments to activities, such as mowing the lawn, after being on the PMP:

But that is one thing, pacing, that's one thing I've learnt. You don't have to do the whole lawn at once. You don't have to do all of anything, you could stop. Now before, I wouldn't have thought it was worthwhile starting if you were going to stop after 10 minutes or something.

Will used the metaphor of "boomed until I busted" to describe the way he had previously done things before applying pacing to activities. He acknowledged "I've got that way now by knowing my limits" using "self-pacing". Maree found it difficult to apply time increments to activities.

Therefore she developed her own way of pacing, using some novel strategies to prevent her overdoing it when gardening:

I would go out and mow or garden or do stuff and then I couldn't move for 3 days and after the pain clinic I was setting the egg timer. Well that still didn't work for me, and what I used to do was I'd go out when there was only an hour's light left and garden then and then I'd have to come inside, so I used to plan it like that until I was able to control that and recognise when I'd had enough so I got a bit tricky then and I only put half a tank of petrol in at a time and when the petrol runs out (laughs) I stop.

B. Victimic

Not getting tasks finished

Some participants had to leave tasks unfinished due to restrictions in their physical abilities. Margaret found she often did not finish tasks such as shopping due to her difficulty standing.

I don't always finish my shopping list because of my back problem. I find walking around shops, I don't know why, but it's much worse when you're in town. Especially if you've got to stand at the check-out. I quite often just leave the grocery shopping in the middle of it.

Being unable to use techniques

Julia tried but was unable to use body mechanics as taught on the PMP. She reverted to previous ways of doing things and rationalised that this was less painful for her.

I just think that when we done the course they said "Bend your knees". But bending the knees for me seems to be more painful than bending straight over. You know because you are down and you are putting all the pressure on your knees. Which is going straight to your back anyway.

Pacing being non-existent

Some participants learned pacing during the PMP but found they could not apply it in the same way once they returned home. Julia thought pacing was "good if you can do it", but she had "a lot of trouble" applying it to her daily life. Consequently she only did things when necessary and then spent the remainder of the week getting over the ensuing pain. Sarah said that for her, pacing was "non-existent". She continued to do everything the same way until she was unable to do any more:

And when we do the pain management, the biggest thing that they teach you and they go over and over it, is pacing – pace yourself. If I have a good day, I kill myself. And if I have a bad

day, I keep going – right. And, of course, then I end up in a bloody heap. And so pacing, for me, is non-existent.

Having a routine

For most participants, having a routine was an important part of their lives. Routine provided structure to the everyday and kept participants securely grounded in the present rather than dwelling on their pain. Associated with routine was the concept of “keeping busy” and “keeping going”. Occupations of meaning or doing something meaningful were also part of routines performed, and in some cases prevented PMP participants from subsiding into depression.

A. Agentive

Having a daily routine

Maree talked frankly about needing the “constant everyday activities and the routine of everyday” to stop her remaining in bed all day with pain. She needed to be on a “constant alert” to ensure that she did not “slip back” into depression. Rosie had a daily routine that she thought other people might see as boring, but it was able to provide predictability to her day:

Well, I'm usually up about seven. I do the washing and the ironing, keep the place clean. And I potter around all morning doing sewing if I haven't got the ironing to do. Look after the dog and the birds... It's pretty boring to somebody else, but to me it's just what I like. My husband comes home for lunch and I cook lunch. Goes back to work and I'll sit down and I do a lot of reading, absolutely love reading. A bit more sewing in the afternoon, and he's home and we relax and have tea.

B. Victimic

Rushing to get things done

Julia did not have a routine. As it took her a long time to get up and get going in the morning she had to rush to get things done prior to her children returning from school:

I get up and it takes me about 3 hours to pull myself together and then everything is done in a hurry, the housework the washing; if I don't do it I get stressed out. I get stressed out if it's not done before the kids get home from school. Because as soon as they come in they make a mess, because I don't need a mess piled on top of another mess.

Keeping busy

Keeping busy was also a theme particular to doing. Doing things allowed participants to focus on something else apart from their pain, and the distraction was a strategy that many of them found useful.

A. Agentic

Keeping going

Will found that keeping busy kept him going and was important in his personal pain management:

That's how I'm dealing with it, I think that's what's keeping me going. If I'm sitting around doing nothing I start thinking about the pain. I think that's what I've been trying to do, thinking and putting your mind onto something else, instead of thinking about the pain.

Using it or losing it

Dawn had a unique way of seeing the importance of keeping busy. She adopted the adage “use it or lose it” and was a great believer in the importance of keeping going to prevent her physical and psychological deterioration:

There is a saying “use it or lose it”. I'm a great believer in that and I've really got to say this as I've got older, I can understand that. You've got a mind, you use it. You've got a couple of hands, you use them.

Having a rest

Counter to the philosophy of the PMP, which was to keep active every day and to avoid bed rest during the day, some participants reported that when their pain was severe they had to rest. They were aware of the idea of keeping busy to distract themselves from the pain, but on occasion they found that resting was important to their pain self-management. Resting allowed them to return to activity, so was seen as a positive strategy to keeping going. Alexandra felt it was unrealistic to expect that people would not need to rest during the day or when having a severe bout of pain:

When you have really severe pain, and normally I know I've got to keep moving, but I just could not get up... And they say on the program [PMP] “No you must never go to bed”. That, to me was poppycock. I just needed the rest, because there is no way on God's earth that I'm going to be able to stay up. So you know I just felt that that was a bit unrealistic.

B. Victimic

Having difficulty finding motivation

Finding motivation to do things was often a struggle for participants living with pain and depression. Some participants, such as Rachel, reported that there were days when she could not get out of bed due to pain and that she had no interest in keeping active:

I have days where I can't get out of bed or I don't want to do nothing and the pain takes over, and that must be with people who suffer from chronic pains. I like to keep myself active by walking, do exercise, I don't do it because I haven't got the motivation. So I lost interest. There are days when I'm in so much pain that I can't stand it.

Finding sleeping difficult

Sleeping was difficult for a number of participants. Sleeping difficulties related to level of pain, stress, and negative thoughts that could not be stopped. For Rosie sleep had been a problem for a long time even prior to her pain condition. She described having “awful sleeps” where “everything goes round and round in my mind”. She felt she had “no way of dealing with it” and sleeping tablets did not help.

A number of different strategies were tried by other participants in an effort to have a decent night's sleep. Will had found sleeping difficult since his knee injury. He attempted to change position, take medication and listen to music to get back to sleep, but his ability to sleep was deteriorating:

I suffer of a night time... I have sleepless nights still, it's every night now, this is what I'm trying to go back and see my own local doctor about. Because lately it's really getting me down. Not getting the sleep and this happened last night, I woke up with pain and I generally get up and walk around for a while and then take another couple of pills and I elevate the foot, that seems to help for some unknown reason. No matter what I'm doing lately, it's just the same.

Doing meaningful things

PMP participants described many occupations within the roles they performed. The meaning ascribed to doing things was universally positive across household, work, self-care and leisure activities. Hobbies and interests had particular prominence in several participant narratives. For

some participants the hobby or interest proved to be a useful strategy to manage their chronic pain.

A. Agentic

Having hobbies and interests

For Bill, being a writer was something he had always valued. He found writing was a good emotional outlet and a “motivation”. He was in the process of writing a novel that he believed to be “the best Australian novel ever written”.

Getting satisfaction out of doing things

Rosie used sewing as a form of “therapy” to calm her down. It increased in importance in her life when other activities became difficult. It was also significant in giving purpose and satisfaction to her life:

It really is like therapy. I can get into myself and concentrate on what I'm doing at that time, and whatever I'm sewing, and I can come out of it really calm. I just enjoy patchwork so much. And it just keeps me going; it's got a big role in my life. Without that I think I'd go under. It gives me purpose and I get a great amount of satisfaction when the article's finished.

Getting others to help

Some participants enlisted the help of others, particularly for heavier chores around the home. Margaret found that getting others to help was a necessity to avoid exacerbating her back pain. She found it easier on herself and those around her if she could have someone help with the housework. This meant she could continue with other valued activities such as bookkeeping.

I have a lady comes once a week to do the chores – showers, things that I can't get down to. They change the linen on the bed so that I'm not bending with a lower bed. And wash floors, vacuum, clean the toilet and bath. And then I do the rest. I mean, I could do the other things too if I liked to make my back a lot worse, and put up with it for a day or two. But it's just much easier on everybody.

B. Victimic

Frustration at relying on others

Most participants altered the way they performed daily occupations. Some participants realised that there were activities they could and could not do. Those who were unable to do certain activities relied on others, which

sometimes caused personal frustration. Alice found she became angry when getting others to help; she was “not good” at “leaving things” for her husband to do. Rachel also became frustrated by relying on others, and found it difficult to reconcile the need for help and the desire to be independent:

If I can't do certain things I have to get my sister and my brother-in-law to do it and it frustrates me. I know that I've got these disabilities that make me worse and I don't want to tell people to do this, I prefer to do it independent[ly]. That's a hard thing to do together [the need for help and the need to be independent]. You don't want pity, you want them to understand but at the same time you need help.

Doing exercise

Many participants commented on the exercise component of the PMP, which included daily walks, gym sessions and hydrotherapy. Most participants were deconditioned prior to the program after spending prolonged periods resting due to their chronic pain. This resulted in some difficulties and challenges for participants when faced with the large amount of daily exercise on the program.

A. Agentic

Trying to do things again

Dawn had not ridden a bike in years and was fearful of using the exercise bike in the PMP gym. With the encouragement of other group members and staff she became determined to ride the “big bike”, which she achieved by the end of the program.

Ian had not been in a pool since his pool-related accident, but he was able to participate in hydrotherapy on the PMP. Although he found this a “big plus” at the time he did not continue with this post-program:

One thing they did, since I had my accident I had never been in a swimming pool, in a river, or anything like that but they took us over to the A... Base [hospital] and we used the heated pool over there and so I attempted the water up to my waist sort of thing which was a big plus. Mind you though I haven't been back in the water since (laughs).

Challenging myself

Willie and Alexandra challenged themselves to see what they could achieve when exercising on the PMP. Alexandra wanted to “test myself”, while Willie found in his particular group: “There was no competition, there was nothing competitive at all, and the one thing that was competitive, was ‘myself’ against the injury, that’s the only thing”.

Making exercise a habit

Although all participants acknowledged the benefits of exercise, few chose to do it on a daily basis as advocated in the PMP. Stacey was one participant who reported doing exercise as part of her daily routine: “I do it on a daily basis; it’s more habit now than what it was. But there’s heaps of benefits from doing it as a habit”.

B. Victimic

Falling off the wagon

Most participants found it difficult to keep exercising after the program, for a variety of reasons. These were related to personal and social factors, such as motivation and lack of support, and the lack of available facilities in the participant’s local area. Alice used the metaphor of falling “off the wagon” due to distance from the nearest gym and not being “a gym person”:

I’ve fallen off the wagon there for probably about the last 6 months, because I have been working 30 kilometres in the opposite direction from the gym, so it’s just too hard. I just am not a gym person and that has been so hard to get into that. But I realise I have to get back into it because I lose that strength that I was getting from doing some weights while I was actually there.

Having difficulty finding the motivation

Rachel kept up with exercising for a year after completing the PMP.

Recently she found it hard to keep up the motivation to exercise as she felt her pain and physical limitations had increased:

The pain was getting worse and I tried to push myself to do swimming, but I haven’t got that motivation, I haven’t got trunk movement. That’s what I put it down to, it’s trunk movement, motivation and strength. If you haven’t got that, you haven’t got the movement to do anything.

Doing more harm than good

PMP participants were given a clear message about the importance of exercise in maintaining strength and flexibility and how that could have a positive impact on pain. Although Julia went for a walk every day she was unsure if it did her more harm than good as she had not kept up with stretching to warm up:

I go for a walk every day but I just don't do the warming up exercises. Which I should because you feel it in the walk. But I don't know if I am doing myself more harm or what? Like some days I can come home and I feel really good and some days I come home and say "Where's the morphine bottle?"

Learning how to relax

Another component of the PMP was learning various relaxation techniques, with sessions held every day over the 3 weeks. Different techniques presented included consciously focusing on relaxing muscles, deep breathing, visualisation and meditation. Most of the sessions were completed lying on mats on the floor. Participants responded differently to the methods presented, finding some more useful than others. Some participants continued to use some form of relaxation at home, whereas others found it of limited use.

A. Agentic

Using a variety of different techniques

A few participants continued to use different relaxation methods on a regular basis. Alexandra used a number of techniques to help her to relax, including "breathing", "going into a yoga-like state" and "massage". Will adopted a particular relaxation method and also used audiotapes regularly to help him relax:

There's one they taught me which was counting backwards from 100 and I quite often use that. And I've got a tape, a relaxation tape that the psychiatrist gave me. It's just to let your mind go and think of something else and concentrate on it and a little bit of music. I've sort of got to rely on it; I... like to listen to it when I really get pretty bad.

B. Victimic

Being unable to relax

A few participants were vehement that they did not gain anything from relaxation. This was related to having to lie down during sessions, which they disliked, but was also associated with their personality and the techniques presented. Rosie found relaxation did not work for her even though she was allowed to sit up during sessions after being unable to get onto the mat:

And relaxing. Every day after lunch, I think it was, you had to lie down on your mat. Well, that was out for me because I couldn't get on the floor, so I had to sit up in a chair. And I don't relax, I cannot relax. Yeah, to sort of imagine that you're floating and that, it did not work for me.

Bill found the relaxation sessions a negative experience and felt that they were “beneath” him:

No, I didn't find any of those things like lying on the ground and saying “oh”. I mean I was alive during the 60s and I think that's probably the best place for those sorts of things. I really just thought that it was beneath me and should have been beneath other people there.

Using cognitive-behavioural strategies

The PMP operated under a biopsychosocial framework similar to that discussed in Chapter 2 (Section 2.3.2.1) and used cognitive-behavioural therapy (CBT) within it. Strategies included thinking positively, challenging negative thinking, and using distraction to avoid thinking about pain. The PMP also educated participants about the nature of chronic pain and the unlikely event that activity would make pain worse. They endorsed seeing pain during activity as “hurting not harming” in nature. Several participants commented on different aspects of CBT used on the program and the “message” they were given about pain by PMP staff. Some participants also spoke about how useful they perceived the CBT methods to be.

A. Agentic

Using positive self-talk

Alice found “using positive self-talk as well instead of the negative is a big thing, it makes a big difference”.

Using mind over matter

Margaret had the message that managing pain was about using “mind over matter” or distracting oneself from pain. She found this to be particularly valuable and thought it “helped me more than anything else”. Will also had the message from the PMP about switching his mind off the pain and that the pain was hurting not harming:

A lot of the thought-provoking matters were good. How to sort of switch your mind from the pain that was hurting, causing you not to do anything. The pain you've got, it's not harming, it's just hurting, and it was sort of how you set your mind. That's what they kept drumming into us.

Side-stepping around the pain

Maree developed her own metaphor for thinking about managing her chronic pain: “side-stepping around the pain”. She used it practically in her daily tasks by thinking differently, as she explained:

Before, when any little upsets stuck in the way, I would go backwards. It would put me back weeks, and now I just look at it that I'm not going to be stopped by that barrier, I'm going to step to the side and walk around it, or go past it or choose another avenue if I can't. I do it in so many things, if I can't carry the washing basket I don't just drop it here and carry one bit [of washing] over, I think well what else can I do? I can get the trolley, I can put it on the back of the car, I can do anything.

Using humour

Although not something directly attributed to the PMP, the use of humour arose in several participants' narratives. Related to thinking differently about pain, some participants mentioned using humour as a coping strategy. Sarah encapsulated how she found looking at the funny side of things essential to her psychological wellbeing and pain management:

But as I told you, humour is very essential to me. So humour is my armour, I suppose. And my smile is my armour. I put it on and I go out there and they're not going to see that I'm dying, or that my pain is 99 out of 100. Why should they? Because if I went out and let myself be miserable and made everyone else miserable, I'd come back here and the pain would be ten times worse. But if I go out and I laugh and I smile, I come back here refreshed.

B. Victimic

Some participants were critical of the CBT methods used on the program. The constant reinforcement of positive thinking and challenging negative

thoughts became onerous over time. This was recalled by several participants.

Experiencing brainwashing

Willie described the constant reinforcement of CBT methods as “brainwashing”. He saw the repetition of the CBT message presented in slightly different ways to be unnecessary:

It was a bit of a surprise I guess to find out it was all lectures and brainwashing. They were saying you can do something if you put your mind to it and it got a bit repetitive after a while. They were drumming it into you, drumming it into you, then coming back to here and trying to be able to apply that. They take you on a journey sort of thing, and then bring you back to all these cognitive sorts of phrases they use, and stages, and then you come back the next day and they'd come at it from another angle, and after a few days you'd think, "This is all about the same thing".

Bill saw himself as an “observer” during the PMP. He was critical of the impact of the CBT message on other group members, as he had encountered similar methods when working in marketing in America. He stated the premise as “you know nothing right. Everything from here on in we taught you”, which he saw as demeaning.

Being unable to change my thinking

Julia found that nothing said at the PMP could change the way she thought about her pain. She was unable to use the strategy of positive self-talk, considering her previous life experiences:

Yeah, nice idea if you can do it. Yeah, because there is nothing that can change the way I think. You know, 'cause these things happen so how can you change the way you think? You can change the way you think in some ways but not all ways. Like pain-wise you can say "I am not going to have any pain today". But it is still there. But they [psychologists] will try and tell you it is not. They are telling me to tell myself that.

In summary, the range of strategies used by PMP participants ranged from those taught during the PMP, or modified based on PMP principles, to those that participants adopted out of necessity. How these strategies were applied was idiosyncratic and reflected each participant's level of problem solving and thinking laterally around a particular problem. Strategies were used to enable participants to engage in occupations that were everyday, mundane and meaningful. The pain experienced by

participants was not static; it changed from day to day. This meant that participants were constantly trying to find ways to manage on a daily basis. Bill summarised the conundrum of using chronic pain management strategies:

And the only problem with chronic pain is that you don't get to be laughing so it must be hurting. And the trouble is when the pains occur they are frequent. Now don't ask me how frequent because they are not at 8, 12 and 4 in the afternoon or something like that. It doesn't follow a pattern. And one of the things I find annoying about it is it doesn't follow logic, a logical cause and effect. If I chopped wood, would it do this? and the answer is probably, no. That is the really annoying part. People say, "You shouldn't be doing that, you will hurt your neck" and the problem is you have no idea, absolutely no idea.

5.2.4 Social World Themes

This final section refers to themes that were inherent to the social world that surrounded PMP participants. The social world influenced how participants interpreted and managed their pain, by either reinforcing or negating certain beliefs and behaviours, strategies and personal characteristics. These influences included family, friends, general practitioners, specialists, therapists, the PMP program, PMP staff and PMP group members. It also included the broader community, community resources and support to which participants returned after the program. To understand the complexity and importance of social world factors in chronic pain management, consideration of PMP participants' social world is presented within the following areas: parental influences when growing up; spousal influences in the relationship; the importance of family and friends; and isolating oneself from others. The influence of health care and compensation providers are considered, as well as the social aspects of the PMP. The availability of ongoing community support on return to home post-program and the community attitudes to chronic pain are also discussed.

Family and friends

The ubiquitous influence of parents, spouses, family and friends affected how PMP participants managed their pain in the social world. The level of

support provided to participants was judged to be critical to the pain management process. Because of the often longstanding nature of PMP participants' chronic pain, changes to the dynamics of personal relationships had often occurred. This was perceived as either positive or negative, depending on individual experience.

Parental influences

As noted in the "Self" section, many participants were either the eldest in the family or held a high level of responsibility at a young age that was seen as culturally appropriate for the time. The pervading cultural perception of pain that existed was also examined by asking participants how their parents reacted to their having pain as children. With the use of this approach, participants talked often at length about their childhoods and their parents, telling stories of particular events that were seen as significant when growing up.

A. Agentic

Being supportive

Alice described growing up on a farm with a caring father who was actively involved in his children's lives. This provided her with a sense of support and stability:

We had our father who did a lot for us five children as well as our mother. He was a bit before his time in that caring dad state but yeah, he was really great and because we were out on the farm and we were away from the town and we didn't do a lot of the things the town kids did. I grew up with and always wanted just that bit of stability in my life.

Growing up tough

Willie spoke about how his parents reacted to his pain, especially as he was the eldest in the family. He was encouraged to be "tough", even when he contracted septicaemia from untreated appendicitis. He reflected on that particular event and how this made his parents more sympathetic to his pain:

"You're tough, you'll get over that..." Oh, you know, I wasn't allowed to be sick. So that was probably the way it was in those days. But I think they got a pretty rude awakening when I was about eight and I came down with a very severe case of appendicitis, more dangerous thing to have then than what it is

today. So for 3 days I was sent to school with a septic appendix. Finally my dad decided to get the doctor who on this particular day the doctor was playing golf, so he had to drive down to the golf course and find the doctor and get me to the hospital. For a long time I was in hospital after that. I think it was a bit of a shock for my parents because after that they were a bit more sympathetic.

Ian grew up in a single-parent family on a dairy farm. He experienced significant hardship in his young life as his mother tried to support the family when living in a “house with dirt floors, no doors and we had no shoes”. He saw growing up tough as something inherited from “dad and my grandfather”.

Being stoic

Similarly Alexandra was the eldest in her family. She was expected to be stoic about pain from a very young age. This included taking herself to the dentist at the age of five:

So you know we were brought up to be very stoic. I can remember my parents never made a big fuss if we hurt ourselves or anything like that. It was just “dust yourself off and pick yourself up and get on with it”. And I can remember at the age of four or five taking myself off to the dentist. So even up to today, if I have to have any dental work done it’s usually without any anaesthetic, so I have a pretty high pain threshold.

B. Victimic

Being in abusive/difficult relationships

For some participants growing up tough was a result of being in abusive or difficult family relationships as indicated in the “Self” category. For those participants, past events continued to provide emotional pain. For Julia, growing up tough was a result of experiencing childhood trauma and institutional care. She consequently had depression from a young age:

I don’t know much about my dad. And Mum, well I haven’t seen her for about 20 years she’s sort of just a runner and doesn’t care about anyone. I remember getting run over by a car when I was nine. Like when I woke up in the hospital I was unconscious for 6 weeks or something, I don’t know. And while I was actually in the hospital, I sort of gave up a bit because I didn’t want to be there, I had to leave in a brace and I couldn’t very well walk out. At 13 I was in TH [name] Boys Village, I was one of the first girls to go there. And that is sort of where I stayed when the boys’ village became co-ed. Then after that they sent me up to live with my mum in G [town]. And yeah I hadn’t seen her for years

and years. Then I started to go up there for holidays and that, but then I just sort of lived on me own [at age 16].

Rachel was part of a large family. She had a difficult relationship with her father and some of her siblings. She thought her father saw her as a “hypochondriac” and her family did not “understand what I’m going through”. This, combined with her deteriorating medical condition, continued to cause her “a lot of emotional pain”.

Spousal influences

Most participants were married or in a significant relationship at the time of interviews. Their partner/spouse was seen as influential in their chronic pain management. The level of support partners provided to PMP participants differed. While most acknowledged how important the support of a significant other was, some participants felt they were treated “like a child”, or their injury resulted in a disruption to previously valued family roles. Others noted that without the support of partner/spouse they would have lacked the resources to manage their ongoing pain.

A. Agentive

Having a shared pain experience

Some participants’ partners experienced chronic pain themselves. This shared experience generally meant that partners were more supportive and encouraging in finding ways to manage pain. Dawn’s husband sustained a back injury prior to her accident. Their shared experience of back pain meant they could understand and support each other as they “dragged one another along” on their pain journey:

Well, when I got hurt, D [husband] had already been put off work. So then when I got put off, he stayed home. From there – we’ve been dragging one another along ever since and it’s been good. If I find a way of doing something that I find easy, I’ll tell him how to do it. And if he finds a way that he finds to do something else easy, he tells me. I’m not saying that it totally works for both, but there is somebody to bounce things off.

Having good support

Ian was “amazed” at the support he received from his wife. She stuck by him even when the relationship became difficult:

I am amazed sometimes; I used to say that to her – not at the time but afterwards. I really don't know why she stuck with me. I really don't know why because there were days when I dare say I would have been a real pig to live with, in the sense of mental attitude, and how M [wife] still stuck by me and still talked to me – sometimes I scratch my head.

Maree also had good support from her partner, especially during the difficult time of dealing with pain and depression. She found “nothing fazed him” and “we just carry on” even when she was largely bed-bound.

Maintaining a sexual relationship

When PMP participants' relationships were discussed, some participants raised the issue of how chronic pain affected their sexuality. Some participants who had supportive partners managed to resume having sex after experiencing chronic pain.

Dawn described her sexual relationship with her husband and also how it was a point of discussion on the PMP:

Sex isn't bad either. Well, it seems strange – it was something in pain management that we all had a bug about. Like sex, sex, sex, sort of thing, and it seems that every group's the same. That's not bad now, that's quite good now. Just keep feeding him oysters. It's worth the effort. (laugh) Says she... oh my god, at my age you'd think you'd forget about it.

Maree discussed the challenge of having a sexual relationship when living with chronic pain and depression, and how she and her partner overcame this by using “understanding and patience” and finding “different positions that don't hurt as much”.

B. Victimic

Having relationships break down

A few participants were not supported by their spouse/partner. For Rachel this affected her attendance at the PMP, as her partner did not understand why she needed to stay away overnight during the weeks she was attending. This impaired her ability to fully apply herself to the program:

I was in a relationship I had a partner who had a mild ABI [acquired brain injury] and we were nearly engaged (Rachel had to write this down on her communication device). He didn't understand why I stayed, why I'd go. My sister said to him that she had to go to tolerate her pain, only my sister knows how much I was in (pain). So it was no good for me to handle there [PMP] and handle here.

Sara coped on her own after her marriage broke down 6 months after the PMP. She found that “he wasn’t dealing with my pain and I wasn’t dealing with my pain and that sort of drifted us apart”.

Being in an abusive relationship

Julia, as previously stated, had experienced a lifetime of abusive relationships. Her relationship with her current partner affected her depression and chronic pain management. How she coped day to day became dependent on the mood her partner was in, the mixed messages he gave her, and how she adjusted to that:

I haven’t had words with R [partner] yet so I don’t know what sort of day he’s had and how I have to learn to cope with what is going on with him. He [partner] will come in and ask me to come and help him do something and I never ever say no. And then while I am in the middle of it, he will say “What are you wearing yourself out for?” Because I don’t know, I don’t think the love is there any more. I think that it has had it. R, I don’t think he wants me. But I don’t think he wants anybody else to have me.

Having difficulty with role reversal

Some participants, although in supportive relationships, experienced a reversal of roles as a result of their chronic pain condition. This required a period of adjustment which some couples were still working through. Alice stated she was “obsessive” about housework and consequently found it difficult to deal with her husband’s way of cleaning the house:

And that was all quite hard for us so it was a bit of a struggle there for a while, quite a role reversal. And that’s where I just have to close my eyes and think, “He’s doing this the best way he knows how and that’s fine, don’t be Mrs critical”, and there is nothing worse. Yeah but it really is awful if someone is doing something and they’re helping and you are saying “but don’t do it that way”. It is better to just try and not notice.

Family influences

The role of family in chronic pain management was noted by many PMP participants. Most reported having good family support, although they noted how individuals within families coped with their illness differently. It was a challenge getting family members to understand what living with chronic pain was like.

A. Agentic

Being supported by family

Having good family support was seen as crucial to ongoing pain management. Alexandra spoke about her “great support team”:

You know, it makes a big difference when you’ve got a great support team, people who really care. So I’ve always got good support, and that’s essential I think. To know that you’re loved ones care. But then I don’t want to be a drag on them either.

B. Victimic

Family being overprotective

Some participants reported although their families were supportive overall, different family members coped with their chronic pain in different ways. Dawn’s grown-up children all saw her chronic pain differently. She saw some of her children as being overprotective, which caused her concern:

The youngest one tends to get cross, and he doesn’t accept that after the pain management – that Mum’s sort of learnt a lot more. The other one, the older one... he’s protective, but because he’s here and he’s seen more of the changes, he’ll say “what can I do to help?” which is different. My daughter, well... there’s a problem. She’s been with me on a few occasions when we’ve gone out and done shopping and whatever, and I’ve had falls. So far I haven’t really hurt myself. She’s worried that the day I really hurt myself, I’ll be on my own.

Having difficulty explaining pain to others

Some participants found that explaining what they were going through was difficult for family members to understand. Finding the right words to describe her pain was difficult for Sara:

I guess it’s hard to explain what I’m going through because they’re not inside my body so I can’t say, “Well, today I’m having a stabbing pain. And yesterday I was having a piercing pain”. Do you know what I mean? it’s just hard to explain to them.

Friends’ influences

Having friends was a significant factor in PMP participants’ lives. Some found that friendships were challenged by injury and ongoing pain. Others found that their pain condition cemented their friendships.

A. Agentic

Having supportive friends

Having supportive friends was seen as vital by a number of PMP participants. Rosie had one “special girlfriend” she had known most of her life who continued to provide support. Bill also had longstanding friends who understood his “weaknesses”:

They just happen to be very good people that I am associated with most of my life and at my age it's a whole lot better, because you understand each other's weakness and you can become sympathetic.

Re-evaluating who my friends are

Sarah's ongoing medical condition and chronic pain resulted in her re-evaluating friendships. She found that some friends left her when she was unable to fulfil her previous community-based roles. She was now aware of who her good friends were:

I've still got my friends. I lost a lot along the way... I found out who my really good friends were... And F [husband]... used to always say “A lot of these people are just using you” because I was so good at organising and all the rest of it. And I'm afraid F got it right, which was a bit sad... But no, I have a great core of friends.

Having pets

A few participants found the company of pets had a positive effect on their pain and depression. Pets became valued in terms of the support they provided to Maree and Ian when they were isolated by their pain. Ian spoke about his dog Bonnie:

Nobody will ever convince me that animals don't know when a person is not well. I would sit over there on my chair and Bonnie [dog] would come in and she would lay beside my chair. If I would get up to go to the fridge and make myself a drink Bonnie would be right beside me. Like the days when M [wife]... had to go to work, I would have been sitting there by myself sort of thing, but to have the dog there, the affection that I have got back from the dog, I have never had that sort of relationship with any other animal.

B. Victimic

Having limited friendships

Will found making friends difficult, even prior to his injury. This further isolated him when his chronic knee pain restricted his activities in the community:

We haven't got a lot of friends, I suppose – in one way, I've always been like it. I've always been a sort of – not shy person, a very hard person to make friends with people, I don't know why.

Isolating myself

Being isolated was a theme that arose in many PMP participant narratives and had positive or negative impacts depending on the individual. Many participants chose to isolate themselves from others as a way of managing pain. Some participants became isolated when they could not participate in former roles due to pain, or became physically isolated when living in rural areas.

A. Agentic

Isolating myself to cope with pain

Many participants chose to isolate themselves from family and friends as a way of dealing with their pain within the social world. Willie had days “when pain is a battle” and he found he had to “retreat mentally”. He preferred that people “forget about me until I come good” by making “meself as scarce as possible”. Retreating when in pain prevented subjecting others to it. Being able to retreat from others was powerfully evoked in Sarah’s narrative:

Pain isolates you; it isolates you in your own family because we retreat. It's far easier if the pain's bad, to go in the bedroom and shut the door, than sit here and paste a grin on your face. It's so much easier to duck out. Pain makes you selfish. You're looking inside yourself all the time, to find the resources to cope with everything else. And people become something else you have to cope with. Yeah. I think anyone with chronic pain finds somewhere to retreat; it's a big effort now to go out, because here I can be me. Out there I've got to smile. And, if I need to get away and not talk to people and pull a blanket over my head, I need to do it.

B. Victimic

Being away from others

Stacey found that her pain isolated her from others because she could not participate at the same level when in chronic pain. She saw this as “another big kick” that affected her psychologically. Some participants living in rural areas became isolated due to geographical factors. Alice became isolated following her hysterectomy after being unable to drive for 6 weeks and therefore being unable to leave her property:

And I had always thought, “Aw yeah hysterectomy, you know it’s just one of those operations”, but it was quite major. It was to recover from. And not being allowed to drive was hard out here, because it was very isolated. Well I actually felt a bit like a prisoner because I just couldn’t do things and I was out on the farm by myself and that was just dreadful. So I felt pinned down for the first time in my life. I felt that I was losing my independence.

Explaining isolation to others and being misunderstood

For some participants, isolating themselves when in pain was misconstrued by others. Sara saw that isolating herself was interpreted by others as them having done something wrong:

There’s times when I’m in a little bit of pain, I’d prefer to just be on my own and deal with it myself. Because I know that, it doesn’t matter what they say or do, it’s not going to help. And people think that because you’re hiding it, that’s there’s something wrong with you. “Why aren’t you talking to me?” and “Ooh, what have I done wrong this time?” And it’s hard to sort of explain that to people.

Institutional influences

Institutional influences also had a mitigating effect on PMP participants’ attitudes towards their pain and their personal pain management.

“Institutions” in this case refer to (a) the medical environment PMP participants were required to be part of when actively seeking treatment; (b) the compensation systems they dealt with, for those who had sustained a workplace injury; and (c) the PMP itself as a program run within a large regional hospital. “Institutional influences” meant the treatment/support provided following procedures and protocols that had to be negotiated by participants. Many participants found this negotiation a difficult process that was at times counter to what they wanted or needed.

Being within the compensation system

Several participants had work-related injuries requiring their injury to be managed by an occupational rehabilitation provider. Although the providers who managed their claims varied, participants struggled to have their pain legitimised when part of the “system”. By the time participants attended the PMP all their compensation cases had been settled. This was determined by being assessed as having a certain level (percentage) of disability and being financially compensated for it. Future medical expenses were usually also covered.

A. Agentic

Having my claim settled and my medical costs covered

Having settlement of the claim and ongoing medical costs paid for by the organisation providing compensation was seen as a positive thing. The process of getting to that stage was often lengthy and harrowing for PMP participants who were on compensation. Willie spoke about the issues of attending the medical assessment board for his workers’ compensation settlement claim.

The insurance company dragged me down to M [city], we had to go by train and there was a panel of four people who had variations in their assessments between over 50% and 100% [severity of injury] and never accepted any of my treating doctor’s assessments... Anyway they had the only x-ray that’s ever been taken since the injury and the doctor said “Well that’s won the day for you” he said, “the good old x-ray”. Needless to say the amount of compensation was well over 100%... and I do know you feel a bit bitter about it. They are insurance people, they are out for profits, they don’t have much of a heart. One bit of satisfaction that I’ve had is since that panel and their findings they have been pretty good with whatever has had to be done... they continue to pay for medical expenses and such for this injury.

B. Victimic

Having to prove my pain

Proving to compensation providers that injury and chronic pain were legitimate took a lot of effort on the part of participants. Dawn talked at length about her involvement with the workers’ compensation system. She spoke about how her doctor and the workers’ compensation doctors were at odds in their diagnosis of her condition. She also spoke about the

difficulty of sustaining the energy to keep proving that her injury was legitimate:

You see, their doctors say one thing; our doctors say something entirely different. They don't meet. They're not there for you. Their doctors would say there's nothing the matter. My doctors are saying there definitely is. I'd had to fight with them so many times to get backwards and forwards on wages. By the time I got to see this Work Care doctor – he was not interested in anything I could or couldn't do... You sort of get to the point where you want to explode... And that's exactly what these doctors (that's my opinion) they do, the insurance companies are hoping you'll drop off the other end.

Seeing GPs and specialists

All PMP participants had attended a number of medical practitioners, specialists and other health professionals prior to attending the PMP. Most participants found the support of a good GP vital to their ongoing pain management. Participants described what they looked for in a health professional.

A. Agentic

Having a good GP

Will described the support his GP gave him when he was going through a suicidal period. He found that the GP was genuine and took extra care of him, which made a lasting impression:

And there was one doctor there I must admit when I was really down and I was real suicidal, he was only a young doctor but he showed me respect. I felt he was really genuine. The manner, the way, he told me to wait out in the waiting room then he said "Look, you wait out in the waiting room and I'll make a few phone calls and talk to different people..." and he came back out and said, "They can't do this for you tonight, are you okay tonight? And tomorrow morning you go and present yourself at the Private Hospital and this doctor's name will come and see you", which was good. Yes, I was really impressed with him.

Stopping doctor-shopping

Many participants consulted a range of different medical practitioners for their pain in an attempt to find a cure. Sarah stopped "shopping around" for doctors and specialists who could cure her condition and subsequent chronic pain. She had a GP who had the qualities she looked for:

And I think the people who shop around and they think they're going to find someone who's going to cure it, I feel sorry for them. Because they'd be a lot better finding the one person, or two persons, that they can trust that they know will battle for them. I think I'm way ahead of people who are still shopping around to find someone who is going to ease their pain, I really believe that. If she [GP] finds me a challenge, and interesting and we're friends, why would I go looking for someone else?

Considering GP a friend

Some PMP participants established friendships with their GPs due to the length of time they consulted them and depth of involvement they had. Like several other participants, Maree had a rurally based GP who helped her over a difficult time with her depression. She now considered her GP to be a friend:

I've got a really great GP. At one stage I told her how suicidal I felt but I said there's a lot of fear involved in it, you know, and many times she lengthened the appointment... we would just go right into it all and she'd say, "What do you want me to do?" She would then ring 2 or 3 hours later when I was at home, ring the next day, she would ring, often two or three times a week when I was like that, to check on me and to make sure that she felt that I still felt safe. She has been out here in the middle of the night, she's gone out of her way to be helpful and find things out, she just sourced so much stuff for me that was in her own time, and she's sort of developed into a friend as well because her and her partner come out for barbies [barbeques] and things.

B. Victimic

Having pain seen as all in my head

Not all participants had positive experiences dealing with GPs and specialists. A common theme among participants was being given the message that the pain was "in my head", or had a purely psychological rather than any physical cause. Stacey saw a range of medical people who gave her that impression and this promoted her doctor-seeking, as she believed there was a physical component to her pain:

A lot of the time people were telling me it was in my head, the pain and everything was in my head, so of course I'd go for a second opinion because I know that I was physically having really bad pain. I was really depressed. I didn't get angry, I just got really upset. I had had enough of people telling me the pain and everything was in my head and I thought "Well if they can't fix it and they keep telling me this, I'm not gonna bother with it".

Rachel saw a range of health care professionals over the years for her medical condition and ongoing pain. Like Stacey she became frustrated when told that her pain was largely psychological. As she stated, “It’s definitely not in my head”.

Seeing specialists as indifferent

All participants consulted a range of medical specialists while actively seeking assistance for their chronic pain. Many participants reported negative experiences when consulting various specialists. Sarah was referred to a rheumatologist by her GP. She found him indifferent to her pain and disliked his professional manner to the point where she became upset after seeing him:

And so, I inherited this guy [specialist] and my doctor was thrilled. She’d worked with him when she was doing her training and she said “He’s fantastic”. So down I go and I don’t know there was something personality-wise – we did not hit it off. And he has no sense of humour – NONE whatsoever. BAD! So, he was so blunt and rude that when I got outside I was so upset, I cried all the way home.

Having specialists miss something

Willie reflected on the poor specialist care he received around the time of his injury and how this affected his progress years later when his pelvic misalignment was finally identified:

Anyway at this time my daughter was seeing a chiropractor and she thought he might be able to help me so she took my x-rays when she went back to see him. And he said, “This is shocking, your whole pelvis is out of alignment”. It wasn’t picked up at the time. I felt like a drowned rabbit, I was angry at the medical profession for this... And if they’d have monitored the injury they could’ve done a lot more to helping in that regard.

Being seen as a malingerer

Like those who felt they had to prove their pain, Ian described his anger at being seen by a hospital specialist as a malingerer when he arrived virtually paralysed immediately after he sustained his injury:

I still couldn’t move my arms and legs. I did have feeling in them but I couldn’t move them and I was on the table and the doctor came in and he said, “I will stitch up your head, and then we will send you for x-rays”. I said, “All right then, anything”. He then said, “We get people like you in here all the time” and I said, “What do you mean, people like me?” He said, “Malingers, people chasing money”. And I said, “What!” and he said, “Yeah, people with supposedly things wrong with them when there is

nothing". And I said, "If I could get up off this table pal I would give you bloody malingerer". I couldn't move, lucky for him.

Going to the PMP

At some stage after consulting GPs and various specialists, having surgery and trying a range of other therapies, participants found their way or were referred to the PMP. The following section details PMP participants' experiences of being on the program, including (a) their impressions of the program itself and PMP staff; (b) being in a group; (c) how their progress was evaluated; and (d) how these social aspects enabled them to benefit from the PMP program or otherwise. The important transition from being on the PMP and returning to the community to live and manage their chronic pain is also examined.

A. Agentive

The PMP being amazing

Some participants, particularly those who were ready to do the program, found it to be a life-changing experience. Maree thought that the psychological methods used within her group to foster group dynamics were "amazing".

Even just recognising what was happening to you and where you were at and that and even though it was only 3 weeks it was just mind-blowing really, and they're just so clever, you know they really are, and I could see them [working] and putting people together and peer group stuff and I'm thinking, "This is just amazing!" (laughs).

B. Victimic

Having multiple conditions

A few participants had ongoing medical conditions contributing to their chronic pain. Sarah initially thought she was at the wrong place as she had multiple conditions that did not represent the usual chronic pain scenario of other participants:

The first lecturer got up and said, "And now that you've had your operation and everything has healed and you now have chronic pain, we'll go from there". And I thought, "Oh, I'm in the wrong place". For a starter I haven't had an accident, I haven't had an operation. Yes, I have chronic pain, but I have a living disease, and I thought, "I don't belong here".

Rachel had a medical condition that did not fit a typical PMP participant. She found her lack of speech difficult for the program to adapt to. As she stated, “They don’t know how to deal with people with multiple conditions”.

The PMP being a negative experience

A few participants were openly derisive of the PMP. It was notable in Bill’s narrative that he found the whole program a negative experience. He had definite views about why he perceived it this way:

But I don’t know whether you know, but that thing is operated more in an environment of secrecy. You got told nothing. And the little bit you’re told is what I would consider, you’d probably talk to a 10-year old. It’s a very unpleasant place to be and why was I there? Because I asked to go there... In retrospect I would never have gone there, nor would I recommend anyone to go there. And anything that was done at all, I couldn’t see that it would be of any benefit whatsoever. I’m honestly giving you my opinion about that... No, I went there in the mistaken belief that it was going to help. I didn’t know how, but you hear “pain management” that sound great; “I’ll go there and I’ll better manage my pain”. And if there is any triumph out of it at all, I never want to be involved in a group like that again or with people like that again.

Interacting with PMP staff

The PMP was staffed by a range of health professionals including anaesthetists, medical practitioners, psychologists, a nurse, a physiotherapist and two occupational therapists. How staff were perceived varied among PMP participants.

A. Agentive

Seeing staff as excellent

Many participants spoke about the staff in positive terms. Ian noted that staff “were nice” and “always there to listen to you”. Rosie spoke about how wonderful she found the PMP staff in general and particularly the physiotherapist:

The whole team of six or seven, whatever, absolutely fantastic. And the physio, he was wonderful because there were so many things I couldn’t do, at first. But by the end of the 3 weeks, I couldn’t get on the bike; I’d never been on a bike since I had my knee done. And he helped me get down on the floor to do some exercises. But he was and they were all wonderful.

B. Victimic

Seeing staff as off-putting

Bill found various PMP staff to be “preserving their patch” when he was unwell during the PMP and called his solicitor friend. He perceived that the program staff saw this negatively, as he was on active compensation at the time, and they therefore reacted by increasing his exercise regime:

The woman over there, the doctor. She turned from what I would consider a very polite person, to a straight Ava Braun. It was instant – she was preserving her patch and I was interfering with this by having this respiratory arrest – it was an inconvenience. And I thought, “How weak is this bloody show” that I was just disgusted. Like, the day I had this [respiratory arrest] I spent the night in hospital actually and the next day they decided they would take me on an exercise regime, which was twice the previous day. And this would prove that there was nothing wrong at all. And as we were heading out the [physiotherapist] took me for a walk outside for about 15 minutes, to remind me on numerous occasions that the insurance company was paying the bills and I should co-operate... You know – there were some very off-putting things there.

Being in a PMP group

Being in a group was an integral part of the PMP. The philosophy behind the program was based on research which showed that the shared experience of having chronic pain and working in a group context could be a positive motivator in pain self-management. As participants also shared accommodation, there was an expectation that group members would socialise and share meals after program hours. The level to which this actually occurred varied from group to group.

A. Agentic

Being in a supportive group

Some participants found being in a group of people who had similar complaints provided support within itself. Margaret pondered why being in a group made her feel better:

I wonder why it makes you feel better? It doesn't make your pain any better, but it does make you feel not as isolated, or something, I think. Better than being by yourself. For one thing, you see other people a lot worse off than you are, or as bad as, don't you? So yeah, you realise you're not the only person in

the world, even though you think sometimes that you are in that situation.

Being a motivator

Some participants found the group process personally motivating. Stacey, who was the youngest in her group, saw herself as a motivator and enjoyed the teamwork and support structure her group engendered. Her statement encapsulates the “ideal” group process of the shared pain experience:

So I thought to myself, cause I’m sort of a motivational person, when it comes to a challenge I’ll jump at it, so most of the people, I was like “Come on, you can do it”, you know, extra stretch, or whatever, and I was feeling better about myself and then gradually over that week it was like, “OK we’re all in a routine, we know each other, we’re living together and, you know, we know each other’s pressures, which you can handle, which you can’t handle”, so I worked on those and it was great. There was a couple of others that were doing the same thing, so just great teamwork.

Socialising out of hours

Stacey also detailed how this process continued out of program hours at the accommodation where PMP participants stayed:

And we were all there to be supportive as a group, and that’s why they accommodated us all in the one area, so if someone did have a bad moment as far as you know, “I’m feeling a bit whatever about this certain condition” or “That’s aggravated it”, we could all just talk about it and work out what other methods you could use, so we did a lot of group sessions in our own time.

B. Victimic

Having nothing in common with the group

Several participants reported they had nothing in common with their PMP group. Some participants actually found being in their particular group a traumatic experience. Rosie was frightened by some members of her group. This contributed to her coming away from the PMP feeling angry about the experience:

There was one man, two younger girls, and the rest were women about my age. But it spooked me, and it frightened me because there was one girl there you know, that had had a really rough life. And had a shot gun wound to her stomach, and lost her arm. And I just didn’t feel that I was in their category, because there was two young girls there who were really

hurting and really mixed up, really sad people, really sad girls. And I spent the whole 3 weeks in their company and I came away really angry, depressed.

Bill found that his group did not match him intellectually. He only found a few members of his group who “I would consider the full quid” [completely sane]. This was another factor that contributed to his negative PMP experience.

Being unable to socialise

One of the assumptions of the PMP was that participants would socialise out of program hours at the accommodation where they stayed. Margaret found the venue (a private hospital catering for cancer patients) was not conducive to this for her particular group:

I found that where we stayed, it was just a bit difficult. It was also a palliative care ward as well. And we all sort of thought, “Oh well, they’re palliative care, we’d better let them have the lounge”. So we sort of just wandered off to our rooms. And I just felt the setting wasn’t right. So I found that the fact that we were supposed to be there, and that was the whole idea; that you were all going to be together and talk about it, really didn’t sort of quite happen.

Rachel was the youngest in her group and found this a disadvantage, especially as other group members did not socialise in the evenings. She saw the PMP as an opportunity to “meet people around my age” but noted “the social aspect at night time of talk, we didn’t have any of that”.

Lumping us all together

Alexandra summarised how she saw the necessity for PMPs to address individual needs, not just the group needs of participants. She found her particular group on the PMP was not conducive to helping her move forward with her chronic pain:

I see that they try to lump it all together. You can’t, because pain is an individual thing. They’re treating you all like one person, one remedy for sort of everything. And as I said it’s all relative to each individual, what someone considers to be severe pain I may not. So you know you can’t block us all together; it’s everything from the pain, to our treatment, our medication, everything, it’s all different, so I guess it’s the whole experience. It’s how people deal with you, the group, the support, everything, it’s the combination of everything, not just, the pain course has got the magic wand, it does suit everybody because it won’t. So, that was my thoughts on it anyhow.

Being assessed

Participants were required to complete a large amount of assessment and evaluation material before, during and after the PMP. This included the use of various pain measures and PMP staff evaluating actual performance at the start and end of the program.

A. Agentic

Using video to show what we achieved

An evaluation technique used on the program was the use of a hidden camera to video participants walking at the end of the PMP. Some participants, such as Will, reported that seeing the video footage showed the group had achieved something:

They did a video of us walking down and around and back again. And at the end they did a video again, and then they did a secret video, which we didn't know about. But to see the video from the before and after, that really showed that we had achieved something.

Rosie did not think she achieved much on the PMP until she saw the before and after video footage of her walking. She stated, "I could not believe how well I was walking" and "there was improvement", even though she did not think that had occurred.

B. Victimic

Being frustrated by pain questionnaires

Participants were required to attend a 6-week review at the conclusion of the program. At this stage results were compared from the pre-program assessment to the time of review. Participants spoke about the various evaluation aspects. Rosie spoke about her frustration with the pain questionnaires as her pain varied so much from day to day. As she stated, one day "I might have no pain, but the next day I might be a 10" and how the measures were not reflective of this. Margaret found that numerical ratings of her pain were not reflective of what she was experiencing. She wanted to write comments as well:

I felt that with some of those questionnaires, there wasn't enough lines there to write. I used to write a few little things every now and again. You know, otherwise you're just ticking

and putting 1, but you're not really a 1, you really need a few more lines after each one to write what you're feeling.

Having a family day on the PMP

The PMP held a family day in the third week of the program that family members were encouraged to attend. On this day family members and PMP participants were given joint and individual sessions to discuss pain management issues.

A. Agentic

Realising the impact of chronic pain on family

Most participants found the sessions useful in helping not only families but themselves to understand the impact of their chronic pain on others.

Maree found this especially relevant:

And then when they had the family day, with the chronic pain, that was just the biggest eye-opener in the whole world because I thought that I was the person suffering from the pain but D [partner] had suffered it almost in an equal way. I remember saying to them that there almost needed to be two family days, so that the people at home could catch up with where you were up to.

B. Victimic

Partner not attending family day

Julia's partner did not attend the family day. She came home thinking differently about her pain and activity after the program and could not explain this to her partner:

See and he [partner] goes crook at me. I come back different from the course. Well I had different ideas didn't I, and he couldn't understand that and I said, "Well they had a family day and if you wanted to know half the things that you should know, you should have been there. Like don't talk that shit to me".

Using CBT methods

Another aspect reinforced throughout the PMP was the CBT-based avoidance of negative pain talk and of displaying pain behaviours. Participants were told by PMP staff early in the program they were not to talk about their pain or show pain behaviours as it did not assist their

process of pain management. Participants spoke about their varying views on the use of this technique.

A. Agentic

Avoiding pain talk and pain behaviours

Stacey had moved forward in her pain management compared to others in her group. She agreed with the pain behaviour message given to participants on the PMP:

“You’re big enough, and you can handle your pain”. And one of the big rules they said “I don’t want to hear oohs and aahs and I don’t want to see you taking a short cut or whatever, you’re here to achieve”. That’s one thing they say: “We’re fine you saying it the first week; we catch you doing it the second week look out”. It’s a personal choice whether you want to do it or not but don’t waste their time.

B. Victimic

Having difficulty avoiding pain talk and pain behaviours

Some participants found it difficult not to talk about their pain or display any pain behaviours. A few participants thought actually talking about pain could be a positive thing within the group. Julia found the imposition of not talking about pain during the PMP very difficult. She felt that it was not realistic to pretend pain was not there:

You know we would have days where you wouldn’t be allowed to say anything about pain. Well they were pretty hard days. Because it might have been all right for that person, that person mightn’t have had pain that day, but this person over here was probably half dead with pain. Like they would give you a week in advance, “Next Wednesday we are not going to talk about pain at all”. Well I am sorry but it is there!

Ian found not being allowed to move when in pain was one of the hardest things in the program, as he actually found the movement useful. He noted how PMP staff would “point it out... you weren’t allowed to do any movements to show that you were in pain”.

Being pulled down by others’ pain

Stacey found by the end of the program that she did not want to think about her or anyone else’s pain. Having others talk about their pain pulled her down from positive pain management:

I was at my lowest before the program, and I saw people going backwards whilst they were on the program. And that was

something that I had said to myself that it's not gonna happen. Anyone that I've associated with that has pain I try and make them change conversation because it pulls me down, it makes me drop a level and I'm not comfortable with it.

Finishing the PMP

Finishing the PMP meant participants returning home and continuing to use the strategies and techniques learned during the program. Most participants found it difficult to go from full-time support to limited support. Several participants, however, reported feeling more positive in their pain management.

A. Agentic

Having more control

After the PMP Willie found that he had gained more control over his pain. He did not immediately reach for medication when in pain, as he had previously:

I suppose I had more control because you didn't go straight away to the tablet box, you were able to seek other ways of controlling the pain from what you'd learnt; you find some other way of coping with it, that was the other thing, the relaxation all that sort of stuff.

Being fitter

Ian felt he was physically fitter and able to cope better with his pain. He also achieved his desired goal of going off his medication:

Because you were fitter you were able to cope better, not so much the pain had changed but you were able to cope with it better and so everything just flowed on from that. It flowed on to the point like with me that I was able to completely get off the pain medication.

Having a newsletter from the PMP

As stated previously, the PMP continued to send out newsletters to participants to keep them up to date with new chronic pain information and to remind them about strategies they had used on the program.

Newsletters were seen as having varying benefits, and most participants found something useful in them. Maree found the timing of the newsletters especially helpful in the early months of her return home:

The other good thing is the newsletters that come from the pain program. That was amazing you know, almost the first three newsletters that arrived, in that week before they arrived I was struggling or something and the newsletter would arrive, and I'd think, "Oh yeah", but it was really good, extremely, extremely useful.

B. Victimic

Going back to a realistic world

Most participants felt fitter and more able after finishing the program. However, even those who benefited found the lack of ongoing support difficult. Stacey talked about the challenge of returning to a "realistic world", even though she had made great progress on the program:

It [PMP] was great, but the thing was, the challenge was, what's it going to be like without their support, like you were going home to a realistic world. In a way, I had no problems but everyone's life is different though and we've all got different backgrounds and living situations.

Falling in a heap

After the intensive 3-week program several participants found it difficult to reconcile themselves to not having the same level of support. Maree reported falling into "a heap" after the program. She found it took time to process the experience of being on the PMP and what she had taken from it:

I did fall in a heap when I got back because there was a 3-week period after it that was almost like I was still taking in and processing a lot of the stuff that I'd learnt and it would have probably been really great to have a phone call or something during that time. I was floundering. I just had to digest everything and work it all out and it took that amount of time you know to do it. And some of the techniques that they'd taught us to use to cope with pain that I used over there weren't working at home and I use them now, but I just had to get my head into gear to do it myself.

Doing it on your own

Managing pain on their own was difficult for most participants. Sara found leaving the PMP very difficult due to missing the friendships she had formed, especially when returning to an unsupportive home environment:

It was really hard leaving... just leaving the friends that you'd met. I think that's why a lot of people fall to pieces because they've been working for 3 weeks, with these nine or ten people, and then all of a sudden they're put back out into the community

by themselves. But it's really hard when you've got to do it by yourself. I mean, when you have to get up every morning and think, "Oh, do I have to do this by myself again?" I think that's what it lacked because once you leave that program you don't have that motivation, because you don't have those other nine people there to challenge each day. And I mean, yes I did it for a little while, but then once my husband, my ex-husband and I started deteriorating, well I just lost all interest.

Being cast off

Some participants felt they were forgotten once the program concluded.

The lack of ongoing support left participants feeling lost or, as Alice stated, "cast off":

I think they could actually have made it more readily accessible and giving us details for where we should go, what we should do and what the most appropriate places for each of us to go to would be helpful. I'm not criticising what they did. They do a really good job. But I just think it is a really intensive 3 weeks and then all of a sudden that's it, you're cast off.

Having ongoing treatment

A few participants were followed up by the anaesthetist on the PMP program for additional procedures after the PMP. This appeared to be contradictory to the PMP's message of self-management and avoidance of treatment seeking. Julia continued to have ongoing radio-frequency nerve block procedures, although she stated that they were of negligible benefit:

I see Dr T [PMP] to get these nerve blocks in or the radio frequency or whatever they do to me. This is probably the fifth or sixth. It doesn't take the pain away. Oh well it probably does for some people but it lessens the amount of pain. Last time I got really sick.

Deteriorating since the PMP

Some participants, although making gains during the PMP, found that they deteriorated significantly over the ensuing years. Willie noted that "slowly the legs seem to be getting worse". Rachel now found it increasingly difficult to think positively about managing her pain.

I did [cope] for a year and then the end of last year it got worse and my doctors said to me, how it got that way, read my notes [from PMP] and "try to overcome some of that pain". Because I suffer from chronic pain and my chronic pain is everywhere on my body, so it's so frustrating when you are in pain and [taking] medication, [and trying to] concentrate thinking patterns.

Community Influences

Most PMP participants resided in small country towns or rural areas, where belonging to and being part of a community was a fundamental element of where they lived.

Using community support

All participants on returning to the community tried to apply what they had learned during the PMP to their home, work and social environments. Access to resources and support within the community varied significantly between participants. This was influenced by participants' location, finances and availability of particular services. As many participants lived in rural areas, there was sometimes a paucity of services available, affecting their ongoing self-management.

A. Agentic

Having buddies

Some PMP participants formed friendships within their PMP groups. Many of these friendships were ongoing in some form once participants left the program. Having these "buddies" was discussed by several participants as a positive way of maintaining community support in the long term. Stacey implemented a buddy system with two other members of her group:

There's three of us that still communicate from the program and I did it what, 3 years ago. And it's just a once every month or whatever we'll have a catch up on the phone and see what's going on in everyone's life.

Sara did not keep in contact with her group. She thought, however, that a buddy system would be a "great idea" as people with pain are "going to have a lot [in common] to talk about".

Joining a support group

The local chronic pain support group was also mentioned on the PMP. Although PMP staff did not directly advocate attending it, they provided information about it. Only one participant of those interviewed joined the group. Maree found she was able to get good information from the group about chronic pain and was also able to provide support to those who were struggling to manage their pain:

It's been really good twofold in one that you've only got to say a few words and because they have got chronic pain as well they understand what you're on about and I find that quite supportive and that we have really interesting guest speakers, but that other thing that I've found is because I'm where I'm at with my pain I've been able to give a fair bit back to people who have got new chronic pain and that's been a really good feeling that somehow all this hasn't been for nothing.

Alice found her support by joining a meditation group. As she lived some distance from the nearest large town she found the group important “to keep people motivated and not to feel so isolated”.

The PMP suggested that participants continue to participate in gym, hydrotherapy or other exercise-based programs once back in the community. For some participants, especially those living in smaller country towns and regional areas, the cost and distance to travel to facilities were prohibitive.

B. Victimic

Having economic constraints

Rachel found it difficult to afford the costs associated with her chronic pain and medical condition in general when on a disability support pension:

[If you have] pain in the back, you go to a physio for that, it all comes down to cost and people can't afford it \$50 for 45 minutes or \$60 for an hour, because you have to budget and you have medication, doctors, specialists. All this comes down to value of your health and you can't afford it.

Ian could not afford the cost of going to the gym which was the “only facility around locally”. With his wife the sole breadwinner, “the prices they ask are just not feasible”.

Distance being a problem

Margaret remembered being given some exercise options during the program. She told the physiotherapist that due to the distance she lived from town, this was not possible for her:

I remember the physio [therapist] showing us “You could join any of these”. So it was pointed out that it was all there and it would be a good idea if you did something. I just find that when I used to go to physio quite a bit you'd go for a session and they'd loosen the muscles up, but then with a 60km drive home

it's not worth it anyway. And so I talked to the physio: "Is it really working? Is it worth doing that?"

Dawn could not travel to a heated pool regularly enough to justify the cost of membership and "actually get some benefit out of it".

Having a refresher

Many participants were keen on the idea of having a "refresher". This involved returning for a short period to the PMP program to revisit what they had learned. Most participants felt that some sort of formalised refresher would be of great benefit to their long-term pain management.

A. Agentic

Being a great idea

Sarah's doctor talked to the PMP staff, who said that they were considering having a refresher in the future:

When my doctor and I talked to them [PMP], they said that they were beginning to think that maybe they should do a refresher. Because I know every so often, you do need someone. You know how you start something and you're doing great, and because you get so familiar with it you begin to slack. And you'll suddenly think, "Oh shit, it's so long since I did it that way". But if you went back and they said "Hey you're not lifting your leg high enough, or you're not doing this, or you're not doing that", you'd get back on track. So I'd love a refresher, I'd go.

B. Victimic

Funding being an issue

Several participants thought refreshers on the PMP would be a great idea. Rachel would have liked ongoing refreshers on a fortnightly basis but saw funding as the issue:

They need to, they haven't got the funding, that's what it boils down to and they need to do it once a fortnight with the people who are in that group of pain management, socialise with them, to see how they cope and try to get some of the staff there, and help us deal with it.

Dealing with people in the community

Going back into the social world outside of the PMP meant participants returning to situations of dealing with other people who did not have chronic pain. Some participants found the attitudes of the general

community either naive or judgemental, with few noting others in the community as being supportive.

A. Agentic

Being supported by others

Stacey was an exception to this as she returned to work with a new positive outlook. She found this reflected in the support she received from fellow work colleagues:

They [work] were very supportive. But I must've come across as very bubbly and very happy because they were responding back the same, whereas previous to the course I was a bit anxious, "They're [PMP] going to make me do this or do that" and 'cause I wasn't the happiest person, everyone else was "Oh you'll be right, you know, it'll fix it". But I come back a different person after 3 weeks. More positive and thinking in my own head that I can choose pretty much anything that I really set my mind to and I think it showed because the work responses were fantastic.

B. Victimic

Being judged

Many participants found that the general community either made judgements about people who had chronic pain or did not understand its severity, especially when their pain was not visible to others. Dawn and Sarah were in the unfortunate situation of being judged as too able to have special provisions made for them in the community:

I have a disabled sticker on my car – I used it today. Look, if I'm walking fine, I'll park over in your car parks. It doesn't worry me – I'll walk. But if I am really feeling it, I will use my sticker. Especially after golf – I park down there on the disabled because I can walk straight through and there's my car, and that's about as far as I'm going to carry myself for the day. And I do get a lot of comment about "You've been out playing golf, why are you parked in the disabled?" Well, I say "Do you want to wear my leg? Then you can tell me why I'm parked in the disabled". They don't have an answer. Yeah it's not just people in the community – they can't see it. They don't understand it. What you haven't felt, you can't judge.

Sarah described being confronted when using a wheelchair when visiting a metropolitan centre with her daughter and friends. A passer-by said to her "You great big fat shit, get up and walk. I saw you standing up; you

shouldn't have these young girls pushing you". She noted how those sort of comments "can tip you from a good day to a bad day".

Finding a lack of understanding

Alexandra spoke about how people in the community saw chronic pain in general:

So people who haven't suffered it don't understand I guess. You know, it's just something foreign and I don't know whether it's just the ignorance or just like not wanting to understand it, or like well, you just get over it and get on with it, and especially chronic pain when it just goes on and on and on and you think my God, you've got this for the rest of your life...

Looking fine but not feeling fine

Alice spoke about being perceived as having no difficulty by others in the community when there was no apparent injury: "If you can't show that you've actually got a broken leg or something. It's very difficult. 'Cause you can look fine, but you don't feel fine".

Having the stigma of chronic pain

Ian talked about the stigma associated with chronic pain. He saw it as the shame of having something not visible and not tangible to people who had not experienced it. He saw that people with chronic pain could be misconstrued by others who did not understand and how this cost him friendships:

I think that's where a lot of my friendships came undone because they don't know how to treat you I think, it's a bit like disabled people. People stand there and look at them so there is that bit of stigma with it. Well I think it's basically because people don't know how to treat them. There is nothing they can see, so there is nothing wrong with you, and of course once you mention your back you know like the old back injury... (laughs) It alters you where you might have been at one stage the life of the party and all of a sudden you might be sitting there and not saying a lot, they say, "Oh Ian has changed a bit" or that sort of stuff and then all of a sudden the invites just stop coming.

How people were viewed by others had a tangible impact on how they were able to negotiate the social world when living with chronic pain. Having adequate support from family, friends and others was seen as vital in the pain management process.

5.3 Summary

The findings that emerged from PMP participants' narratives were discussed in this chapter. The impact of chronic pain on participants' lives was significant and affected how they saw themselves within the context of role performance and their sense of who they were. How they thought about chronic pain influenced the process of pain management and acceptance of ongoing pain. What they did from day to day was impacted by the various strategies and techniques that they employed in daily life. The influence and level of support from family, friends and the broader social world affected how they interacted with others and how they perceived others saw them. Institutional influences such as dealing with compensation authorities and negotiating the health system impacted either positively or negatively on their well-being. Ultimately the advent of having and learning to live with chronic pain was a life changing event. The following chapter, Chapter 6, details the findings from therapist-participants who worked with people in chronic pain programs and practice. The various practice settings and individual and group approaches used represent a broad spectrum of current approaches to chronic pain management.

CHAPTER 6: FINDINGS – THERAPIST-PARTICIPANT PERSPECTIVES

6.1 Introduction

This chapter discusses the themes that arose from the practice narratives of occupational therapists working with people who have chronic pain. Semi-structured interviews were used to elicit stories from practice that highlighted factors therapists believed predicted ongoing chronic pain management. Therapists discussed which aspects of their programs resonated with their clients and helped them to adopt the pain self-management message. As noted in Chapter 4 (Section 4.3), the occupational therapists worked in a variety of practice settings and had various levels of experience working in the area. This provided a range of responses regarding what worked for their particular clients in the particular practice settings. During the interviews therapist-participants were encouraged to describe various case studies from their practice to illustrate the concepts they discussed. The themes identified in the tables arose from the therapists' narratives based on client cases. Responses to the key questions presented in the Chapter 3 related to what factors therapists felt influenced ongoing pain management for their clients. Thus the themes were mostly reflective of their experiences with the clients they saw in practice. Some themes, however, related to the therapists' experiences of using various methods in practice with their clients. This was their interpretation of what they had found useful or otherwise for clients' ongoing pain management. A few themes related to the personal characteristics that therapist-participants brought into practice, which they felt assisted their therapeutic relationship and thus benefited clients. As in Chapter 5, themes that emerged from the practice narratives were grouped within the conceptual thematic categories of person/self, meaning ascriptions, strategies, and external/social world factors. Themes were mostly coded using the verbatim language of the therapists. Whether a factor was seen as positive or negative (agentic or victimic) was determined by the therapists, based on their experience. Areas within the

agentic/victimic tables left blank indicate that no themes emerged from the data that were either agentic or victimic for that category. Fewer negative factors were identified by the therapist-participants. This could be due to therapists defending their pain programs approach and wanting their interventions to appear helpful to their clients. Nevertheless, a few therapists were critical of some aspects of their programs and the approaches used. These appear in the tables and themes as “points of divergence”, where the dominant methods supported by other therapists were seen as counterproductive by some.

There were many similarities in the terms used by both PMP participants and therapist-participants. These similarities could relate to the terminology used in pain programs and adopted by clients, such as “pacing” and “black hole”. Furthermore, therapist-participants who had worked in chronic pain management for many years had also witnessed their clients’ range of social backgrounds and the coping strategies used, and were thus conversant with the language of their clients.

6.2 Stage 2: Therapist-Participant Findings (client-related themes)

Table 6.1: *Person/Self Themes About Clients, from Therapist-participant Perspectives*

1. Person/Self	Agentic	Victimic
Having roles; having worker roles	Having valued roles; valuing self as a worker	Having role loss; having worker role loss
Having personal control	Being in control	Losing control
Being a certain type of person	Being who I am; having a diagnosis; having capacity to change; committing to self	Being a victim; being abused
Having depression	Managing depression	Being severely depressed
Seeing people with compensable injuries	Giving people a second chance	Having secondary gain; being manipulative
Dealing with relapse	Finding the personal resources to deal with relapse	“Falling off the wagon”; being unable to sustain it by yourself

Table 6.2: *Meaning Ascriptions About Clients, from Therapist-participant Perspectives*

2. Meaning Ascriptions	Agentic	Victimic
Accepting pain	Having acceptance of chronic pain	Looking for a cure
Readiness for change	Being ready for change	Being unable to take on the pain management message
Timing	Being the right time to do a pain program	Being the wrong time to do a pain program; endlessly hoping for a cure; not knowing what to expect
Pain management as a process	Moving through the pain process; going from patient to person	Having fear avoidance
Having ways of thinking about pain	Believing in yourself	Pushing through pain; being the last hope

Table 6.3: Strategies Clients Used, from Therapist-participant Perspectives

3. Strategies	Agentic	Victimic
Using overall strategies	Using a range of strategies	Being unable to use a range of strategies
Using goal setting	Being able to set goals; having future plans	Difficulty setting meaningful goals; difficulty seeing the future Point of divergence Having limited evidence for goal setting
Using medication	Being dose- and time-contingent	Using too much medication
Using education	Understanding the mechanisms of chronic pain; having a folder of information/resources	Therapist lacking understanding about chronic pain
Using exercise	Being able to keep up with exercise	Being unable to keep up with exercise
Using meaningful occupation	Having structure and routine; doing something meaningful; problem solving around activity; using adaptive equipment; using pacing	Being unable to use pacing; having limited meaningful activities
Using relaxation	Using diaphragmatic breathing; using recorded relaxation techniques	Point of divergence Using relaxation techniques that exacerbate pain
Using cognitive behavioural techniques	Changing thinking; hurting does not mean harming	Point of divergence Meeting a force with a force
Managing the “black hole”(relapse)	Talking about the “black hole”	Being scared about relapsing
Using pain measures	Pain measures being useful	Pain measures not being reflective of pain
Unique features of pain programs		
Doing an art session	Being creative in expressing pain	
Having a contract	Agreeing to do everything	Contract perceived as harsh
Using video	Finding video useful	Seeing people annoyed at being video-taped
Using metaphors	Finding what makes your heart sing; playing a beautiful symphony	

Table 6.4: Social World Influences on Clients' Pain Management, from Therapist-participant Perspectives

4. External/Social World	Agentic	Victimic
Social factors overall	Social factors supporting pain management	Social factors impacting negatively on pain
Family influences:		
Being part of a family	Having good family support; having a family day; isolating yourself from others as a way of managing pain	Having a difficult family life; losing role of carer; family being unsupportive of family day; avoiding social responsibilities
Institutional influences:		
Seeing compensable clients		Being a barrier to good pain management; being in the system
Having English as a second language	Needing an individual approach	Being a challenge to explain pain concepts in another language
Seeing the influence of other health professionals in the community	Having health professionals supporting pain management	Being told "it's all in your head"; reinforcing treatment seeking; being at the mercy of health professionals
Having a therapist-client relationship	Having rapport; being a motivator for change; being an explorer; being a coach	Reinforcing pain behaviours
Using individual versus group approaches	Being flexible; getting the group mix right	Having one set approach; seeing the group as a "box of chocolates"
Having post-program follow up/refreshers	Having formal review of clients; having refreshers	Having no review procedure in place; being unable to offer refreshers
Community influences:		
Using buddies/support networks	Having buddies/support networks	Having support groups reinforce pain
Having a pain program environment	Having the right environment to run pain programs	Having an artificial environment

6.2.1. Person/Self Themes

Factors about the person the therapist saw in practice were noted as influencing successful pain management. Therapist-participants referred to the person as “patient” or “client”. This section uses the terms “person” or “client” in preference to patient. Person/self factors related to clients’ roles in their lives, idiosyncratic personality traits, dealing with depression and relapse, and having a compensable injury.

Having roles

Therapist-participants recognised the importance to the person of having a variety of occupational roles and being able to perform them to a satisfactory level. The importance of familial, relationship and worker roles were noted by several therapists.

A. Agentic

Having valued roles

Having roles that clients valued in their lives was noted as important by therapist-participants. Marie observed that familial roles assumed increased importance when returning to work was no longer a priority for some of her clients.

By the time we get them I think work is often a lower kind of priority, in terms of all the things that they’ve lost. You know, worker role is one thing but being able to tie my shoe-laces, and run around after my kids, and cook the dinner, I think people tend to look closer to home first. And I think that’s important to be able to do that, to be able to focus on those normal roles.

Elizabeth saw the importance of familial roles and finding alternative roles for clients when return to work was not an option. She noted the importance in sustaining roles that added to the person’s quality of life and made “lives more worthwhile”. This included “voluntary work”, doing “courses” and meeting people.

Having worker roles

Therapist-participants recognised how important the worker role could be for individuals. For some clients who had participated in pain

management, considering returning to some sort of work became an option.

A. Agentic

Valuing self as a worker

Therapist-participants recognised the importance of being a worker for some of their clients. Patricia discussed her perception of the social importance of work and how the people she saw “value themselves by their productivity – what they make and what they do and what they’ve achieved”. Louise described a case study where a client’s view of himself changed to the point of making returning to work an option after completing the pain program at her hospital.

All I can remember about this fellow is how knowledge and experience changed the whole face of what he was able to do. I certainly think that working with therapists who knew about chronic pain, and how to move out of that space that he was in, was really important and he was just taking it on wholeheartedly, so it’s that combination; somehow it’s very powerful. And we have had a number of people who that combination has meant that at the end of their time they’re saying, “Can you help us get back to work?” So the people’s view of themselves has changed to the point where they are resetting what they think is possible for them.

B. Victimic

Having role loss/having worker role loss

For most clients seen by therapist-participants, having chronic pain meant the loss of valued roles and the subsequent psychological impact. Marie described the effect of role loss for people she saw and how they found “life just feels like it’s really not worth living”. Patricia noted how chronic pain had negative implications on work, familial and relationship roles, for some of her male clients in particular:

Most of them felt like failures in terms of their male role; their role of being provider and caregiver for their family. Most of them felt sexually de-masculinised because usually their sexual relationship with their partner was limited or defunct.

Having personal control

Having personal control over their lives was also recognised by therapist-participants as important to clients with chronic pain. Being in control was important to the person's sense of independence.

A. Agentic

Being in control

Alison described a client who had lost and then regained control of his life by completing the chronic pain program in which she was involved.

There's one man that comes to mind who had really stopped doing just about everything. He was spending a lot of his day lying down. He was a very keen gardener and he had previously been very fit; he used to jog and do canoeing and things like that. He really didn't have any goals, he wasn't planning things. He'd really lost the motivation, I suppose, to plan. By the end of the program he would say things like "This has changed my life", "This has given me back control, it's saved my marriage".

B. Victimic

Losing control

Therapist-participants also noted that people with chronic pain often reported feeling that they had "lost control of their lives". Alison described what she commonly saw in practice:

A lot of people report when they come in that they feel bitter they've lost control of their lives. So it's really a matter of getting that control back and being able to maximise their independence and maximise their enjoyment in what they're doing.

Being a certain type of person

Related to working with a range of clients in both group and individual programs was recognition of the variety of personality types and idiosyncratic elements clients brought to the various programs. Some of those elements were considered positive to chronic pain management, and others had a perceived negative impact.

A. Agentic

Being who I am

Matt felt that for his clients, having a personal sense of identity and being comfortable with their sense of self was important in being able to apply strategies from his program and move forward in self-management.

I think because the whole identity thing is a factor, whether they have a concept of who they are. And if they do, then it's easier to apply the strategies after that. If they don't, it's a whole lot more ground work you need to do.

Having a diagnosis

Elizabeth found that people she saw with a similar diagnosis could present very differently. She saw that individual personality factors influenced how well they did.

Well, diagnosis doesn't tell you anything other than the cause of the problem and whether there might be something that you can do medically about it. But, the impact of diagnosis on function, it's the individual factors that will impact on that. One person with chronic pain may have exactly the same symptoms as the next, and one of them is working 40 hours a week – living a full life. It's how has that diagnosis impacted on the person and their ability to deal with it.

Having capacity to change

Louise discussed how people's capacity to change was influenced by their individual characteristics and view of themselves. Having the capacity or will to "move forward" was seen as a positive factor in pain management.

And sometimes there are factors in people's lives that change. And I think that's reality. And I think what we've got is a chronic condition, that affects people in different ways. And that different people have got different capacities to move forward on.

Committing to self

Elizabeth described how having clients make themselves the priority and committing to themselves were important factors in the program in which she worked. In her experience this was particularly difficult for women to do, but taking part in her program gave them that opportunity.

And that their mind is in a place where they can commit to themselves and that they've not got a whole lot of other things going on in their lives that are distracting them away from actually committing themselves for 3 weeks. Making themselves the priority. Particularly for a lot of women who are busy caring for everybody else but don't actually take time to care for themselves. And sometimes the program is the first time they've actually stopped and taken stock of what is happening for them.

B. Victimic

Being a victim

Many therapist-participants described clients who saw themselves as victims of their chronic pain. Therapists characterised these people as mostly those who played a passive role in their pain management. Patricia described what she saw as the person having “an external locus of control”, when responsibility for pain management was not within the person’s control. Elizabeth described clients she saw within groups who blamed everyone else for their pain. She saw this as a significant negative factor in moving forward in pain management:

It’s always clear in the group – when people are in the victimic sort of perspective where they’re blaming everybody else, or blaming the accident, or blaming the surgeon, or blaming the GP, or their family, they will have a much greater struggle to move on – if they ever do. But the ones who I’ve seen make the least progress are the ones who are the most entrenched in that “it’s everybody else’s fault” and it’s about other people doing something to them, rather than them taking on what works for themselves.

Being abused

Therapists noted that some clients they saw came from challenging social backgrounds that had influenced their personal ability to manage pain. Liz described a case study where previous child abuse was an issue. This continued to affect the person who had experienced the abuse, in relation to her long term pain .

But I’ve also worked with a person just recently, who’s been a teacher who’d had extreme arm pain for a number of years, and she has been doing counselling to help her address issues of being abused when she was a child. And at some point in time, she actually came to see me to address the pain issues. The pain was becoming worse and worse, and she was becoming more and more limited in what she could do. And the psychologist suggested to her maybe she would benefit from doing some pain management. And during the sessions, she became aware that she’d been held down on her sore arm when she was a child, and when she was being abused. So we could work through those kinds of things, and she said, “Oh, do you think that might have a connection with the pain that I’m having now?” Anyway she’s actually doing really well these days.

Having depression

Concomitant to having life issues and chronic pain was the high incidence of depression reported by clients to all therapist-participants. The impact of depression on chronic pain management was noted in terms of severity and how it affected activity participation.

A. Agentic

Managing depression

Liz saw depression as a huge issue. Yet she also saw that, by improving clients' quality of life through improving function, depression could be lessened:

It's a huge issue, so a lot of people are on anti-depressants and feel that that does make a difference for them. Some people, during the time that we work together, their depression will become less. If it's a reactive depression to the pain, then as they improve – functionally, and also possibly with the pain – then the depression will become less too. And it's looking at empowering people. So I guess often, if their depression is a result of them feeling disempowered, because they feel at the mercy of the pain, then by changing that around and improving their quality of life, the depression will often become less.

Matt found by providing “structure to their day” and “social support” within his program, people tended to do well despite having depression.

B. Victimic

Being severely depressed

Patricia described how her awareness of the impact of depression had developed over her years in chronic pain practice. She noted that being severely depressed meant her clients could not engage in the therapy process:

But another factor that's really important in change, I think, is how depressed people are. I guess I didn't recognise this when I first started working in this area, and I think it's incredibly underestimated, the effect of how moderate to severe depression really affects people's ability to make change and to work on the sort of pain management strategies we're talking about. I certainly found this in the treatment program, for people who are really severely depressed, they can't take on board new information, and they can't concentrate for long enough, their memory is poor, their motivation is so rock-bottom that sometimes it's better to just really look at medical interventions

for a while first, to just get their mood up to a level that they can actually actively engage.

Seeing people with compensable injuries

Most therapist-participants worked with both compensable and non-compensable clients. Several therapist-participants talked about the issue of compensation and the added stress it caused for people. This arose as a theme in the “social world” section, but the personal impact of being within a compensation system often affected people’s sense of who they were within the world and the way they approached chronic pain programs. This was considered a particular issue when financial gain was dependent on having chronic pain.

A. Agentic

Giving people a second chance

Marie talked about giving people a second chance even though she thought their compensation issues would be challenging after having multiple interventions with no improvement:

But by the same token I think we need to give them a chance, so even if we do think, “Hang on a minute, you’re going to be really challenging”, I think they still deserve that opportunity to improve their occupational performance and their quality of life. You know, “Nobody else knows what to do with me, so I’m useless and hopeless and this is what I’m stuck with”.

B. Victimic

Having secondary gain

Secondary gain was seen by therapists as clients having their own agenda for attending a pain program. Often secondary gain was attached to the person’s perception of having a financial incentive for remaining in pain. Several therapists found this a major challenge in their pain practice. Alison always flagged secondary gain as a possibility for people receiving compensation who attended her program, particularly when they were “struggling” with the concepts of pain self-management. Liz was also aware there could be cross-motivation for attending her program, particularly if clients had been referred by a compensation agency:

I guess I’m interested to know if they are keen to improve or not. Sometimes they’re actually sponsored by an insurance

company, they're requested to come, and I'm always aware then that there may be cross-motivation as far as whether they wish to attend or not.

Being manipulative

An issue that arose for some therapist-participants involved clients who were labelled as “manipulative” or who “played off” one staff member against another. This was seen as another form of secondary gain as clients had their own agenda for doing this. Matt detailed a case study from his practice when he had identified a manipulative and difficult person to work with:

And she had a crook back, she was just a very distressed lady because she was very weepy and she was quite manipulative and sort of tried to split staff. And... was really able to recruit health staff to her side. But then you'd see her on the ward when there was no-one watching and she'd sort of run into the tearoom and run out, because she wasn't supposed to be in there getting coffee sort of thing. So she was really quite able, but was sort of manipulating the system to her end, for the benefit of her.

Dealing with relapse

Inevitably, therapist-participants saw clients who had relapsed at some stage after the pain program. Some programs provided education sessions on dealing with relapse, and others saw clients at review who had experienced relapse. How clients dealt with relapse was seen as idiosyncratic and dependent on their personal characteristics.

A. Agentic

Finding the personal resources to deal with relapse

Leah recognised that managing chronic pain was difficult for people to do on their own. She saw people who sometimes needed reminding of their personal resources to manage relapse. This might take the form of a few extra sessions with her:

All people move on. And yeah, they have a relapse. They might come back for one or two sessions, but really if they don't need a lot, they know what it is, they need to be reminded, in a way.

B. Victimic

“Falling off the wagon”

Kristine saw managing pain as difficult for her clients to sustain by themselves. She used the metaphor of “falling off the wagon” to convey this. She noted that once clients returned home they often lacked the level of support that they had experienced on the pain program and had to rely on their personal resources. This theme was similar to that noted by PMP participants at their program conclusion, when support abruptly ceased. The need for ongoing support arises again under “social world” themes.

I think some of the falling off the wagon is they're in a program, they get lots of attention, they're getting some hands-on treatment, they're learning lots. And they go home and it's kind of they're on their own. Often it's because the program provides them with the exact opposite of what they have day to day. I mean, I think often some of the stuff that happens afterwards is that it all becomes too hard again.

Although personal factors were considered to affect pain management, the meanings clients ascribed to their pain were also seen as critical by therapist- participants.

6.2.2. Meaning Ascriptions

“Meaning ascriptions” refers to clients’ beliefs and ideas about their pain as recognised by therapist-participants. Because they used biopsychosocial and CBT approaches to practice, different pain programs had similar philosophies regarding how clients were to think about pain. Yet therapist-participants saw a range of thinking about chronic pain in their actual clientele.

Accepting pain

Many of the pain programs in which therapist-participants worked recognised that “acceptance” and being ready for change were important factors. These factors have been the subject of research interest in chronic pain programs, and therapists were aware of the terminology. Acceptance of pain was regarded as acknowledging that pain would be ongoing regardless of activity level, and that continuously looking for a pain cure was counterproductive to pain management. Being ready for

change was identified as the point in time when clients were ready to take on board thinking about how to manage their pain. Therapist-participants spoke of this in the context of “moving through the process”. This recognised that arriving at the point of acceptance and being ready often occurred over some time, after other treatment methods had been exhausted. These factors were seen by therapist-participants as inter-related. Thus, some of the following themes of acceptance, readiness for change, and pain self-management as process are considered relative to each other.

A. Agentic

Having acceptance of chronic pain

Patricia spoke about the complexity of accepting pain and being ready to change over time and how difficult it was for many people. She also acknowledged that getting to that point was important if people were going to be successful in their pain management:

One of the things that I've noticed that seems to be a big factor is people's understanding and acceptance of that – the pain is likely to be a permanent factor in their lives. While people still have a belief that the pain can be cured, and that there are treatments out there that have yet to be tried that can cure their pain, it's really hard for them to engage in the sort of management strategies that we're talking about and for them to be successful. Essentially by the time people are ready for change, I guess I feel they have got to that point of acknowledging that their pain is likely to be with them in some way, shape, or form – long term. That obviously takes a bit of working around, because in essence what you're asking the person to come to terms with is that changes for the future need to have pain, as an ongoing factor, factored in to it. You know, learning all these strategies for managing your pain are hard work, very challenging, and can turn your life upside down.

Elizabeth recognised the complex process of people's acceptance, being ready to take responsibility, and timing as critical to the success of the program in which she worked. She found that the “big challenge” was sometimes it was not until years later that people had moved on in the process. She acknowledged that for some people “it just took them a long time to get there”:

B. Victimic

Looking for a cure

Patricia believed that sometimes when people were focused on a cure for their chronic pain it was better to send them away than engage them in a PMP.

Sometimes when we see people and they're very fixed on the idea that they just want, and need a cure, it is more useful to allow them to go off and look for cures. And to encourage them, if that is not successful for them, we'd be very happy to see them again if they choose to come back in 6 months' time or whatever.

Readiness for change

How ready people were to take on the self-management message espoused by PMPs was considered important by therapist-participants. Being ready meant that clients had arrived at the point of accepting the ongoing nature of pain, or that they were ready to try to implement self-management strategies in their lives.

A. Agentic

Being ready for change

Liz saw readiness for change as the person being “interested in learning new ways” and recognising that he/she was “ready to make changes”. Marie talked about clients seeing the cost of being able to change (getting better) as not being outweighed by the possible financial and other benefits of remaining in pain:

I mean, I think it really depends on the person. So another thing, with being willing to change, so the cost kind of doesn't outweigh the benefits. So that secondary gain kind of idea, you know. “If I get better I don't get money” or “I don't get as much attention”, so that the cost isn't too great to change and to get better.

B. Victimic

Being unable to take on the pain management message

Matt spoke about clients who were resistant to changing their thinking about and ways of managing pain. Matt saw this as being unable to take on his program's self-management message:

It was more the patients who really weren't wanting to come off their opioids, or might have had some issue with one of the doctors. The difficult groups were the ones that didn't want to take on the message, I think were more the people who weren't willing. And maybe people who weren't willing and also were expecting a cure. I think it was the wrong time.

Timing

The concept of time was mentioned in several PMP participant and therapist-participant narratives. "Being the right time" for the client to engage in the therapy process was seen as related to acceptance and being ready. Therapist-participants also saw people where it was the wrong time to benefit from pain management. Working out the right time for clients to engage in a PMP was considered an ongoing challenge for therapists.

A. Agentic

Being the right time to do a pain program

Marie spoke about what she saw as the right time for clients on her program to most benefit from pain management. She said that this would be "in a perfect world", which often did not apply to practice:

But we're also pretty particular, because it needs to be the right time. We don't want to get people here who are going to go in, and they'll get half way through it and go, "I can't do this. I need to leave". I think we need to be convinced that they're going to get the most out of it, that given their circumstances, they could possibly get. I think the right time, from my point of view, would be (and this is in a perfect world): no current litigation, they've been through their WorkCover system, they're at the point where they can focus on getting themselves better.

B. Victimic

Being the wrong time to do a pain program

Kristine saw clients for whom it was definitely not the right time to participate in pain management, as they were not ready to take on any responsibility for their pain. "Sometimes they're just simply not ready to take any responsibility, so sometimes they might just be told that now probably isn't the right time".

Endlessly hoping for a cure

Many therapist-participants spoke of clients who were hoping their chronic pain could be cured. This was often flagged as a negative factor inhibiting clients from benefiting from PMPs. However, it was also remarked that it would be unrealistic for those clients not to hope that the programs provided might alleviate their pain. Elizabeth spoke about one client who felt that “there must be something that can be fixed” and was looking for “a magic surgery, or injection, or medication”. Alison detailed how some clients would come in “hoping that we will be able to cure their pain” even though they were aware of her program’s self-management focus. Marie expressed understanding that people would continue to look for a cure, but believed that this would hinder their moving forward in pain management:

And ideally we try not to take people who are seeking a cure, they're still clinging to that little bit of hope. And I guess it would be hard not to, too. If you were in pain forever it would be hard not to have that glimmer of hope. And if we're saying, "Well, this is what you've got, you've got to manage it", sometimes if they're still in that grief and loss stage, they grapple with that.

Not knowing what to expect

Marie said that although people were fully informed about what the pain program in which she worked required in terms of level of activity, most clients had forgotten by the time they actually started the program. Consequently she found that most people did not know what to expect, which resulted in them feeling unprepared.

The first person that we see we give the whole "This is how it works, this is what a day looks like, this is where you stay, this is what the meals are like", just all of the ins and outs of things. So we give them all of that. I think they might remember 10% of what we tell them. And I don't know that they can truly know what they're in for until they get here and go "Hang on a minute, I wasn't prepared for this, I don't feel like I'm ready". Because a lot of people say, "Look, I didn't realise that it would be such hard work" despite the fact that we've said that it would be really hard work; it starts at 8.30 and finishes at 5.00 and you're on the go for that whole time. And I think when they get here, I think some of them feel quite unprepared.

Pain management as a process

The process of arriving at acceptance and readiness for change was time-contingent. A client’s ability to move through the process to reach a point

where self-management became possible was seen as complex and often unpredictable by therapist-participants. Individual personalities and personal idiosyncrasies of the clients they worked with meant that determining where someone was in the process of managing pain was uncertain.

A. Agentic

Moving through the pain process

Several therapist-participants detailed the clients they saw as moving through the process. Louise noted that people were at different points at different times in their pain management and that her program tried to be supportive of that:

I think that's the difference, we don't have just a one-stop program for people to fit into, we try to be flexible and try to focus on what we see as achievable goals for that particular client at that particular time in their process.

Going from patient to person

Marie saw the program she was involved in as a process within itself for clients to manage their pain. She saw the imparting of information and working out what applied to the individual as moving them through the process of being “a patient to a person”.

So it is very much a developmental process of getting all this information, sifting through it, working out what behaviours you need to change, and then going through and doing that and living with that. So trying to move from a patient to a person who lives in pain... Because they're essentially never going to get rid of their pain, so it's really about are they going to manage it, rather than it manage them. But it's definitely a process. Some people go through the process really well, and some don't go through so well.

B. Victimic

Having fear avoidance

Current research areas of interest in chronic pain also arose in therapist-participant narratives. Several therapist-participants noted fear avoidance (a term used to describe people avoiding activity due to fear of exacerbating their pain) as something they commonly had to work on with their clients. Marie saw fear avoidance as important to consider, especially when people became stuck in the process of pain self-management.

Don't underestimate the value of fear avoidance in stopping people from doing things, and your ability to challenge that. Knowing that you're full of pain, but we need to look at other ways of doing this so you can still be functional, you can still achieve your goals and you can still have the roles that you want.

Leah also noted fear avoidance in her practice and described how it became entrenched over time into “patterns of thinking... based around grief and fear” that were challenging to work with.

Having ways of thinking about pain

The way clients thought about their pain also influenced their approach to pain self-management. Meaning ascriptions about their ability to manage pain or otherwise were seen by therapist-participants as influencing how successful clients actually were in ongoing pain management.

A. Agentic

Believing in yourself

Liz saw factors such as believing they could do the pain program and improve as positive in her clients' pain management: “Believing that they can, actually just having that belief in themselves that they can improve, and sort of being more constructive than destructive, in their thought processes.”

B. Victimic

Pushing through pain

Patricia described the two extremes of thinking about pain she saw in people who attended her practice: ignoring the pain, and having fear avoidance around activity. Both had an equally negative effect.

Invariably the people I see tend to fall into two extremes. On one extreme; the people who try to manage their pain by pushing through the pain and pretending it's not there – so trying to ignore the pain, invariably leading to significant bouts of pain and crashing – badly. On the other end of the scale, people who have become very fearful of activity and fearful of any pain experience, and therefore become more and more avoiding of activity. And a fair amount of people that flip-flop somewhere in between those two, at various stages.

Being the last hope

Therapist-participants found that clients often had to try all other options before reaching a point of acceptance. Although this could be seen as positive, some therapists noted that it increased clients' reliance on the program and their risk of failure. Marie reported that often her program was seen by clients as their last hope:

Quite a few people have tried acupuncture, homeopathy, naturopathy, every surgeon known to man, anaesthetists, physios, OTs, just everybody that they can think of. And get to us and go "You're the last hope that I have". So I think those people are hard work extremes, it's a bit of a risk hanging all of their hope on us, and we say, "We're really sorry, I don't think we can help", there's a fair risk to those people in terms of suicide risk and stuff too, when they're hanging their hat on us as the only option.

Although the meanings clients ascribed to their pain were seen as important, therapist-participants saw the strategies that clients used to manage their pain as of utmost importance. Therapist-participants viewed strategies as their therapeutic domain and what they primarily offered in their role as occupational therapists. Themes related to strategies identified from therapist-participant narratives are now detailed.

6.2.3. Strategies

Strategies were the practical aspects of the various pain programs that therapist-participants used with their clients. Most programs utilised a similar range of strategies based on therapist experience, skills and knowledge of existing PMPs. The main strategies that were applicable across programs included education about the nature and physiology of chronic pain, goal setting, pacing, exercise, relaxation, engaging in occupations, and using CBT. The perceived value of various strategies was raised in therapist-participants' narratives. Some therapists were critical of strategies and methods that had a limited research base or were applied ad hoc in pain programs. These themes are signalled as points of divergence and are discussed as being contrary to those stated by other therapist-participants. This section also considers the assessments and outcome measures used in the various programs and how useful they were at actually validating the programs provided.

Using overall strategies

Therapist-participants were asked a general question about what strategies their various programs covered in general that they found useful.

A. Agentic

Using a range of strategies

All therapist-participants used multiple strategies in their pain programs or practice. Louise advocated using “active self-management strategies” that enabled people to “maintain maximum participation” within her program. The most common strategies utilised centred on the use of goal setting, pacing activity, use of correct body mechanics and relaxation strategies. Therapist-participants recognised that providing a range of strategies was important to meet the diverse needs of the clients they saw. Matt talked about applying strategies to activity, such as having routine and changing thinking, as being a more practical approach.

I think while they're here [on program] they've got structure to their day. They're a lot more social, and they're talking to people who've got a shared experience. And certainly the activity programs in the gym, we certainly did see a lot of improvement in pain people after that. And with that behavioural stuff, it's applying those cognitive type strategies, and challenging people on their thoughts. So while they're doing something, and they sort of have some kind of pain behaviour, addressing that on the spot: "What do you think is going on?" and sort of correcting some of those cognitions as you go, in the moment.

Therapist-participants stated although they provided clients with a range of strategies, what they continued to use over time depended on the choices and experiences of individual clients. Alison saw that different things worked for different people and how they often had to go away and try strategies at home, to see what worked best for them.

I suppose that when they leave they're using more strategies. By the time they come back for review they're probably using a fewer number, but by then they've sorted out which ones work best for them and fit in best with their lifestyle. And they're probably using them much more frequently. I would say the main ones would be the regular walking and stretching, regular active relaxation. Controlled breathing, increased socialising... pacing also is a big one.

B. Victimic

Being unable to use a range of strategies

Therapist-participants found that for some clients applying strategies to their lives was difficult. Elizabeth saw clients who had difficulty applying strategies to everyday life by the time they came for follow-up review. She linked this to their lack of readiness and acceptance of the need to maintain active self-management strategies for pain.

Well I think it's that readiness, the acceptance, the actually applying stuff. I mean you can see it when they come back to follow-up and they're saying, "Oh, nothing's got any better" and then you say, "Well, what are you doing?" "Oh, well I haven't done any exercise for 3 weeks, and I stay in bed in the morning and I'm not doing my relaxation – I haven't got time". And you think "Well... okay, you're not doing anything. You're not actually applying the stuff".

Specific strategies were detailed by therapist-participants in the course of their practice narratives. The perceived importance of particular strategies was highlighted by therapists and these are now considered individually.

Using goal setting

Goal setting and making future plans were common themes across programs. Goal setting was related to simply increasing activity tolerances such as for walking and standing or related to re-engaging in valued activities. Making future plans was related to (wished for) clients' long-term goals. Therapists noted, however, that many clients needed assistance with setting goals and that some people had no life goals at all beyond finding a way to reduce their pain.

A. Agentic

Being able to set goals

Having clients be able to set personal goals was an important element in most pain programs. Elizabeth saw that goal setting could involve a number of different areas in people's lives such as "social activity, physical activity and relaxation" and be highly specific:

And the sort of goals vary but they could be things like "I want to finish painting the bathroom" to "I want to take my dog for a walk" or "I want to take the kids to the park" or "I want to be able

to timetable half an hour a day for my relaxation” or “I want to bake a cake” or “I’d like to invite friends for dinner”, I mean it could be any one of a number of things.

Marie used the acronym of SMART goals in the in which program she worked. This provided a formula for people, centred on making goals “specific, measurable, achievable, relevant and timed”. She found this acronym useful for clients to apply when thinking about goal setting, although she acknowledged that some clients thought that they had to be “smart” to use it.

Having future plans

Having future plans was seen as a positive strategy by most therapist-participants overall. Alison saw making future plans as a statement about people themselves and what they wanted out of life. Making future plans meant that clients were looking beyond the program to what might be possible for them in the future.

It’s really important; the whole thing of goal setting, and thinking positively about the future, provides the motivation for people to go on and start achieving and feeling good about themselves. And I think that the goals that people set really reflect the types of people that they are, so people’s goals reflect their ideals and their interests and the goals are really a statement about the person themselves.

B. Victimic

Difficulty setting meaningful goals

Leah described a client who had difficulty setting meaningful goals. She saw this as affecting his quality of life and sense of achievement when unable to do so:

So, what was interesting to me – he has no goals at all. Didn’t have a clue, couldn’t do half the things he wanted to do. I did get him to the point where he was sleeping better, his moods were more regulated, he could reduce his medication, all of the external parameters were okay, but he was still a very unhappy man. And so trying to find something for him to do that was meaningful, that would give him more of a sense of achievement was really very difficult.

Difficulty seeing the future

Matt saw making future plans as difficult for his client population. He thought that they tended to view the future negatively in terms of

deterioration in their pain condition and subsequent preferred not “to think about it”.

They idealise their past, but they have a negative feeling about their present. Whereas, about their future, they're either too scared to think about it, we always knew when patients would come in and they'd mention a wheelchair during their first interview, that you're going to have to really work to change some cognitions there. Because their view of the future is very negative, so they don't want to think about it, so they don't. So I found, with our patient population, that it was really quite hard to look at the future.

Point of divergence

Having limited evidence for goal setting

Matt believed there was limited research evidence for goal setting based on increasing activity levels, although it was used in the program in which he worked. He reflected that his opinion regarding this was opposed to that presented in the pain program, as he thought that setting life goals was more important to people rather than whether they could walk an extra 50 metres.

With goal setting, I think there really is limited evidence that goal setting really improves people's quality of life, or sets up a process. But I think goal setting could be done better with regard to looking at more self-type goals, and life goals, as opposed to a patient when they leave the program: “can walk an extra 50 metres than they could when they first came in”. Because what are they going to do with that extra 50 metres? How are they going to actually get out there and live a better life because they can walk an extra 50 metres?

Using medication

Medication taking was applicable to all therapist-participant programs. It was recognised that people who had chronic pain either generally overused or underused medication. Although occupational therapists were not involved in medication management, they supported the prevailing ethos related to their particular program. Most programs advocated using the lowest dose of medication on a time-contingent basis.

A. Agentic

Being dose- and time-contingent

Marie and Elizabeth saw the value of taking medication in increasing activity tolerance. This was promoted on a time-contingent basis for the programs in which they worked and was something they reinforced with the clients they saw. Marie stated that the demands of “higher levels of participation” in her program required adequate medication coverage. Elizabeth considered that using time-contingent medication was similar to the use of activity pacing:

We definitely work on the principle that regular medication is better than “as needed” medication. If they’re going to take medication it should be on a time-contingent basis and paced along with their activity and everything else that they do.

B. Victimic

Using too much medication

Like several other therapist-participants, Marie spoke of the extreme amounts of medication some of her clients used. Apart from educating people about the health hazards of taking pain medication, doctors on her program tried to find more suitable substitute medications. This was done on an individual basis:

Some of them will take a packet of Panadeine Forte in a day and we’ll say, “Hang on a minute”. So, obviously we’re looking at “What would be a better medication to be taking to give you better coverage and make sure you’re not stuffing up all of your other systems and whatever”. So my overview about medication is that it’s something that needs to be worked out individually with each and every person.

Using education

All therapist-participants were involved in educating or reinforcing educational principles about chronic pain. Therapists’ methods of using education varied according to the pain program or practice. However, principles of central sensitisation (see Chapter 2, Section 2.3.1.3) as a cause for chronic pain were explained in line with current thinking about chronic pain.

A. Agentic

Understanding the mechanisms of chronic pain

Having people understand why they had chronic pain was considered important in practice. Patricia saw the importance of understanding what

pain was all about as a “big thing” for her clients. She used the example of the “boom and bust” cycle of overactivity and rest with her clients. Interestingly, this was also the terminology used by Will in Chapter 5 (Section 5.2.3).

The big thing that probably is – the primary factor we find with a lot of people we see, is that they actually need to understand what chronic pain is all about. And that they need to have an understanding of “how their pain’s developed” “why is it continuing to cause problems?” and the inter-connective pattern that pain has with other areas of their lives. I will certainly go into a model of pain, in terms of how pain and activity interact. And I find that really useful with clients that there’s often that real “Aha!” experience when I explain to them the interaction between over-activities stirring up their pain, needing to rest, their pain settling and then going back into that cycle of boom and bust. And they are usually particularly pleased that someone is understanding what it’s like for them.

Having a folder of information/resources

The program Marie worked in provided a folder of information for each client. Some past clients continued to refer to these years after finishing the program, which she found affirming of its usefulness:

And we say to people that even if the wheels fall off as soon as you go home and you’ve got that folder full of information, all you need to do is go back to it and go “Right, what did we try that worked?” so even if it’s been hard work that we didn’t think they got much out of it, a few years later we’ve run into people in the supermarket and they’ve said, “Hey I’m working and I wasn’t able to do that until 12 months ago and I went back to my folder and found some stuff that I wasn’t ready to hear about when I was there”, so there’s been a few kind of examples of that too, which is nice.

B. Victimic

Therapists lacking understanding about chronic pain

A professional practice issue Matt identified was the lack of education about chronic pain at an undergraduate level. Matt discussed what he saw as a lack of therapist understanding of chronic pain. He saw that therapists who had not been trained specifically in the area could sometimes reinforce pain by providing compensatory or hands-on strategies, rather than active management strategies.

Yeah, and I think it’s okay to validate their pain, I just think it’s a lack of education regarding chronic pain, a lack of understanding of what actual process is going on. I guess I think

it's a systemic sort of issue that, the research certainly points out that OTs and Physios, when they graduate, don't have a great understanding of chronic pain.

Using exercise

Many pain programs included an exercise component that was usually run by the physiotherapist, sometimes in tandem with the occupational therapist. The type of exercise advocated varied from program to program or practice.

A. Agentic

Being able to keep up with exercise

Alison described how exercise had been applied successfully to one client case on return home. Exercise had been included in the person's weekly routine, resulting in a positive outcome:

He attends the gym 3 or 4 times a week, he's got very fit and both he and his wife report that they're lives are much fuller and a lot happier. And when he left the program he was able to plan a day and implement pacing strategies into that. And he realised the importance of having hobbies and active leisure that was interesting for him.

B. Victimic

Being unable to keep up with exercise

Therapist-participants such as Marie, although advocating ongoing exercise post-program, reported that in her experience it was perhaps one of the most difficult strategies to keep going. She thought this could possibly be explained by people reverting to their previous thinking about non-acceptance of pain:

I think that the things that are harder to maintain for most people are the exercise sort of strategies. I don't know whether it's just that fact that it needs to be so consistent to maintain a gain. So, you need to walk every day, you need to stretch every day, you need to do the circuit regularly. I don't know whether it's like any habit, which kind of falls off over time, I'm really not sure why some people find it harder. And how much they've gotten into that belief about hurt versus harming, how much they've really taken that on board, and how much they believe it in terms of accepting that they have chronic pain and that they're not doing any more damage.

Using meaningful occupation

The following themes centre on engagement in meaningful occupation. Being involved in meaningful activities was seen by therapist-participants as paramount to quality of life. Considered here are the importance of having routine, doing something meaningful, problem solving around activity, and using pacing to enable activity engagement. The importance of motivation in maintaining activity was also highlighted.

A. Agentic

Having structure and routine

Marie spoke about the importance of having structure and routine in the day for the clients she saw in practice. She related this to a personality type of being a “structured type of person who needs routine” and she tended to model this behaviour herself. Liz noted that people who had previously worked had already operated within a structured routine. She found having structure and routine could provide personal motivation for her clients.

So the reason I mention the connection with work, is that those people have had to get out of bed, they've had to work within a structure of a working day, they've needed to motivate themselves, they understand what it's like to kind of have a commitment to do something, and to follow that through. They're people who are likely to succeed.

Doing something meaningful

Being engaged in meaningful activities and occupations was seen as critical for clients both during programs and after returning home. For Elizabeth, the “focus of achievement” on the program she worked for was “people being engaged in their lives”. Matt found that doing something meaningful distracted clients from their pain. Activity that had purpose and meaning was a positive strategy for his clients:

And when they're actually engaged in doing something that they feel is productive and leading somewhere, there were very few pain behaviours, there were very few reports of pain. And I think it's more than just distraction, I think it's distraction with purpose and meaning.

Problem solving around activity

Therapist-participants reported that problem solving around activity also promoted re-engagement for clients. Sometimes therapists provided the impetus for this or sometimes the group or individuals themselves could develop possible solutions to enable engagement. Alison described the problem solving session she ran around activity and how group brainstorming had helped a client return to horse riding:

And we do a problem solving session, as well, which is great; it just gives them a process to use if they get home and come up against an activity that they want to do, or return to and they're not really sure about how to go about it. We had one great example was a lady who had come in, and the one thing she really wanted to do was return to riding her horse. And she just hadn't been able to do that. And once we got into the problem solving session, she realised when we broke down the task, that the only thing that she couldn't do was put the saddle on. So with the group we brainstormed about maybe leading the horse into a lower area or her building up an area, or whatever. And when she came back she had used those strategies and was riding the horse again every day. So she's got a whole lot of pleasure out of that.

Using adaptive equipment

Marie was able to suggest the use of adapted equipment and alternative methods to facilitate activity engagement with some of her clients. She checked back with them once they had returned home and attempted the task to see if the strategies had worked:

Some people pick up little practical things like, "You said about sweeping like this" or "You showed me this piece of equipment that might make it easier. And I tried that and that was really good". So the practical stuff sometimes goes down really well. So I get them to brainstorm all the things they can do to make that activity a little better and which one to then action. And then I review it as they come back, "Did it work?" "Yes, great", "Next time I do the vacuuming I'll do it in the same way".

Using pacing

Pacing was a universal strategy employed across therapist-participant programs. Although the way pacing was taught varied, all therapist-participants agreed it was a useful concept to apply with clients. Using pacing enabled activity engagement and prevented clients overdoing activities and therefore avoiding them due to subsequent pain. Patricia used a series of time and repetition targets to educate clients about the

practical aspects of pacing. She reported that it could be challenging for some clients but was usually found useful:

With setting baselines and then setting targets for activity, in essence what I find with the people is that I'm superimposing a structure into how much they think is appropriate for them to be doing on a day-to-day basis. So, for most of my clients, they find that really useful to set a structure. And I often get people to use the countdown timers, so when their timer goes off they need to stop and walk away – have a break, come back and do some more later on. And that artificial approach is challenging, it's really hard for them to use this paced approach. However most of them report fairly quickly that it's useful in managing their pain, of keeping down the extremes of the pain, of keeping the pain more under control. I think it's a really, really important step in pain management.

Marie also found pacing to be a big factor in maintaining activity engagement over the day. She found that “scheduling... time... to break tasks down” meant that people could “manage... around the pain”.

B. Victimic

Being unable to use pacing

Conversely, Kristine saw clients who could not change the way they performed daily tasks or apply pacing to their lives. She saw people entrenched in their usual activity patterns, which meant they did not want to know how to use pacing.

Yes, I can think of people who don't want to know, who swear by the four hours of housework a day, and no they couldn't possibly do less than four hours of housework a day. And “Yes, of course I have to do the dusting every day”. So there are the people who don't want to know [about pacing].

Having limited meaningful activities

Some clients had lost the concept of what was meaningful and pleasurable in their lives. Patricia had seen people who had become increasingly passive due to their ongoing chronic pain.

These people have lost any concept of leisure activities, or they can't imagine any leisure activities that are actually within their physical capacity. So that their time at home, and they have huge amounts of leisure time – is just usually spent very passively; watching TV, sitting around, smoking – they're not actively engaging in a pleasurable meaningful occupation very much at all.

Using relaxation

Relaxation techniques were utilised in many of the therapist-participant pain programs. The actual types of relaxation taught and the perceived merits of the various techniques differed across participants.

A. Agentic

Using diaphragmatic breathing

One technique therapist-participants applied was diaphragmatic breathing or deep regular breathing. Louise would routinely “start off with diaphragmatic breathing” as an easy technique people could “do throughout the day... that people can do independently away from here [hospital]”. Marie discussed how she advocated its use as an easy strategy to teach and practise to control pain and emotions:

I think controlled breathing is something that they tend to carry over really well. So, it's really diaphragmatic breathing, would probably be the anatomical term for it. Now whether that's because it's something they see, whether it's an easier strategy to get your head around, or whether it's because we practise it so much. Or whether it is just something that is good because it's good for your high pain, it's good with anger, it's good with quite a few sort of different things.

Using recorded relaxation techniques

Several therapist-participants gave relaxation CDs to their clients to use at home. Patricia developed her own relaxation CD that covered a variety of techniques as she was not satisfied with what was commercially available:

I've developed a CD I recorded a few years ago, which has got about eight different tracks on it for relaxation for people with chronic pain. And I did that because I guess I wasn't really happy with anything on the market, so I often use that as a tool. So ranging from quite a structured progressive muscle relaxation, through to the guided imagery and meditative ones, through to a couple of scripts that are just quick short relaxation techniques that they can use when sitting in the car.

Point of divergence

Using relaxation techniques that exacerbate pain

Not all therapists advocated certain types of relaxation techniques. After 20 years of practice Kristine found that she no longer used a tense/relax technique or progressive muscular relaxation. This was

counter to the practice at the hospital where she consulted, as therapists there continued to use it. She explained her reasoning behind this practice issue, having found that the technique actually increased people's pain:

I would have taught progressive muscular relaxation – never teach that now. About once a year I do an educational session with the staff there [hospital], and I did it, progressive muscular relaxation because this is what the patients get taught, so I thought, “Well damn it, we’re going to do it”. And one of the young OTs [occupational therapists], who had some pain himself, said to me afterwards, “Gees, that hurt” and I thought “Thank you, because this is exactly why I no longer teach that”. He said it aggravated his pain and didn’t actually allow him the relaxation that other methods do. And I don’t like it, and I don’t like it when other people do it.

Using cognitive behavioural techniques

Using cognitive behavioural techniques was also a common method underpinning therapist-participants' pain programs. This method has been widely used and researched as valid in the treatment of chronic pain. It primarily focuses on changing thinking about pain from being negative to fostering positive thinking. Again, the way it was applied was specific to each program.

A. Agentic

Changing thinking

Liz talked about how CBT changed people's thinking. She described a case study where she had utilised strategies to help a client recognise the negative impact of dwelling on his pain:

And talking about the cognitive behavioural approach's addressing people's thinking. That approach teaches people to be more mindful and bring their thoughts to the present time, because they're focusing on – how they can attend to how they are in their body. And that's time out of the pressure cooker because they're not worrying, they're not dwelling on their thoughts. But you could see it and his thoughts were actually jumping from one thing to another. And so I'd bring his awareness to that, and the need to maybe change what we were doing. And he's now able to use relaxation strategies and other strategies that I've taught him, so he's able to recognise the thought process going down, spiralling down into a pain

pattern. And actually then start to work on – how he can change his thinking to come out of that.

Hurting does not mean harming

Louise described the cognitive methods her program espoused about chronic pain. This included changing clients' thinking about pain to hurting rather than harming. By using this approach clients could be encouraged to re-engage in activity, particularly if they had been fearful of movement.

I think having a different understanding of what their pain is signifying. And that sort of “hurt doesn't mean harm” sort of idea. And that they can experience a sense of control while they're participating in activities. Changing the way they conceptualise pain, and their experience of pain, certainly their cognitive strategies, their cognitions around that and their experience of it. And what is happening in their life that's actually reinforcing them moving forward and becoming more active. And what is it that's actually reinforcing their staying the same.

Point of divergence

Meeting a force with a force

All therapists acknowledged that CBT was widely used in PMPs and most supported it. Matt noted that it was “the best approach we have got” although he questioned how effective it was for everyone. As the researcher, I had also questioned its use as a universal approach in pain practice, as clients in my experience wanted to share their pain story and have their pain validated, rather than ignoring or challenging it. Leah did not advocate the use of CBT routinely in her pain practice, although she did utilise aspects based on these methods on occasion. Over her years of experience in practice she found that challenging people on their thinking when they were vulnerable was like meeting “a force with a force”. As she was trained in a variety of psychological methods she utilised what she found most useful with her clients individually. She described what she saw as the difficulty in health professionals using CBT as a blanket approach:

And the one thing that a cognitive approach, the challenging approach does, is say to people, “You're wrong. This is irrational – you're wrong”. So, as a practitioner with that thinking umbrella that I have, that would be very foolish for me to go there because what does “you're wrong” elicit from someone?

Especially when they're confused, because they haven't got a bloody clue what's right. I saw a guy today who's seen upwards of eight different professionals. And he says, "none of them have really helped. They've all got a different idea". So I think, "Well, is that helpful?" I'm not saying that CBT is wrong – at all, but I think, as a singular approach, it's flawed. And it doesn't allow enough creativity from people, it sort of like tramples on the defenceless. You know, as far as I'm concerned, it's very unintelligent to meet a force with a force.

Managing the “black hole” (relapse)

Due to the nature of chronic pain several programs covered sessions on relapse and what to do when it occurred. Different terms were used to describe this, including “maintaining change” and “falling into the black hole”, which covered what to do about actual pain exacerbation and also depression.

A. Agentic

Talking about the “black hole”

Alison described a session her program ran about falling into the “black hole”. She recognised that relapse was common in the clients she saw:

And we give them education on that in the last week; we call it the black hole. And how to recognise when they're falling down into that and what are the best strategies to use to get themselves out of that. And we also find out that it's really common that most people fall into the black hole at least once, or even several times. And that all you really need to do is get the strategies going again.

B. Victimic

Being scared about relapsing

Marie described how talking about relapse could be confronting, particularly when people were going well on her program. She recognised that some people did not want to think of the possibility of relapse eventuating:

I also do a session called “maintaining change” which is about how to recognise relapse. It's also a scary session, I guess, in that they feel like they're going so well and you start to talk about relapse. So it can be a bit scary when you come along and talk about something negative, and there can't be a space for anything negative because “I'm going so well”, and it does sometimes change.

Using pain measures

Assessments and outcome measures were used in the majority of pain programs. These differed according to the types of clients seen and the sometimes limited opportunity to conduct assessments and outcome measures in relation to program efficacy. One measure that was commonly used across programs was the Canadian Occupational Performance Measure (COPM). This measure is widely used by occupational therapists in a variety of practice settings, not only on pain programs. The measure required clients to nominate five activities that they would like to perform better and rate them in terms of performance and satisfaction with performance.

A. Agentic

Pain measures being useful

Patricia found the COPM was helpful to clients “who can conceptualise and articulate” their problems. It was used as a basis in problem solving around activity by identifying “five main problem areas” to focus on. Marie found that the COPM not only measured actual change in performance but also attitudinal change towards activity as well:

Well, we're certainly using the COPM, so we're measuring occupational performance and satisfaction. And it's a nice way to measure sort of functional tasks. It's not how well they pace their vacuuming, it's how well they can perform their vacuuming. And I think often we're measuring the change in attitude, too with that measure. So often if you get a statistical change, it's not just a physical thing of “how well I'm going”, it's changing “how I think I'm going”, too, which you can't do that with other measures.

B. Victimic

Pain measures not being reflective of pain

Although she found the COPM useful for some of her clients, Patricia also saw the limitations of using it with everyone in practice, particularly those with below average intelligence and those with limited ability to speak English. The concepts of activity performance and satisfaction with performance were difficult to describe to clients and difficult to evaluate subjectively, particularly if understanding was limited:

For clients who have difficulty conceptualising problems and I guess those more concrete thinking clients – sometimes it's not

a particularly useful tool. As with most tools, I think, they're particularly useful in the sort of middle class, average intelligence people – it works well. For people who struggle with concepts it's hard. And it's just not working with a lot of those people with English as a second language, it's too complex – that whole concept.

Kristine had found that pain measures such as the Visual Analogue Scale (VAS) focused on a single dimension of the pain experience, which was problematic when trying to understand a client's pain. Therapist-participant programs used a number of pain, depression and activity measures that “varied enormously”. This increased the demands on clients and therapists alike in administering and evaluating them.

Unique features of pain programs

The following themes are related to aspects of particular programs that emerged from therapist-participant narratives. These particular aspects were of interest when considering the uniqueness of the pain programs offered. Therapist-participants saw these unique aspects as important to ongoing pain management.

Doing an art session

Elizabeth worked in a program where she ran an art session that was often attended by other members of her pain team.

A. Agentic

Being creative in expressing pain

Elizabeth found the art session to be particularly useful as a different way of allowing people to express their pain.

The art session is a session we do within the first week of the program. And it's an opportunity for people to take some time to reflect on what their pain has meant to them and use visual tools to present that. Because it's a very revealing session, people often talk much more honestly about their journey in that session. When they're presenting their picture they have things like volcanos and traps and cages and isolation and loss and grief and lots of powerful stuff. So that session is a really important one.

Having a contract

Two programs used a specific contract that clients had to sign before being able to participate. These contracts stipulated that clients had to participate in all sessions and had to attend all days of the program.

A. Agentic

Agreeing to do everything

Marie described the benefits of having a contract as providing a basis to ensure program participation. The formality of having a signed contract meant that the person agreed in principle to participate in all aspects of the program.

They have a contract. So it is quite a formal thing, it's, "You agree to put in 100%, and that you agree to try as hard as you can". But also that we respect them, they should respect us, and that we will respect them. And it kind of gives us a bit of leeway if they're not toeing the line; we can say "You signed a contract, you're not adhering to what we agreed to in the contract". I think we need that contract that says, "You're going to do everything – including hydro that you hate because it hurts, and stretches because you're weak and tight and sore and stiff but you're going to do everything, you're just going to do it within your limits".

B. Victimic

Contract perceived as harsh

Although Marie acknowledged the benefits of having a contract, she also thought those outside the program would perceive it as "a bit harsh", especially when clients were given three warnings then ejected from the program:

And it probably sounds a bit harsh. But we will allow you to pace, but we won't allow you to avoid. And they'll be warned three times and then, if they haven't managed to commit, then obviously we don't have time for them.

Using video

Two programs filmed participants on videotape when engaged in activity in their programs. This was usually done within the first few days and on the last day of the program so that clients could see how they had progressed. It was generally done covertly without the client's knowledge at the time.

A. Agentic

Finding video useful

Elizabeth found video to be a good form of feedback on progress for her clients:

We do a video on day 1, and often they look again on day 15. And they look at day 1 and then they compare themselves with day 15 and how they are and that's often great feedback.

B. Victimic

Seeing people annoyed at being videotaped

Alison, although perceiving videotaping clients as useful, perceived that some became annoyed at the covertness, especially those with compensation issues who had improved over her program:

Some people get a little bit annoyed that we haven't told them. A lot of those people are sort of identified early in the program and I can see that they're thinking that it's not in their best interest to improve. Particularly if they have a comp[ensation] claim in and they're waiting for a pay-out.

Using metaphors

Many therapist-participants used metaphors within their pain practice. Most metaphors related to ways of seeing pain (e.g. "black hole") or applying strategies (e.g. "booming and busting"). A few therapists had developed metaphors specific to their practice that they found particularly useful to use with clients.

A. Agentic

Finding what makes your heart sing

Leah referred to "finding what makes your heart sing" as a metaphor for finding out what was really important to the people she worked with. She saw one of her roles as helping people to find positive metaphors around their pain:

You work with people to figure out depending on the person sometimes I get all poetic, and I say, "What is it that's going to make your heart sing?" "What are we going to do together that will allow you to fly again?" Because that's the stuff, the metaphors are what help people a lot. So I help people to find metaphors.

Playing a beautiful symphony

Liz used the metaphor of the body as an “orchestra” to describe the effects of chronic pain and how pain management could help the person “play a beautiful symphony”.

The way I explain it is that the muscles in the body are like members of an orchestra, and when they come to see me some of the members of the orchestra, these are the muscles that are tense and working overtime, are out of control, they're doing their own thing. It might be the percussion, it might be the strings – they're noisy and rowdy. And the conductor, which is your thinking and your brain, is not able to control them. So over time, what we're doing is helping the conductor – yourself – learn how to bring all the members of the orchestra into line and play a beautiful symphony or – beautiful music. And that seems to make sense to people, and really it does work, very well.

As evidenced above, therapist-participants found that having a range of strategies was useful in managing clients' chronic pain. These ranged from physical and psychological, to activity-based methods aimed primarily at re-engaging individuals with occupations and roles that had meaning to them. The following section considers the impact of social/external world factors on chronic pain management and how therapist-participants saw clients negotiating those factors.

6.2.4. External/Social World

External and social world factors that arose from therapist-participant narratives were seen as having significant impacts on long-term pain management. These factors included family support, compensation issues, dealing with health professionals, having individual or group pain programs, and support post-program. They are significant because the time spent in the external/social world was considerable in relation to the time spent within the various therapist-participants' pain programs. Also, the ongoing management of pain was to some extent related (as stated by therapists) to what occurred once people returned home.

Social factors overall

The first theme considers the overall impact of social factors on successful pain management. Therapist-participants identified a range of factors within the social world that would influence this. These factors included the attitudes of family members, health professionals and the wider community.

A. Agentic

Social factors supporting pain management

Marie explained that she was unsure how people would go after her program. She noted the significance of social factors in determining how successful they ultimately were in their pain management:

So the ones that you think, “I don’t know how well you’re going to go?” come back and go really well. So, for whatever reason, they went home and something just clicked. And I think it often depends on what’s happens after they leave here. There’s a lot of factors that kind of feed into people with pain and how well they go when they leave, socially.

B. Victimic

Social factors impacting negatively on pain

Kristine found that a “grab bag of things” could have a negative influence on how successful intervention was for people she saw in practice. She considered it was the subtle, often intangible things that made an impact, depending on specific events that had happened or were happening in people’s lives:

I think there’s a whole kind of undercurrent of subtle things. You know: Do they get on with the physio? Do they think they’re understood? Has the pain specialist told them off, what are things like at home? Has the wife bugged off? Are there problems with child care? “It’s a hassle getting here” and “Was my taxi late this morning?” and “I got a parking ticket yesterday”, it’s this whole kind of grab bag of things.

Matt also saw social and environmental factors as significant. He worked in a pain program that sourced clients from across the state. He noted that being “isolated geographically” could be a negative factor in access to support for some of his clients. He also saw that general practitioners who were “very physically... and medication focused” were not supportive of “a self-management type approach” such as the one his program advocated.

Family influences

Being part of a family

The influence of family on chronic pain management was recognised as critical by therapist-participants. The complexity of family dynamics could facilitate or sabotage change for clients when returning home after completion of chronic pain intervention.

A. Agentic

Having good family support

Alison considered the benefits of having “good appropriate family support” important to successfully managing pain. Patricia spoke about how bringing families along in the pain process was critical to their understanding of how to provide the right level of support to their spouse or partner. She found that families “being a support for change” could be helpful in the pain management process:

I think it's really important that families are brought along in the process. And I just think that other family members can be so powerful. One could be reinforcing appropriate behaviour, but certainly really punishing people, too. We then try to give them messages on what is helpful support, from partners, and children, or parents. Encouraging them with activity, encouraging them when they're trying to make changes, avoiding criticism if possible, avoiding wrapping them up in cotton wool and not allowing them to do an activity. Being a support for change, rather than a punishment for change.

Having a family day

In terms of involving families in chronic pain management, several programs ran a component where family members were invited to attend. Marie discussed the relative merits in running a “family day” within her program and how the impact of having pain resonated for clients and their families. This allowed families to move forward in being able to provide the right support:

Yeah, we have a family day. It's interesting to see the impact that the pain clients see it has had on their life. And it's really similar to what the families are seeing, as well. And just getting them to kind of open up and communicate about what's happening. And it's just a way of opening up some

communication: Where to from here? and What is the best way to help with that? So the social support is a huge thing.

Isolating yourself from others as a way of managing pain

Various therapist-participants discussed the impact of isolating oneself from others when living with chronic pain. Liz saw that isolating oneself from others was sometimes a useful strategy in managing chronic pain. This was noted also in PMP participant narratives. Liz described a case example where being able to leave a social situation and isolate oneself was an appropriate alternative:

So we talked about what she wanted to do, and, I said, “What would you have liked to have done in the situation?” She said, “I would have liked them to have gone”. And I said, “Yes, but assuming they were going to stay for a while, what would you need to do?” So we talked about strategies of her actually going upstairs to her bedroom and having a rest. And so I walked her through, I said, “Let’s go and do that now”. I think with a lot of people, they need permission, and learning that it’s okay to put yourself first – in that situation. And by doing that you’re actually being probably more useful to other people.

B. Victimic

Having a difficult family life

Many therapist-participants commented on their clients’ difficult family backgrounds. Elizabeth saw people who came from challenging family situations that limited the value of family support available and made pain management more difficult:

It’s not just the pain, it’s they’ve come from an awful family, they’ve been abused, they’ve had a terrible accident, their kids have been sick, their marriage has broken up. It’s like the sort of litany of disasters and yet there’s still a life that’s trying to get in there.

Patricia described the impact of chronic pain on personal relationships and how people could become “just absolutely fed up” with the person with pain and the “frustration and bitterness” at the extra work they had to do. She saw the “marital conflicts” that some of her clients and families experienced as being as big as, or a “bigger problem” than pain management.

Losing role of carer

Within some families the partner had assumed a carer role for the person with chronic pain. Alison found that partners were sometimes reluctant to

relinquish this when “they’re set into a particular role as carer”. Marie saw some partners accustomed to being needed and grieving about losing what had become a valued role.

And I think not always people are happy with somebody getting better; it can sometimes have been filling a need to look after someone and be good at that and whatever. And really that’s been their role as a carer. And there’s a grief, I guess, associated with losing those sort of roles, “Somebody is getting better and I’m sort of not required in that role so much”.

Family being unsupportive of family day

Not all programs found a family day a success. The program Matt worked within tried to have a family session but families failed to attend. He could not identify the reason for this: “Most of the families weren’t supportive, they just didn’t come to the session, for whatever reason. I’m not sure whether that reason was explored too much really”.

Avoiding social responsibilities

Patricia saw isolation as a way for a person to avoid social responsibilities. Being able to opt out of social situations using pain as the excuse was seen as a negative factor, which did not allow the person choice and control:

I think we sometimes see that the pain is useful to avoid social responsibilities. Sometimes it’s easier to get your pain to talk for you, rather than to say “no”. So I talk with people about the importance that they make the decision, rather than let the pain make the decisions for them.

Institutional influences

Therapist-participants saw the influence of various institutions as having a significant impact on how well clients did on their programs. The perceived power of compensation organisations, medical specialists and other health care practitioners could positively or negatively affect clients, depending on their involvement. Therapist-participants noted that generally, by the time they saw people, they had negotiated a number of institutional environments.

Seeing compensable clients

Seeing clients who were within a compensation system was a recurring theme across therapist-participant narratives. As most programs accepted compensable clients from a variety of sources (motor accident insurance, workers' compensation insurance), they noted the effect not only on program participation, but also on the clients and their families. Non-compensable clients were funded through the Federal Government Medicare system. Compensable clients, however, often had to wait a long time for approval through their compensation organisation, as pain program costs were significant (>\$5,000). Therapist-participants overall saw that being within a compensation system was negative to the success of pain management. They found that often it was not until an active claim was settled that the person could move forward in pain management.

B. Victimic

Being a barrier to good pain management

Within her program, Alison perceived receiving compensation as the number one barrier to self-managing pain. Although compensation organisations provided funding to attend pain programs, it was usually with the assumption that the person would improve and ideally be ready to return to work. But improvement was not in the clients' best interest if they were expecting a large compensation settlement:

I can see that it's really not in their best interest to improve. Particularly if they have a comp[ensation] claim in and they're waiting for a pay-out. As the OT I would say that is the number one barrier that I find to good management of chronic pain. When people have that in the back of their mind, then it's very hard for them then to focus on what we're trying to achieve here. And some people actively come out and say that. And for some people \$5,000 is such a huge amount of money, that we sort of can't blame them in a way, if they're feeling anxious about that.

Being in the system

Leah provided a thoughtful commentary on what she saw as the influence of compensation upon client's progress. She saw the influence of the "system" as taking away people's autonomy when they became reliant on benefits. She also saw that the system placed enormous constraints on what people did, which affected them psychologically.

I think it's profound, the influence of the system. On the one hand it's profoundly conflictual. On the one hand people wouldn't be able to undertake programs without it because most people have lost their livelihood, or their families are under enormous strain and there are not the resources to support them to go to private treatments. So it's a lifeline. On the other hand, the constraints that are built into that system are often very undermining of the person's ability to feel like they're autonomous, and like they have some self-efficacy. They are feeling scrutinised pretty well all the time and therefore not free in themselves to do what it is that they feel they might want to do. And all of that means that people are exceedingly vulnerable. And all it takes is an uncooperative employer. That, or a very pushy insurer. Or, one or two visits to one of the insurance doctors where the doctor has very little empathy and is unable to give feedback to the client, but basically treats them like a number or a piece of shit. A lot of people are devastated by that stuff. And psychologically it's a very powerful negative weapon held up against them all the time.

Having English as a second language

A factor that did not emerge in PMP participant narratives (there were no non-English speaking participants) but featured particularly in therapist-participant narratives in metropolitan areas concerned clients with English as a second language (ESL).

A. Agentive

Needing an individual approach

Therapists found that a standard program did not cover the needs of this group. Kristine found that working individually with clients with ESL was more effective than a group-based approach. She could cater for this need within her pain practice:

I mean with groups there is that nice dynamic thing that can happen. But I think, in M [city], the difficulty with pain groups is that you get so many people who don't have English as their first language and those people can miss out. They might not miss everything, but they'll miss some things. So I think, for M [city] populations, individual stuff is probably the best.

B. Victimic

Being a challenge to explain pain concepts in another language

One of the practice challenges noted by participants was how best to impart educational material to people with ESL. Patricia found the

concepts of chronic pain difficult to translate to another language and culture. She needed to simplify what she normally would do and take a more general approach. She admitted she and her colleagues were still finding out what methods were useful:

I've been working quite a lot with a very large population of people where English is a second language. And that very structured approach, when English is not your first language, is just sometimes too difficult. The concepts are too complex, so with some of those clients I'll just talk more in general concepts. And we're still really learning what helps.

Seeing the influence of other health professionals in the community

Therapist-participants raised the issue of having a client population who often consulted a range of health professionals. This was considered to have positive and/or negative aspects, depending on the type of therapeutic relationship and the professionals' approach to chronic pain management.

A. Agentic

Having health professionals supporting pain management

Liz, who worked as the sole therapist on her individual program, recruited other health professionals from the community to assist with various aspects, such as counselling, for her clients. She described a case where working with a psychologist was beneficial for her client.

Now at this point, he's [client] actually made a lot of progress and we're looking at working with a psychologist on desensitising him in using the bus for public transport. So that was really useful, we had a joint session the other day with the psychologist. And we've negotiated for him to see her on 2 days a week – Monday and Friday. And he'll come by train to see me on a Wednesday, and we'll start to work on the desensitisation using one of our buses here.

B. Victimic

Being told "it's all in your head".

The messages provided to clients by health professionals were usually perceived as negative, contradictory or ambivalent. This often had to be worked through with clients by therapist-participants when they came into pain programs. Patricia reported that many of her clients were told that the

pain they were experiencing was psychological or imagined and did not include a physical component. She thought that validating the person's experience of pain was important for them to move forward:

The messages that I invariably hear from my clients in my initial interview with them is that they often feel as though they have been disbelieved. They often feel as though people are annoyed, or angry with them. Or, that if they just tried harder these problems would go away. So, one of the things that I've always thought was important, I guess it's the way I've always worked as an OT but certainly this type of work is just reinforcement, that these people need validation that the experience is real. I guess the other big message that they've always had is that "it's all in your head, the pain isn't real".

Reinforcing treatment seeking

Marie found that doctors also reinforced passive treatments rather than active strategies in an attempt to treat the pain rather than advocate pain management:

I think some of the medication-seeking behaviours and stuff is reinforced from the doctor, "Well if you feel like you're not managing then I can give you this" or "Poor you" can kind of feed into it and it's that health kind of adage, "We really want to help people, only pain's an awful thing and if someone comes to me then obviously I'm going to want to get rid of their pain". And that's kind of what health professionals like to do. But in chronic pain, I mean it's something that's not going to go away. We need to manage it rather than seek treatment for it.

Being at the mercy of health professionals

Leah acknowledged that the clients she saw were often "at the mercy" of health professionals when seeking pain intervention, due to personal fear and the contradictory messages they had been given:

Because I think many people who are still confused and have had multiple explanations of what's going on by the multiple professionals that they've seen, are fearful because of their pain and they're fearful because they've got lots of different ideas from lots of different people about what's going on. So they're really lost and at the mercy of people, if you like – people like us.

Having a therapist-client relationship

What the therapist brought to the therapeutic relationship within the various pain programs was considered important. How they worked with

clients depended on their level of experience, type of program and personal approach.

A. Agentic

Having rapport

Patricia found that establishing rapport with her clients was a critical factor for them to take on board the pain management message.

It's made me realise how much, with my clients, I invariably built a rapport and a relationship as part of my approach of educating and encouraging and supporting. It's my challenge to build rapport with that person to find one thing, at least, that you connect with people about. If they don't like you they won't hear the messages.

Kristine also found "rapport incredibly important". She tended to "use a lot of humour" in her approach to people.

Being a motivator for change

Marie saw herself as a powerful motivator for change in enabling people to adapt what they did every day to manage pain and overcome their fear of activity:

So, I think we can be a powerful motivator, in terms of just helping people to believe that they can do these functional things. Because often that belief's been trampled on by lots of failures. "I tried it this way and it didn't work so I'm not going to do it again because that will hurt". And I think, as an OT we go, "Yeah, that hurt", but we can be adaptive when we go, "Right, let's have another look at this task and see what we can do differently".

Being an explorer

Leah used the term "being an explorer" to describe how she worked with clients to find out what was possible for them. This involved her and the client working in a team:

So it's not me telling him what's wrong. It's not me assessing him and finding out all the faults; we're sort of exploring. So, if anything, it's like being an explorer with somebody; you're on an expedition and you're in the team. That's what I say to people: "We're a team, we're going to work together with this – I don't have all the answers so we're going to find them together".

Being a coach

Liz saw her role of therapist as being a coach to the clients she saw in practice. This was achieved by providing a range of strategies that applied to the person's life:

I take an approach where I talk to the person about me being their coach to help them to understand more about their problem. And the aim is, by the end of the 10 weeks, that they've developed a range of tools. So I'm teaching them to coach themselves.

B. Victimic

Reinforcing pain behaviours

Matt had found in his experience that occupational therapists who did not understand the self-management message could often reinforce pain and pain behaviours by prescribing adaptive equipment. Although adaptive equipment had proved useful for some PMP participants, Matt saw it as inadvertently reinforcing disability:

If we're giving someone a long-handled device to help them, so that it's easy for them to bend, what is the thought process going on in their head? Are they thinking – and patients have told me this – that “The OT [occupational therapist] gave this so I didn't have to bend”. “Why shouldn't you be bending?” “Oh, because if I bend my back's going to break” sort of thing. Are we sending the right message by giving that sort of equipment?

Using individual versus group approaches

The merits of individual versus group programs were discussed at length in most therapist-participant narratives. Some therapists had worked in group programs but now worked individually, whereas others had only ever worked in group programs, and thus their experience was different.

A. Agentic

Being flexible

Louise worked in a program that could provide both individual and group elements for people. She found that this flexibility enabled her to tailor programs to individual needs:

So there are some group aspects to the individual program, but they are people who I've seen individually. They may go to some groups and not others. They may be seen individually,

and then eventually they're put into a group. So there's a lot more flexibility in our approach.

Liz saw some people who were not suited to a group program and preferred “one-on-one sessions”. She was able to provide “very specific techniques... rather than a general approach” in her current practice:

Getting the group mix right

For those who had worked within group-based programs, getting the mix of people right was identified as an important factor to facilitate pain management across the group. Most therapists reported that when a group worked well the benefits outweighed the negative impacts of group work. The ability to share “common” pain experiences and the “group camaraderie” were seen by Liz as some of the most valuable aspects.

Patricia saw the “power” and “energy” of groups something she missed now that she worked predominantly in an individual program:

But the downside that I really miss from groups was the power and energy of the group itself. For a lot of people it was really empowering; to meet other people who are in the same situation, to actually know that it wasn't just them. It was really when you had a great group dynamic going, it was fantastic – when people would actually encouraging, supportive, sharing ideas, gently challenging things that were unhelpful – all of that stuff, that was great.

Louise's program staggered the intake of group members over an 8-week period. Having clients at various points in their pain management along the program helped to provide positive role models for others:

But what we found is that it's really a very, very useful measure because clients learn from people who are further along in that pain management journey. And so, you know, instead of having eight people who are all in pain and all angry in week 3, we've got someone in week 3 who's angry, but someone in week 8 says, “You know, I remember back there, just hang in there”, so we actually get a lot from that process. And we find that there can be some really good models within the groups themselves rather than the therapists who are always coming up with the strategies.

B. Victimic

Having one set approach

Some therapists worked within group programs with a set structure. While they thought that group programs had their merits, the inability to spend time with people individually was seen as a drawback. Marie noted that in

her group program some people would get more out of it than others, as individual needs were different:

So it's not a one size fits all, even though it's a group kind of program. Some people need different aspects of it, more than others. So some people are pretty good problem solvers; that activity-wise they're doing pretty well. They're still working and they're still managing their daily tasks. Yes, they're difficult and yes, it's painful, but the depression side and stress might be through the roof. So they're going to get much more from the psych component of things. Yeah, they'll pick up a few sort of practical things, but not as much as someone who's spending all day, every day, in bed. So, although the basics of chronic pain are very similar for everybody, everybody is still quite different.

Seeing the group as a "box of chocolates"

Alison compared groups to a "box of chocolates". You were never quite sure of what you were going to get! In her 3-week inpatient program it often took only a few disruptive people to upset the dynamics of the group when being constantly together:

It's a box of chocolates... that's right. And it usually, comes back to one, or two personalities in any group as to how well it will work. Often the people who are most disruptive are the ones who won't join in with the exercises as required and they will come very late to sessions. Some of them will have their mobile phone on and they'll get up and leave sessions – that kind of thing. With 10 people living together for 3 weeks anything can happen, and anything does.

Having post-program follow up/refreshers

Following up clients after program completion did not occur across all pain programs. Therapist-participants who did not follow up cited lack of time and staffing issues, although ideally they thought it was important. For those who did follow up clients, a formal process was generally in place within their programs.

A. Agentic

Having formal reviews of clients

Elizabeth detailed the formal procedures in her program that actively monitored clients for a 1-year period. This time frame was seen as beneficial to address any emergent issues.

And we have the three formal follow-ups, so basically we say to people “You’re actually engaged to us for 12 months”. Well they come in for their 1 month, 6 month and 12 month, but if at any stage any of them hit the wall, have a problem, want to chat with me about anything, they’re very welcome to ring up and if we can we will arrange to see them.

Marie worked in a program that had a “review day” 10 weeks after program completion. She found this provided a “real litmus test” of how people coped on return home in terms of “managing their life better and reducing the impact” of their pain.

Having refreshers

The use of “booster programs” or “refreshers” was seen as a valid tool to maintain clients’ pain management post-program completion. These refreshers could take the form of single sessions or short programs to review clients who were having difficulty in ongoing pain management. Louise’s program saw people “come back for refreshers, years... or even months” afterwards. She found she had to be clear on their motivation for returning and also “what would make it more likely that they would continue the self-management” post-refresher. Patricia had found that follow-up was important to gauge how people were progressing in the group program in which she worked and whether they needed a “booster program” to maintain their pain management:

Three month, 6 months and 12 months evaluations we tried to do. We usually did quite well at 3 months, but at 6 months they were dropping. And so we developed some booster programs where people would come in for a 1-day booster program – which were fantastic actually. It was really good and I had a very big role in those.

B. Victimic

Having no review procedure in place

Matt stated that there were no formal review procedures in place in his program. Although clients might be reviewed medically at some stage, they were not seen again by the pain program as such. This was related to lack of resources and the demands of running programs continuously for up to 200 clients a year.

Hugely demanding on the therapists. It’s nonstop. I guess seeing 200 patients coming through a year, there’s very limited capacity for us, the in-patient allied health team, to follow up. Because you’ve just got that constant flow of patients and then

you're very focused on them while they're here. Once again, that's a source of frustration.

Being unable to offer refreshers

Some therapist-participants' programs had no capacity to have refreshers. Marie's program had offered refreshers but ironically no one had attended. The program was no longer able to offer these due to organisational constraints, although she thought they would be valuable:

I think there is no harm in refreshers, we've offered them before and nobody comes. It's hilarious. Because then they'll say, "Well, why are you not following us up, why can we not come back?" And whether it's just that our timing wasn't right. So you know, it's a challenge and I would like to do some more sort of out-patienty things... But with our waiting list, and our groups are full, and there's no time, and there's no space to run anything. So we're pushing uphill to kind of get that.

Community influences

Although some therapist-participants recognised the need for ongoing support for people with pain, this did not feature significantly in their narratives. Discussion centred on informal support networks established within their pain programs that transferred to the community. Also they considered how pain program environments needed to be representative of what people would encounter on return home.

Using buddies/support networks

A noted occurrence within pain program groups was the development of "buddies". Therapist-participants commented that some group members gravitated to others and set up support networks that remained in place after the completion of their programs. Most therapists saw this as a useful and natural progression for the clients with whom they worked.

A. Agentic

Having buddies/support networks

Elizabeth recognised the "ad hoc" nature of the development of buddies in the group program in which she worked. The uncontrived way this occurred promoted some groups to form strong bonds:

So a lot of the groups build their own sort of ad hoc support network. It might be two or three people who keep in touch with each other, it might be the whole group. Sometimes they email each other on a regular basis, so they often maintain their own little informal network. And some groups form a really strong bond, and you know it's going to happen, and other groups – it would be artificial if it happened.

Alison also found that clients reported informal support to be one of the best things about her program. She noted that support networks saw “some really good friendships gained”.

B. Victimic

Having support groups reinforce pain

As part of ongoing support for clients, therapist-participants were aware of community-based pain support groups. Therapists rarely recommended these groups to clients as they were generally equivocal about their benefits. Elizabeth and Louise had perceived their local support groups to be reinforcing of chronic pain and thus did not recommend them to their clients. Elizabeth had seen people become “very miserable and introverted” in one support group she was aware of. Louise had seen groups “divide to reinforce the [negative] behaviours” for “particular clients”.

Pain program environment

The environment refers to the physical surroundings of the program or practice. Several were based in hospital or clinical settings which could be seen as unrepresentative of settings to which where clients would return.

A. Agentic

Having the right environment to run pain programs

Having the right sort of environment was considered important. Louise felt she worked in a program that provided a therapeutic environment, as a range of activities could be provided or simulated: “We’ve got our own sorts of areas here, so we’ve got a kitchen. We’ve got a cleaning/laundry sort of area. We’ve got a garden, and we’ve got a workshop. And we simulate tasks as well”.

For therapist-participants who worked in individually-based programs, home visits to clients were seen as a useful way of teaching strategies in the actual lived environment. Patricia found this particularly useful compared to what she had previously implemented in group programs.

So a lot of the education, I'm doing at home. They are just sort of in situ-training in "How do you approach household tasks?" And I find it works really well to actually be looking at the tasks that you're discussing and "Let's try different body mechanics, let's try a little bit of different equipment to see if that helps", "How can you pace it better?" And invariably, in a home environment, I find people tend to be fairly open about their experiences.

B. Victimic

Having an artificial environment

Marie thought that the artificial environment of her hospital setting could develop dependency in some of her clients. She saw that the level of support provided in her program could be counter to promoting self-management.

It's a clinical, quite artificial setting that we run our program in. You come and you're staying in accommodation where there's no dishes that you have to do, and there's no family stress because you're not living with it. And it's usually about Wednesday of the last week, sort of half way through that they start going "Hang on a minute, I have to go home and I'm not going to be here with this nice supportive group of people who really understand me and who I've made good friends with". So look, I think there is a tension, and it builds up as they get closer. Some people are really excited by going home and trying all this new stuff and seeing how they will go. And others go "I just don't want to do it, I just want to stay here forever".

6.3 Summary

This chapter has considered the themes related to the self/person, meaning ascriptions, strategies, and external/social world factors that were identified in therapist-participant narratives. Therapists saw the complex interplay of these factors as having a profound influence on the outcomes of self-management for their clients with chronic pain. In the next chapter these themes are considered in relation to Chapter 4 (Introducing the participants) and Chapter 5 (PMP participant findings), where they are considered in relation to relevant literature.

CHAPTER 7: DISCUSSION AND IMPLICATIONS FOR THEORY AND PRACTICE

7.1 Introduction

The purpose of this study was to explore how people live with chronic pain on a daily basis, from the perspectives of people who completed a chronic PMP and therapists working in chronic pain practice. In particular, the following objectives had significance for this study:

- To explore how people live and do (perform) everyday activities with chronic pain post-attendance at a chronic PMP
- To investigate PMP participants' perspectives as to what influences long-term successful pain management
- To ascertain occupational therapists' perspectives of what predicts long-term successful pain management.

Narrative inquiry based on in-depth interviews was used to elicit data in the form of interview transcripts. Fifteen past-participants of a chronic PMP and nine therapist-participants consented to participate in the research. The themes that arose for both PMP participants and therapist-participants related to: aspects of the self or person, meaning ascription given to pain, strategies used to manage pain and impacts of the social world. In this chapter I discuss the findings from Chapters 4, 5 and 6, with particular reference to Chapters 5 and 6 in relation to the above questions. The narrative slopes of PMP participants in Chapter 4 are also considered relevant, depending on their dominant agentic or victimic features. The discussion section of this chapter centres on extrapolation of the findings that arose from PMP participants' and therapist-participants' narratives, with reference to relevant literature. Findings are compared and contrasted to identify differences and commonalities between the results for Chapters 5 and 6. By this process, definitive factors influencing chronic pain management in the long term are presented from PMP participants' and therapist-participants' perspectives. The second section of this chapter provides a synopsis of the findings and proposes conceptual models of factors influencing pain management or non-management. The

final section considers the implications of the findings for occupational therapy theory and practice.

7.2 Synthesis of the Findings

7.2.1 Introduction

The following discussion considers findings of significance that appeared from the in-depth analysis of the narratives. Most of the findings were apparent in both PMP participant and therapist-participant narratives, which showed a shared perception of factors that could influence long-term pain management. A few factors were unique to either PMP or therapist-participants only.

7.2.2 Self/person

7.2.2.1 *Having valued roles*

The immediate significance of having valued roles was identified in PMP participant and therapist-participant narratives. As the lead-in question in PMP participant interviews was “Tell me about the roles you have in your life”, it would be expected to elicit this information. However the significance of family, worker, volunteer and other social roles was reiterated by PMP participants and noted in therapist-participants’ narratives. For PMP participants, the rating of roles resulted in familial roles predominating, with worker and volunteer roles being seen as more important than roles of being a friend or hobbyist. Therapist-participants noted the significance of engaging in roles for their clients, and perceived that clients in their experience preferred to devote more time and energy to familial role enactment than to work and other roles. The importance of role, role enactment and performance has been noted by several authors (McKenna, Liddle, Brown, Lee, & Gustafsson, 2009; Unruh, 2004). Townsend, Wyke and Hunt (2006) found that negotiating illness and fostering actions that affirmed valued roles such as parenting allowed their study participants to assert control over their lives. Similarly, PMP participants noted that the agentic qualities of maintaining familial roles gave them satisfaction and a sense of place within the family (see Chapter 5, Section 5.2.1). For example, being a “hands-on grandmum” was seen

as a fundamental role for Alexandra to fulfil even when living with significant pain.

Worker roles for PMP participants who managed to return to work were seen as essential to their sense of identity, both personally and socially. The challenging aspects of work kept participants motivated and prevented them from relapsing/regressing. Hakansson (2005) similarly found that actively working was associated with a higher sense of wellbeing in the women studied, and was predictive of them valuing their worker role more highly than those on long-term sick leave. In case-study research, Unruh (2004) recognised the social value Western society places on the worker role. This was supported by findings from this study, where participants also identified how people could be judged socially, in terms of their employment status (unemployed/employed). McKenna et al. (2009), studying role participation following stroke, found that having more roles was correlated with greater life satisfaction. Thus loss of roles could impact on perceived quality of life. This was evident in PMP participants' narratives such as that of Ian, who noted how losing his worker role had resulted in other negative effects such as loss of friendships, and had contributed to his social isolation.

For some participants who were unable to return to paid employment, establishing or extending volunteer roles proved an effective strategy for worker "role continuity" (Hillman & Chapparo, 2002, p. 309) by allowing them to continue to provide others with a service of perceived social value. Ian and Will saw helping others as a way of reflecting pride in their community, and it enabled them to perform a role with perceived social value. These findings support the conclusions in Hillman and Chapparo's (2002) study of retired men post-stroke.

The importance of roles and occupations of meaning in the construction and maintenance of identity when living with pain has been explored in several studies (Reynolds, 2003; Sissel Alsaker & Josephsson, 2003; Townsend, Wyke, & Hunt, 2006). In a study of women with chronic illness, Reynolds found that engaging in artwork was pivotal in regaining a

positive identity. This was achieved by the person reconnecting with aspects of their pre-illness self and developing a new, reconstructed identity through participation in creative occupation. Creative occupations were also important to several PMP participants, such as Rosie who included these in her daily routine, and were also used by therapist-participants to explore the pain experience.

7.2.2.2 *Being responsible*

A common theme across PMP participant narratives was entitled “being responsible”. This theme encompassed being the oldest (which was directly related to six participants), being self-sufficient, and taking on leadership roles within the family. Social psychologists have studied birth order and oldest siblings, primarily with a focus on education level achieved and employment status. Research has also examined the psychological characteristics of older siblings, family relationships between parents and siblings and influence on sibling behaviour (Stewart, Stewart, & Campbell, 2001). Stewart et al. (2001, p. 384) noted that the first-born in families tended to have traits of “directing, leading, achieving and attempting to please”. Argys, Rees, Averett and Witoonchart (2006) found that oldest siblings were less likely to participate in risky behaviours and adopted more responsible behaviours than middle and younger siblings. These findings support the statements of PMP participants who were oldest siblings. They described the large amount of responsibility they had, not only for the care of younger siblings but also for the larger share of domestic tasks performed. Stacey noted how she had to mature “extra quick” when taking on parental roles for her younger step-sisters. This sense of being responsible appears to have carried positively into oldest sibling PMP participants’ later lives. For those who were not the oldest, being self-sufficient was related to independence. Dawn saw her self-sufficiency as a product of her rural upbringing and the culture of the WWII years when women had adopted more usually male-dominated roles. This had persisted to her later years, when she continued to carry out home repair maintenance as well as other domestic roles. Being responsible related to chronic pain management in that striving to maintain independence and self-sufficiency had been a trait manifest in PMP

participants' early lives. It was seen as a positive factor related to their view of self that had continued into later life.

7.2.2.3 Childhood abuse

Four participants shared a history of child and/or ongoing intimate partner abuse within their narratives. This was challenging for the researcher as the information shared at times was graphically depicted. For some of these participants there were ongoing, unreconciled feelings about the past and its impact on their current pain. Childhood and partner abuse has been highlighted as having a causal association to chronic pain in many studies (Engel, 1959; Nicolaidis et al., 2008; Raphael, 2005; Roy, 1998), although according to Raphael most studies were based largely on retrospective data from case reports. Raphael also found that due to small effect sizes it was difficult to draw conclusions about occurrence and clinical significance. The incidence of post-traumatic stress disorder (PTSD) and chronic migraine was explored by Peterlin, Tietjen, Meng, Lidicker and Bigal (2008), who found that the frequency of PTSD was significantly higher for those with chronic migraines. Nicolaidis et al. (2008) found that physical complaints such as pain were considered more significant for those with a history of abuse. They also found that abuse history, physical pain and depression had a compounding effect. Therapist-participants likewise reported that clients with a history of abuse had ongoing, physical and psychological issues.

For PMP participants who experienced either childhood or partner abuse, the victimic features of their narratives were apparent. For Julia and Rachel in particular, being unable to "change the past" had a continuing impact on their lives, highlighted by a lack of self-management strategies. Sara moved away from her home and previous life to make a "new start" that she acknowledged was difficult. Rosie felt that she gained little if anything from the PMP and had returned to previous ways of managing her pain, including fear avoidance.

7.2.2.4 *Having depression*

Depression was frequently reported in PMP participant narratives. Therapist-participants also noted depression to be commonly associated with chronic pain in practice. In interviews, PMP participants who had experienced depression were asked if it preceded their chronic pain or developed after their injury/condition occurred. Most PMP participants replied that their depression had occurred after the onset of chronic pain, with only one participant reporting a previous history of depression. When depression was present, chronic pain was reported as exacerbated and motivation decreased. Extensive literature has identified mental disorders such as depression as being “antecedent, a consequence of or a common co-morbid complication of chronic pain” (Nicholas, 2007, p. 231). A prevalence study of chronic pain in Australia noted that chronic pain was associated with high levels of psychological distress (Blyth et al., 2001). In a systematic review of the pain literature, McCracken and Turk (2002) found that high levels of psychological distress were associated with poorer treatment outcomes. Similarly, in a comprehensive review of literature on work-related injuries, Lee (2010) determined that a combination of biological, psychological, social and vocational factors led to the development of depression. Nicolaidis et al. (2008) identified a consistent relationship between intimate partner abuse and depression along with other co-morbidities such as substance abuse. Thus the combination of chronic pain and depression is common.

Therapist-participants noted that clients presenting with depression often had more complex needs than those without. Having depression made pain more difficult to bear for PMP participants and reduced their motivation to engage in everyday activities. The degree of depression was also considered a significant factor in how well people could participate in pain programs. Those with severe depression required additional support, such as seeing a psychologist and/or taking a course of antidepressants, prior to undertaking pain programs. Therapist-participants noted that people with low or moderate levels of depression could actually benefit from being part of an active management program. A recent study of an interdisciplinary chronic pain program supports this. Oslund et al. (2009)

found that interdisciplinary care resulted in lower levels of emotional distress at 6-month and 1-year follow up. They did, however, note the need for continued follow-up care to maintain the psychological gains.

Nicholas (2007) recommended treating both chronic pain and depression within PMPs. This was supported by the therapist-participants, who reported using various psychological and activity-based strategies to assist their clients manage pain and depression. Several therapists had observed that engaging in activity and having a structured routine sometimes provided the impetus for depression improvement. Finding that clients could return to valued occupations was a first step in regaining some self-control. Most PMP participants found that staying out of the “black hole” was an ongoing and at times difficult process. Strategies such as keeping busy and being positive were useful in managing this. A few PMP participants continued to take anti-depressant medication as they could not manage their depression using psychological or activity-based strategies alone.

7.2.2.5 *Being in control*

Being in control referred to how PMP participants saw themselves in relation to their chronic pain. Several participants found that pain had dominated their lives and prevented them from doing things they wanted to do. For some participants, pain had deflated their sense of self for a considerable time, but being able to manage pain had given them a sense of personal agency. Perceived control for PMP participants was related to having power over and being in charge of pain. For the therapist-participants, having personal control was identified as an important factor for clients with chronic pain.

Brown (2003) surveyed occupational therapists and service users (clients) about the elements of pain programs they believed were significant in contributing to control. Service users scored “outpatient programs, lifestyle counselling, access to print/tape information... use of analgesics and transcutaneous electrical nerve stimulation (TENS)” (p. 1121) as the interventions most significant in pain control. Occupational therapists

tended to score all interventions as important, with education, medication review, psychological assessment, pacing and relaxation rated most highly. Ongoing support, access to information, and analgesic use were also noted in PMP participant findings as significant. The therapist-participants in this study also considered practical strategies such as pacing and relaxation as essential elements of their treatment programs, consistent with the findings of Brown. A randomised control trial of people with temporo-mandibular joint pain found that perceived pain control was a significant mediator of treatment effect using CBT approaches (Turner et al., 2007). Two randomised clinical trials of CBT for fibromyalgia by Goosens, Vlaeyen, Hidding, Kole-Snijders and Evers (2005) showed that treatment expectancy using CBT methods was related to personal beliefs in “better pain coping and control” (p. 24). Thus, if CBT was anticipated as of benefit to the person, the likelihood that it would assist in controlling pain increased. PMP participants such as Stacey and Maree, who were ready to do the PMP and expected that their pain self-management would improve, continued to maintain control using various methods including CBT in their daily lives. Personal control was thus viewed as an agentic factor relating to self in maintaining chronic pain management. Others such as Julia, however, were unable to use methods from the PMP and manifested an external locus of control where victimic factors dominated.

7.2.3 Conclusions from Section 1 – Self/person

For both PMP- and therapist-participants, factors related to the self, including familial, worker and other roles and occupations and meaning related to these, were seen as important. The importance of being responsible and self-sufficient was also prominent across several PMP participants’ narratives. Having depression and experiencing abuse often created ongoing difficulties in achieving pain self-management. Having control over pain in relation to self was aspired to and valued, although not achievable for all PMP participants. It was seen as a mitigating factor to management by therapist-participants.

7.2.4 Meaning Ascriptions

7.2.4.1 *Readiness for change*

“Being ready” was a universal theme in both PMP and therapist-participant narratives. Being ready alluded to participants’ willingness to undertake the PMP and it being the right time to participate. This usually meant that PMP participants had explored most other avenues of pain intervention and management techniques and were at the stage of thinking that the PMP would provide some benefit. Therapist-participants found that clients’ readiness to participate in their programs or interventions was also critical to how well they managed their pain. Therapist-participants interpreted being ready as clients being prepared to adopt pain management methods and changing their thinking about pain. Both therapist and PMP participants found that actually considering or actioning change was important.

As described in Chapter 2, readiness for change has been the subject of significant quantitative analysis in chronic pain research. Measures such as the Pain Stages of Change Questionnaire (PSOCQ) (Kerns, Rosenburg, Jamison, Caudill, & Haythornthwaite, 1997) have been proposed to determine whether an individual is at a stage of contemplating change. Contemplation of change has been found predictive of actual change in a number of studies (Biller et al., 2000; Kerns & Rosenberg, 2000). Studies have shown that contemplating change and actioning change are related to lower pain severity, decreased disability and depression and increased goal achievement (Hankin & Killian, 2004; Kerns & Rosenberg, 2000). Jensen, Nielson, Turner, Romano and Hill (2003) found that action and maintenance scores on the PSOCQ were related to increased use of coping strategies to manage pain, and Xu et al. (2007) found that return to work for injured workers with chronic pain was significantly predicted by their scores on a readiness to change indicator.

Being ready for PMP participants was related to taking on board the pain self-management message from the program. Stacey and Maree reported being ready to be better and continued to actively use strategies to that end in the long-term. For those who had not known what to expect from

the program, such as Rosie, actioning change failed to occur in her daily life, where she reported continuing to struggle to manage her pain and her fear of falling.

Although being ready was seen as important, over time most PMP participants had adopted their own methods to manage pain. Therapist-participants commented on clients they had seen years later, who had not been ready to change at the time of program attendance but had adopted strategies in the long term. Different stages of change may require different approaches and interventions to engage clients in the change process (see Pain as process, Section 5.3.1.3). Although it therefore appears important to consider stage of readiness as a mitigating factor in pain program success, management of pain was seen by participants as ultimately time dependent.

7.2.4.2 *Acceptance*

Acceptance of the long-term nature of chronic pain and the ability to continue activity while in pain was another recurrent theme in PMP and therapist-participant narratives. Acceptance has been defined as “a willingness to let thoughts, experiences and sensations be as they are in the present moment, whether pleasant or unpleasant and neither change them nor act on them” (Lunde & Nordhus, 2009, p. 296). Margaret learned to live with her pain, “accept it and move on”, which was one of the most valuable aspects she had gained from attending the PMP. Other PMP participants such as Willie had accepted the presence of chronic pain over time, but with regret. Therapist-participants noted the perceived difficulty many of their clients experienced in arriving at the point of acceptance. Elizabeth and Patricia considered that acceptance that pain would be a “permanent factor” in a person’s life was required before change could be actioned. They also saw the importance of the individual taking responsibility for acceptance and change, and how difficult this could be when contemplating a future with unremitting pain. The interwoven nature of acceptance and readiness for change were seen as contingent in several therapist-participant narratives.

Acceptance and value-based action are the formative tenets of a “third generation” of psychological approaches which include acceptance and commitment therapy (ACT) (Hayes et al., 2006, p. 3) These methods have been applied to a number of conditions including chronic pain management. “Acceptance and mindfulness-based interventions” (Hayes et al., 2006, p. 3) aim to provide flexible change strategies rather than the extinction of negative behaviours. Vowles and McCracken (2008; 2010), evaluating the use of a contextual-acceptance-based approach, noted the importance of people realising that pain does not prevent activity and that choosing to do valued and meaningful activity in spite of pain is possible.

The value of acceptance-based methods in improving activity engagement and wellbeing has also received significant research attention (McCracken, 1998; McCracken & Vowles, 2006; McCracken, Vowles, & Eccleston, 2005). Accepting pain and its presence in activity performance may appear contrary to CBT methods (Turk et al., 1983) of negating painful thoughts, challenging pain beliefs and avoiding talking about pain. For some PMP participants, however, elements of both methods appeared to have been useful to change thinking about pain and subsequent management in the long term. Stacey, Margaret and Maree accepted their pain but continued to use strategies “to alter the form or frequency of maladaptive thoughts” (McCracken & Yang, 2006, p. 142), such as avoiding pain talk (Stacey), challenging negative beliefs (Maree) and not dwelling on the pain (Margaret). In a case study by Lunde and Nordhus (2009), the use of CBT and ACT improved sleep quality and acceptance of pain after 8 weeks of pain intervention for older adults. Other researchers have noted the use of contextual CBT methods which have elements of traditional coping approaches. These also include psychological flexibility by promoting acceptance, value-based action and cognitive diffusion, “a process entailing change in the influences exerted by thoughts without necessarily changing their form or frequency” (Vowles & McCracken, 2010, p. 141). Being flexible in adopting psychological methods of thinking about pain may prove to be a more reasonable approach, particularly for people who find CBT methods prescriptive. This was evident in Bill’s and

Willie's narratives, where the CBT approaches they experienced were seen as repetitive and formulaic.

7.2.4.3 Pain as process

Both PMP- and therapist-participants used the term "process" to describe the way people with chronic pain progressed from being debilitated by pain to being able to self-manage it. PMP participants such as Stacey and Maree talked about the "long process" of being able to manage their pain. Stacey acknowledged that she had to do it "all herself", and Maree had lived "hour by hour then day to day" before being able to see the positive aspects of her life. The narrative slopes (life trajectories) (Kielhofner et al., 2008) of PMP participants reflected where they were in the chronic pain process. Those who maintained stable or upward trajectories were moving forward in their pain management. The temporal aspects of moving forward in pain management were unique to each individual and were recognised by therapist-participants such as Marie as moving "from a patient to a person that lives with pain". Other therapist-participants such as Louise noted that the variety of different programs their health services offered enabled them to cater for where the person was "in the process", whereas those practising alone often felt that people came to them far too late to be able to effect change in the process.

Peolsson, Hyden and Satturlund Larsson's qualitative study (2000) found that living with pain was a dynamic learning process. Their participants described pain that was initiated, worsened and alleviated over a course of time. The participants developed learned behaviours around being sensitive yet flexible towards changes in pain and environmental triggers. This was seen as necessary in order to negotiate balancing their "internal resources and environmental circumstances" (p. 114) in their management of pain. A similar study by Richardson, Ong and Sim (2006) identified a dynamic relationship between thinking, responding and managing chronic pain. Participants in that study were optimistic, pessimistic or uncertain with regard to their pain. This influenced the cognitions and meanings they attached to their pain. The authors noted that chronic pain was characterised by uncertainty about the future and whether pain would

always be present. By accepting the ongoing nature of pain people were also placed in the difficult situation of recognising that it would therefore be a part of their future.

A focus group study of clinicians working in chronic pain explored themes related to the clinical encounter and how they influenced successful rehabilitation. Bullington et al. (2003, p. 325) used the term “meaning out of chaos” to illustrate the process of clients moving through diagnosis towards heightened self-awareness and finally taking responsibility for self-management. In the present study, PMP participants who appeared to have moved through the process were at a stage of active self-management. Some PMP participants, however, became stuck in the process when unable to accept the life changes that had occurred, persisted in looking for a cure for pain, or had significant ongoing depression. The narrative slopes of these participants were characterised by downward trends or by oscillations, depending on their prevailing mood and recent past events. Therapist-participants also saw clients who were stuck in the process. Patricia described the two extremes of behaviour she witnessed in practice. These extremes were either people “pushing through the pain”, denying it existed, or people who were fearful of pain and activity, leading to fear avoidance. Miles, Curran, Pearce and Allan (2005) described the process people went through to maintain “a normal life through constraint” (p. 431). They reported that for some of their qualitative study participants, pain was “confronted” (p. 431) when constraint was rejected in favour of preserving pre-pain activities despite increasing pain. When pain was “subverted” (p. 431), people minimised pain by avoiding activity or significantly constraining what they did. These typologies would fit with those noted by Patricia within her practice. Moving forward or getting stuck in the process was therefore contingent on time, activity level, aspects of the self, and thinking about pain.

7.2.5 Conclusion for Section 2 – Meaning Ascriptions

Meaning ascriptions applied to chronic pain influenced how self-management progressed for PMP participants and therapist-participants’ clients. Being ready to change, actioning change and accepting the long-

term nature of pain were considered important although difficult to achieve for some. Findings from this research would suggest that flexibility in psychological approaches applied to pain management would be more inclusive of individual needs. This would also involve taking into account where the person was in the process of pain management, based on their narrative slopes.

7.2.6 Strategies

This section details the strategies PMP participants used in daily life and those that therapist-participants advocated as part of their chronic pain practice. Although some strategies were not uniformly taught across all pain programs, others such as goal-setting, education, resumption of activity/engagement in occupations of meaning, pacing, exercise and psychological approaches were commonly used. Occupational therapists utilised strategies which were inherent to chronic pain practice and were relatively uniform across Western chronic pain programs. It was acknowledged, however, that the effectiveness of these strategies had often not been evaluated by therapists and indeed, as pointed out by Matt, often lacked an evidence base.

7.2.6.1 Goal setting

Goal setting was commonly used across therapist-participants' programs and was a strategy used extensively on the PMP. PMP participants were encouraged to set short-term and long-term goals and to continue to do this after program completion. Setting "little" goals was seen as a way for PMP participants like Maree and Ian to resume daily activities and begin to deal with overcoming severe depression. Some PMP participants, however, such as Julia, had learned goal setting but were unable to apply it to their daily lives. Therapist-participants based goal setting around increasing activity level, pleasurable activities and making future plans. They used tools such as the Canadian Occupational Performance Measure (COPM) (Law et al., 1994) and the Goal Attainment Scale (GAS) (Kiresuk et al., 1994) to facilitate this in their practice. Most found it a valuable strategy for their clients. One therapist (Matt) noted the lack of evidence to support the use of goal setting, based on activity level alone.

A study using the Goal Attainment Scale (GAS) (Kiresuk et al., 1994) as a way of evaluating a 3-week pain management program found that gains made were maintained from discharge to 6-month review (Fisher & Hardie, 2002). Goals set related to daily activities such as cooking and studying. Fisher and Hardie also noted a correlation between GAS and increased walking and improved scores on a disability index.

Filoramo (2007) evaluated therapeutic goal setting and reported that setting measurable, achievable goals was advocated for people with chronic pain. Goals set had to be concrete (such as walking for 5 minutes) and had to be accompanied by a personal belief that they were achievable. Goal attainment was seen as providing personal satisfaction and direction for maintaining improvement. This was evident in Maree's narrative, when goal attainment led to further goal setting and satisfaction at being able to resume valued activities. Davis and White (2008) used goal setting and attainment in a pain management program for older adults with arthritis. They found that over a 4-month period 13 of the 17 participants attained or exceeded their goal as measured using the GAS. The researchers observed that achieving goals was related to being a better self-manager of pain. PMP participants such as Julia, who could not apply goal setting, were dependent on others and used more medically-based pain management interventions rather than self-management.

In an extensive review of evidence-based studies, Brown and Pinnington (2007) found limited evidence for a number of chronic pain interventions used by PMPs. Dealing with the "contextually diverse nature of chronic pain treatment" (p. 56) confounded research into treatment method efficacy. This finding would support Matt's assertion about the effectiveness of goal setting. The variety of different methods of goal setting used across programs and in practice made judging successful outcomes difficult even when using goal-specific outcome measures. The lack of a standard approach to goal setting, use or non-use of activity baselines and methods of delivery would make it difficult to research empirically between programs. Although goal setting was used by most

PMP and all therapist-participants, its effectiveness varied depending on the person and the program. Overall findings from this research support the use of client-centred, activity-based goal setting.

7.2.6.2 Education

Education about the current understanding of chronic pain, psychological methods and strategies occurred in some form in all therapist-participant chronic pain programs. Patricia, an experienced occupational therapist, saw understanding the nature of chronic pain and its impacts as a “primary factor” in chronic pain management. PMP participants had daily education sessions about chronic pain and self-management methods. Although creative methods were used to conceptualise chronic pain and its management in an understandable way, therapist-participants noted that some concepts were difficult for some people to understand. Matt saw the “systemic issue” for occupational therapists who did not work directly in pain programs, who lacked an understanding of chronic pain processes. In a quantitative analysis of pain-related knowledge, Mosely (2003) found that therapists untrained in pain neurophysiology had poor understanding of pain mechanisms. He also found that health professionals tended to underestimate the ability of their patients to understand pain-related information. He found that psychologists in particular may exclude “currently accurate information” being “incorporated into management” (p. 188) if perceiving a lack of clients’ understanding. A systematic review of primary care practitioners (GPs) and their patients found that although GPs thought pain education was important, they believed their patients were not motivated to act upon it (Parsons et al., 2007). Patients, on the other hand, stated that they listened to their GP’s advice but it was often unclear and could not be applied to daily life. PMP participants such as Rosie said that although “a lot of good information came out of it, it still didn’t help me to sleep any better”. This frustration at being unable to apply theory to real life was evident in several PMP participant narratives.

Martensson and Dahlin-Ivanoff (2006) studied participants in a chronic pain rehabilitation program and found that dissatisfaction with the program was related to theoretical sessions being too long and too extensive, with insufficient time to integrate the new information into their chronic pain

management. PMP participants on program had been provided with a large amount of information. Only a small proportion continued to refer back to this regularly. Henrotin, Dedraschi, Duplan, Bazin and Duquesnoy (2006) conducted a systematic review of the value of providing written information to people with low back pain. Their review of randomised control trials, longitudinal and survey research indicated that providing written information did increase people's knowledge but did not equate to a reduction in health care costs in the long term. They found that information commonly utilised in chronic pain programs was mostly in booklet form. Some evidence was found that the use of booklet information increased exercise adherence. This was confirmed by PMP participants such as Stacey and Dawn, who continued to refer to the "bible" of information provided by the PMP to check that they were continuing to use strategies effectively. Although not evident in therapist-participants' narratives, available research indicates that education into pain mechanisms and management needs to be presented in a comprehensible yet concise way that meets the diverse cultural needs and literacy capacities of clients attending pain programs.

7.2.6.3 Finding different ways of doing something meaningful

"Finding different ways" refers to PMP participants' abilities to resume activity and participate in valued occupations despite chronic pain. While some participants no longer undertook certain activities such as sport, these were replaced by hobbies and other interests. Finding different ways involved any of the following: using equipment, using correct body mechanics and applying pacing. Therapist-participants described their methods of engaging clients in meaningful occupation, including doing something meaningful, problem solving around activity, using adaptive equipment, and pacing activity.

Studies have identified the impact of chronic pain on the performance of daily occupations (Aegler & Satink, 2009; Fisher et al., 2007; Keponen & Kielhofner, 2006; Satink, Winding, & Jonsson, 2004). These studies have highlighted the complex relationship between the person, the pain, activity and the environment. Satink et al. studied the process of resuming

occupations after examining the narratives of seven participants with long-term pain. They found that people tended to ignore the pain and continued to engage in daily and social occupations. As the pain continued, however, people withdrew particularly from social situations, as isolating themselves meant they had the resources to manage their pain. At process end several of their participants had accepted pain and resumed activities, albeit in a different way; that is, by taking frequent rests and doing things more slowly. This was also reflected in several PMP participant narratives. In a cross-sectional study by Viane, Crombez, Eccleston, Devulder and DeCorte (2004) acceptance was also characterised as positively related to activity. They found that acceptance was related to increased engagement with daily activities and higher motivation and self-efficacy to perform daily activities.

A qualitative phenomenological study by Fisher et al. (2007) explored the reciprocal relationship between chronic pain and occupation. Their participants engaged in preferred activities while avoiding those that aggravated their pain. Several PMP participants had also altered the activities they performed. Some avoided heavy activities such as digging in the garden and vacuuming, seeking assistance from others. Other strategies participants in that study used included novel adaptive responses such as taking more time, shortening activities, using correct body mechanics and assistive equipment. Again this was reflected in PMP participant narratives. Dawn had altered her way of gardening and used a “skateboard on wheels”. Bill used a pick-up-stick which he acknowledged was “wonderful”; Stacey used a “body technique” to perform activities using correct biomechanics.

Therapist-participants such as Matt were ambivalent about the prescription of adaptive equipment. Matt saw it as reinforcing the use of compensatory measures rather than re-engaging in an activity. He felt that occupational therapists inexperienced in chronic pain management overprescribed equipment, contradicting the concept of self-management. It is my view, on the basis of findings here, that being independent or active with equipment (while context-dependent) is overall an agentic factor.

Aegler and Satink (2009) focused on how people performed occupations with chronic pain. In their qualitative study they found that the people wanted to engage in occupations because of the meaning attached to them. Alterations to activity were also noted in the theme that emerged of “taking breaks is not easy” (p. 49), which described how their participants had to stop tasks periodically before starting them again. This was echoed in several PMP participants’ narratives which described slowing down and using pacing as difficult. The theme of the “challenge to finish performing” (Aegler & Satink, 2009, p. 53) related to their participants’ desire to work through the pain when engaged in pleasurable activity. PMP participants such as Alice chose to engage in meaningful occupations even though pain was present, so that she did not miss out on the enjoyment.

PMP participant Rosie found that sewing had become “like therapy”. She looked forward to sewing once her daily chores were completed and felt the concentration required had a calming effect. Reynolds, Vivat and Prior (2008) concluded that engaging in leisure-based arts and crafts was “manageable within the constraints of ill-health” (p. 1279). They noted that art and craft making increased subjective wellbeing by increasing feelings of satisfaction, hope for the future, and social contacts. Rosie valued the sewing group in which she participated once a week, although she did not actively seek out other social contacts. Therapist-participants had also observed the therapeutic effect of art and craft making. Elizabeth used an art session within her program to help program participants find another way of expressing their pain. Other therapists had used creative activities within programs to re-engage their clients with leisure activities, particularly when returning to work was not a priority.

Keponen and Kielhofner (2006) examined the narratives of 17 women focusing on the meaning of occupation in their lives. They found that women used metaphors to describe how they problem solved around occupation. They identified themes of moving forward, slowing down, fighting and standing still (p. 214). The themes related to where their participants were in the pain process and were characterised by an uncertain view of the future. In a study of people living with chronic

rheumatic disease, Alsaker and Josephsonn (2003) also found that meaning pervaded the everyday activities of their participants. Being able to continue to engage in doing everyday things was linked to a sense of performing well to engender feelings of mastery. Their participants used strategies to ensure they could continue to perform valued activities even in the face of diminished capacities. PMP participants likewise gained satisfaction from being able to engage in work, home-based activities and hobbies that had personal meaning.

The parallels between the themes presented by Fisher et al. (2007), those of Keponen and Kielhofner (2006), and that of meaning related to doing (Alsaker & Josephsson, 2003) are significant when related to the agentic and victimic factors noted in PMP- and therapist-participants' narratives. Doing meaningful things was stated by Bill and Rosie to be an important part of their day. Gaining satisfaction from doing relates to moving forward in the process of pain management. Several participants found using pacing and slowing down difficult but necessary. Sarah noted that slowing down was a "major bugbear in [her] life". Her feelings of ambivalence relate to the theme of "slowing down" noted by Keponen and Kielhofner (2006) and the reciprocal relationship of chronic pain and occupation noted by Fisher et al. (2007). Fighting the pain was also noted in PMP participants' narratives. They related this to not giving in to the pain and keeping going one day at a time. Alsaker and Josephsson (2003) saw this as the ongoing "challenges of everyday occupational life" (p. 167). Thinking about the future was related to setting goals, and both PMP- and therapist-participants generally viewed this as a positive indicator of moving forward in self-management. Matt, however, had noted that his clients viewed the future negatively in terms of possible deterioration and fear. Julia used few strategies around occupational engagement and goal setting. She had learned various strategies but had not "done anything about it yet". This relates to Keponen and Kielhofner's (2006) concept of standing still; Julia did not have the personal resources to move forward.

A study exploring the meaning and experience of everyday life of people with chronic pain showed that the time factor was also significant

(Richardson, Ong, & Sim, 2008). The minute-by-minute or day-to-day nature of living with chronic pain could disrupt daily activity. The authors reported that participants found that activities of daily life took longer and changes were needed in how time was managed due to symptomatology. Managing time was related to feelings of being in control, and when routines were disrupted or restrictions were placed on time available, control was lost. The authors noted the need to understand issues of control and time in reference to daily activities. Several PMP participants found taking extra time necessary to retaining independence and this included periods of resting. This was an instance where PMP participants' perceptions of what was beneficial for them was contradictory to what pain programs in general endorsed. Being able to rest helped Alexandra retain control over her pain and activity engagement. She felt it "unrealistic" to expect that people would not have to rest at some point during the day. Thus for some participants resting was agentic in maintaining activity engagement and was idiosyncratic. Finding different ways of occupational engagement and performing meaningful occupations was related to how PMP participants saw themselves and was important in the creation of their reconstructed identities when living with chronic pain and subsequent limitations. Therapist-participants such as Elizabeth and Matt reported that for their clients, doing meaningful things and using different methods around activity had allowed them to engage in doing. The benefits of this were seen as more than distraction, or as Matt stated, "distraction with meaning and purpose". The interconnected relationships between occupation, time, and managing pain as process are evidenced by the literature considered in this section, as well as the self and meaning ascriptions above.

7.2.6.4 *Using pacing*

Pacing as a pain management strategy was mentioned in every PMP participant's and therapist-participant's narrative account. It is considered here in relation to finding different ways but is also recognised as the strategy most used by PMP participants and commonly presented in therapist-participants' pain practices. Curran, Williams and Potts (2009)

found pacing to be the strategy patients used most consistently at follow-up. This is consistent with the findings for PMP participants in this study.

The concept of activity pacing as a pain management method was introduced by Fordyce (1976), and was based on operant conditioning principles which made activity engagement contingent on time, not pain. Thus people with pain were encouraged to engage in activity for set time periods which were gradually increased. Methods of pacing employed by PMP participants varied. Some used time increments of 10-30 minutes. Others such as Maree used novel methods to limit activity duration, such as half-filling her lawnmower, when she was unable to use time increments. Yet others imposed self-related restrictions dependent on the activity. The methods used by therapist-participants to educate their clients about pacing also varied. Patricia, like several others, set baselines and targets for activity, which were timed. Therapist-participants in general promoted 15-30 minute blocks of time for people to be engaged in activity before having a break or moving on to another task.

The discrepancies noted in PMP and therapist-participant narratives are reflective of the literature involving pacing. In a structured review of the evidence for pacing, Gill and Brown (2009) noted that it was an “ill- or undefined construct” (p. 214). After extensive searching of the literature they found no outcome studies “specific to pacing as an intervention for chronic pain” (p. 215). Studies were either theoretically oriented or considered pacing as a component of PMPs rather than in isolation. The authors concluded that the lack of consensus on what pacing was and how it was presented in pain programs could result in ineffective treatment delivery. This was not reflected in participants’ narratives in the present research.

McCracken and Samuel (2007) in a quantitative study focusing on level and patterns of activity for people with chronic pain, found that increased pacing was positively related to activity avoidance and increased disability. Although surprised at this result, the authors acknowledged that activity patterns of people with chronic pain were complex and multidimensional.

They noted that pacing “done for the purposes of reducing pain” was different to that done to “reduce pain’s influence” (i.e., keeping going despite pain) (p. 124). They advocated using a functional approach to pacing which clearly identified the purpose of using it. Therapist-participants in this research used pacing for both the above aspects. Karsdorp and Vlaeyen (2009) also focused on measuring pacing, activity avoidance and disability level (Nielsen et al., 2001) for people with fibromyalgia. They questioned the conceptualisation of pacing by McCracken and Samuel (2007) who saw pacing as a “behavioural technique to reduce pain” rather than as a technique used “to avoid the negative consequences of pain” (Karsdorp & Vlaeyen, 2009, p. 147). They found although pacing did not contribute to disability in comparison to other variables such as pain severity, people who used more pacing strategies reported greater impairment. They thus concurred with McCracken and Samuel’s findings. They also challenged the necessity of pacing being inherent in pain programs rather than activity exposure and other cognitive behavioural methods.

Vowles and McCracken (2010) compared traditional treatment methods such as pacing, relaxation and CBT to psychological flexibility methods, including acceptance and value-based action consistent with an ACT (Hayes et al., 2006) approach. They found that although the frequency of use of a pain management strategy increased, such as activity pacing, this did not appear to significantly vary scores of disability, depression or pain level. They noted that activity pacing could be used to avoid pain or maintain activity level over time and that the method of use could result in different outcomes. They suggested that behaviour “positively directed toward the achievement of meaningful and successful daily activity” would counter the need for methods aimed at avoiding pain and negative experiences of activity (Vowles & McCracken, 2010, p. 144).

Although pacing was presented differently in various therapist-participants’ practices, they agreed overwhelmingly that activity pacing was a useful strategy for organising activity engagement. This was corroborated by the fact that it was the most commonly reported useful strategy by PMP

participants, one that they continued to use several years after PMP completion. The idiosyncratic ways that they had adapted pacing would appear to relate to Vowles and McCracken's (2010) view of engaging in successful and meaningful activity for activity's sake rather than pain avoidance.

7.2.6.5 Using exercise

PMP's with multidisciplinary teams included some form of daily physical exercise such as gym work, hydrotherapy or walking. These aspects were all present in the program PMP participants undertook and both therapist- and PMP participants acknowledged the benefits of regular exercise to maintain health and fitness. The difficulty with this strategy arose when PMP participants returned home, where most participants found adherence to be an issue. The reasons for lack of adherence related to social and personal reasons, including not liking exercise, "falling off the wagon", lacking motivation, and difficulty accessing local facilities because of distance. Exercise within the social context of the PMP group provided impetus to challenge oneself within the supportive group structure; however, this was often not available when the person returned home.

A systematic review of physical activity in daily life found few adequate measures to evaluate level of activity (Verbunt, Huijnen, & Koke, 2009). The most reliable measure was the use of a movement registration device such as a pedometer. It is interesting to note that although timers had been used to monitor time spent on activities, movement registration devices were not mentioned in any participants' narratives in this research. Thus it is unknown as to whether or not these were used.

In a study of exercise adherence from both clients' and physiotherapists' perspectives, Dean, Payne, Smith and Weinman (2005) noted that managing time was a major problem. For people who were prescribed low back pain (LBP) exercises, over 60% either did not adhere or only partially adhered to them. Qualitative interviews conducted by the researchers found that from both physiotherapists' and their clients' perspectives, finding time to exercise became a low priority. Also, some physiotherapists

advocated a pain self-management approach, but found that some clients resented this when looking for a “quick fix” for their LBP. For PMP participants, finding time was not cited as the main reason for lack of adherence. Availability, cost and distance affected the use of organised exercise programs such as a gym. Lack of motivation was an issue for Rachel, and Julia was not doing warm up exercises because she did not know if they did more harm than good. Julia’s viewpoint is supported by research conducted by Sullivan et al. (2009) which focused on the psychological influences of repetitive activity on pain summation. In their study of people with work-related chronic LBP they found that fear of movement was associated with higher pain levels during repetitive activity. From a therapist perspective, Marie found that people got out of the habit of exercising because it was something that had to be done every day. As noted above, there are many individual and contextual reasons for lack of exercise adherence.

7.2.6.6 *Using relaxation*

Relaxation in some form was presented in all therapist-participants’ pain programs or practices. Methods used ranged from diaphragmatic breathing, imagery, muscle tense-relax techniques to using meditation. PMP participants took part in relaxation sessions on a daily basis while on the PMP. The methods used within the PMP were extensive, providing PMP participants with the broadest range of relaxation options to continue with on return home. The effectiveness of relaxation varied among participants. Some continued to use relaxation methods regularly, including relaxation CDs, but others did not use them at all. Therapist-participant Kristine no longer used methods that, in her experience, increased pain and tension, such as progressive muscle relaxation (tensing and relaxing muscle groups sequentially through the body) whereas other therapists continued to use such methods.

Although relaxation methods are routinely included in chronic PMPs and often administered by occupational therapists, there is limited evidence for their use. An early systematic review of relaxation for the relief of chronic pain was conducted by Carroll and Seers (1998), who noted the

methodological limitations in studies they considered. They recommended “more well designed studies with adequate sample sizes” (p. 485) to determine the effect of different types of relaxation, and also development of a consensus on particular methods of delivery. Brown (2003) noted the lack of agreement between occupational therapists and service users as to the effectiveness of relaxation. Although over 50% of therapist and service-user respondents rated relaxation as one of their 15 most useful treatments for chronic pain, therapists rated relaxation higher than their clients. In a later study, Brown and Pinnington (2007) noted that although the paucity of evidence for the use of relaxation methods remained, 89% of occupational therapists endorsed its use in chronic pain management.

A systematic review of randomised control trials and studies of single relaxation methods by Persson, Veenhuizen, Zachrison and Gard (2008) produced results similar to those reported by Carroll and Seers (1998). Persson et al. concluded that relaxation methods might be useful but scientific designs needed to be “of improved scientific quality and should include clear self-training relaxation protocols and suitable control groups” (p. 355). In a recent meta-analytic review, Palermo, Eccleston, Lewandowski, Williams and Morley (2010) found that relaxation along with other psychological interventions had significant effects on pain reduction. These studies concerned adolescents and children only, and no similar recent literature has been identified for adult populations. From the PMP and therapist-participant narratives, it appears that although not evidence based, relaxation methods continue to be taught in pain programs and used on an ongoing basis by some PMP participants.

7.2.6.7 *Using CBT*

Cognitive behavioural methods were integral to the PMP and were also utilised in many therapist-participants’ pain programs and practice. Methods used included therapists challenging negative thinking, pain behaviours and talking about pain, as well as using thought stopping and distraction to engage in activity. These methods are consistently applied across chronic pain programs and positive impacts have been noted in depression alleviation, pain coping and reduced pain behaviours. There is,

however, limited evidence for their actual relationship to improved functioning (Morley et al., 1999; Vowles & McCracken, 2010).

PMP participants reported the use of various cognitive behavioural methods during the program. How these methods were perceived by participants varied. Some found “positive self-talk” and using “mind over matter” useful; others, such as Willie and Bill, found the cognitive behavioural message repetitive and of limited application. Julia was adamant that no one could change the “way I think” about pain, and was unable to utilise these operant components of cognitive behavioural strategies. Jensen et al. (2005) in a 3-year follow-up study of participants of a multidisciplinary pain program hypothesised that “women would benefit more than men from a cognitive behavioural program” (p. 274). They found that at 3-year follow up women had reduced work absence and better perceived health. They were unable to draw conclusions for males due to a poor response rate at 3 years. Cognitive behavioural methods were only significantly better than control groups when combined with a physical activity focus, but not when used alone.

In the main, therapist-participants used a variety of cognitive behavioural strategies combined with activity-based approaches in their programs and practices. Liz and Louise described how they found the methods useful in changing people’s thinking about pain, which was echoed in several therapist-participant narratives. Only one therapist, Leah, felt that challenging people about their pain was not indicated and using one behavioural method such as CBT was “flawed”. She admitted using some aspects of CBT in her pain practice, although she also thought it was unwise to “meet a force with a force”. She saw that refuting people’s thinking about pain and extolling the operant aspects of CBT methods was tantamount to telling clients that they were wrong and the therapist was right. She did not see this as positive to establishing a therapeutic relationship. I support this view, as in my own experience I found that some people did not want to ignore, refute or challenge thinking about their pain. Neville-Jan (2003) echoes this sentiment about behavioural therapy in general in her auto-ethnography. She noted the dilemma of

having to perform as if she did not have pain in her dealings with practitioners, which often led to them not believing she had significant pain. She was aware that complaining about and showing pain was seen as displaying pain behaviours which were expected to be ignored.

Vowles and McCracken (2010) recently suggested that being flexible in the use of behavioural methods might be more advantageous to pain program treatment outcomes. They contend that being mindful of the “nature of interaction between behaviour” (p.144) and the situational and environmental context might be more useful than focusing behaviour away from pain or unwanted thoughts. They see the addition of flexible psychological processes such as acceptance and mindfulness as useful to integrate into existing pain program models. Leah’s narrative indicated that she similarly used a number of different psychological methods to meet the needs of her clients.

7.2.6.8 *Using pain measures*

This finding was particular to therapist-participant narratives in the main and is considered under social world themes of therapist-client relationship, group versus individual approaches and post-program follow up (see Section 6.2.4).

7.2.7 Conclusion for Section 3 – Strategies

Strategies utilised by PMP participants in the long term were adapted to suit the individual. Those that proved useful and simple to implement were retained (such as pacing) and those that became too difficult to continue, such as exercise, were not maintained by most. Having a range of strategies provided the resources to maintain progressive narrative slopes for some PMP participants. Therapist-participants also found that some strategies were more likely to be continued post-program. Pacing, using simple relaxation techniques and modifying activity were deemed helpful for the majority of clients. Some strategies were considered contentious by PMP- and therapist-participants. These were certain relaxation methods, the use of CBT, and not resting. These strategies were viewed negatively

by some PMP- and therapist-participants. Evidence to support the inclusion of some strategies in pain programs is lacking in current pain literature. However, anecdotal evidence, from narratives here, appears to be a powerful indicator for continued use by PMP- and therapist-participants.

7.2.8 Social World

The social world had a profound impact on how PMP participants continued to manage chronic pain or otherwise on a long-term basis. PMP participant narratives discussed the influence of family members, friends, medical practitioners and specialists. For those who sustained a work-related injury, institutional influences such as compensation funding bodies were a prominent negative factor in moving forward in the pain process. Various aspects of participation in the PMP were also mentioned, as well as adjustment back into the community following the PMP. Although the social world findings included the early influences of childhood as well as clients' current social life, present social factors are the foci of this section. Parental and childhood influences were considered under aspects of the self.

For therapist-participants, social world factors were significantly related to predicting who would do well following intervention. The importance was raised of family, general practitioner support, therapist support and individual versus group-based interventions. The importance of follow-up and ongoing social support was also evident from the findings.

7.2.8.1 *Being supported by family and friends (and pets)*

Having good family support encompassed and acknowledged the importance of spouse, immediate family and friends. PMP participant narratives highlighted the importance of family roles and the satisfaction obtained from engagement in these roles. They also stated how spousal, family and friend support had been critical to maintaining their sense of self when living with chronic pain.

Some participants shared a pain condition with a spouse or family member. This awareness in most cases promoted a deeper level of understanding and empathy. Having spouses carrying on as normal was also seen as important by some PMP participants, as was maintaining a sexual relationship. A few participants had assumed co-dependency within a carer-cared-for relationship that could be positive or negative depending on the relationship. For some participants, however, the burden of chronic pain had resulted in relationship breakdown when partners did not understand the nature of their condition and could not provide adequate support.

Extended family support involved parents, children (both living in and away from home) and grandchildren. Most PMP participants acknowledged the importance of family in terms of their personal roles and the support provided. Obtaining the right level of support was a struggle for some if family members became overly protective. Describing what pain meant personally was difficult for some participants, which led to misunderstandings with others. This affected family relationships.

Therapist-participants acknowledged that good “appropriate” family support was critical to ongoing pain management. Various therapist-participants noted how “powerful” family members could be in reinforcing pain or encouraging the use of strategies around pain. Having family actively involved in pain programs was also considered important to have them informed about the pain management process. Ultimately spouses and family continued to be the primary agents supporting positive pain management when their partners/parents returned home.

Having a “family day” within programs was generally considered a good way of informing families about concepts of pain management and the importance of ongoing activity and exercise. Not all programs offered this; some had tried to run them with poor attendance. Poor family support was noted by therapist-participants as a major factor in their client’s non-management. Returning to situations of marital conflict was often seen as a “bigger problem” than trying to manage ongoing pain.

The importance placed on the carer role and the financial incentive of maintaining care was perceived by therapist-participants as a negative factor in supporting ongoing pain management for their clients once returning home.

In a qualitative study of people with chronic pain within the family context Richardson, Ong and Sim (2007) noted how family members provided support but could also receive support from the person in pain. They noted how the “complexities” of family life could be “illuminated and exaggerated” by the presence of chronic pain (p. 347). They identified practical and emotional support as inherent in family relationships. Practical support could be physical support around the home or helping avert negative events, such as falling and exacerbating pain, by accompanying the person outside, thus protecting them. Emotional support was noted as flexibility in response to the unpredictability of the person’s pain, and legitimising the pain experience. Some PMP participants described a role reversal, where spouses had taken on the previous practical support roles of the person in pain. Alice found this difficult as she was used to doing heavy work around her farm. She felt at times that her husband treated her “like a child” by telling her not to do things around the home for fear she would hurt herself. The need to establish reciprocity in the roles of caring and being cared for created tension in a number of relationships. Julia explained how her partner would want her to help him outside and then complain about her “wearing herself out”. He was unable to respond flexibly to the fluctuating nature of her pain. Unwillingness to recognise and understand a person’s pain failed to validate a person’s pain experience or provide emotional support (Richardson et al., 2007). Both Rachel and Sara were in relationships where their partners had been unable or unwilling to understand their pain, leading to relationship breakdown. Similarly, in Closs, Staples, Reid, Bennett and Briggs' (2009) study of the impact of neuropathic pain on family relationships, several participants experienced relationship breakdown due to lack of understanding.

Family members' awareness and acceptance of chronic pain often meant making adjustments for the person with pain. Being aware of the person's limitations and the type of support preferred was also seen as important in the study of Richardson et al. (2007). Making suitable supportive adjustments was often difficult for PMP participants' family members. Dawn reported that her family members reacted differently by providing little or too much support. Alexandra had the balance right, seeing her family as a "great support team". Closs et al. (2009) found that it was more difficult for men to accept the loss of roles and need for help from others in the family. Ian similarly, reported that the loss of his worker role and assuming child care and home-based duties affected how he saw himself as a husband and father.

Friends also influenced how people managed in the long term. When moving through the pain process most PMP participants noted changes in friendship groups with a subsequent loss of friendships while finding out who their "real" friends were. Most managed to retain at least one significant friend, although a few struggled to maintain any social contact outside of their immediate family. Closs et al. (2009) similarly found a change and loss of relationships in their participants. They related this to a lack of understanding and the "invisibility of pain" (p. 406) being difficult for friends to comprehend. Bill found his friends knew his "weaknesses" and were more sympathetic of each other as time progressed and they aged. Rosie had one special friend she had known most of her life whom she phoned every few weeks. Sarah retained a "great core of friends", but acknowledged she had lost many along the way. Ian had few friends and often dwelled on the past and the social person he had been. This is consistent with Closs et al. (2009) who found increased difficulty for their participants in maintaining a normal life, including the maintenance of social networks.

Two participants (Ian and Maree) affirmed the significance of pets as an important factor in overcoming pain and depression. For Ian, the constancy of having a pet dog around was comforting, while for Maree the companionship of her neighbour's dog also led to her becoming

responsible for the dog's care during the day. In a phenomenological study of chronic pain, Strandmark (2004) confirmed that domestic animals could compensate for being isolated during the day for some participants. The unconditional loyalty of pets was seen to "facilitate both companionship and an escape from loneliness" (p. 141) when other social networks retreated. Ian supported this view, stating that "the affection I got back from the dog" was like nothing he had experienced.

7.2.8.2 *Isolating yourself*

Both PMP and therapist-participant narratives claimed that isolating oneself from others could be either agentic or victimic. PMP participants such as Sarah and Willie isolated themselves from others as a way to cope with their pain. The ability to retreat meant they did not have to deal with other people and could focus their energy on dealing in private with their pain. Sara, like some other PMP participants, found that isolating herself socially was misconstrued by others as blaming them for doing the wrong thing. Other victimic views of isolation included being isolated due to geographical distance, as in the case of Alice. Living a long way out of town and being unable to drive was a contributing factor to her low mood and loneliness. Therapist-participants like Liz noted that isolating oneself from others could be useful when the social context was overwhelming for the person with pain. Others, such as Patricia, saw isolation as a way the person could avoid social responsibilities, with pain giving legitimacy to opt out of activities.

Peolsson et al. (2000) explored the dynamic learning process for people with pain regarding being in touch with the quality, nature and best ways to manage pain. Richardson et al. (2007) likewise found that this process could apply to the emotional skills required by family members to know the person with pain's bodily limitations and preferred ways of coping. Awareness or lack of awareness of this by family members of PMP participants could cause tension when misconstrued. PMP participants whose family members knew their coping styles allowed them to withdraw until ready to deal with social situations, but others felt they had to justify the withdrawal. Closs and colleagues (2009) identified many factors that

could lead to social withdrawal by participants with pain in their qualitative study. They noted that triggers such as “physical, emotional or environmental factors” (p. 407) could all influence self-imposed isolation when the expectation of stress, heightened activity and even outdoor temperature might influence the person’s social participation. White and Siebold (2008) found that social participation led their participants to have a “pay-back system” (p. 63) whereby participating in pleasurable events led to days of recovery and enforced bed rest. Some PMP participants engaged in social events, even though they knew that it would aggravate their pain. Isolating oneself can therefore be agentic or victimic, depending on the reason.

7.2.8.3 *Being in the compensation system*

Several PMP participants had sustained work-related injuries and had been through a compensation system for loss of earnings and payment of medical expenses. All therapist-participants worked with clients who received compensation and for some therapists this was their sole clientele. Being within “the system” was generally viewed negatively by both PMP- and therapist-participants. The institutional structures that governed these systems were seen as imposing restrictions on PMP participants’ access to specialist care and services like the PMP.

Participants reported having to go through a process of legitimising their claim and proving they had ongoing pain. Although the participants interviewed had received settlement of their claims, they spoke of their bitterness at what the system put them through personally and how the system pushed them to the point Dawn termed “where you want to explode” in an attempt to get them to drop their claim. Therapist-participants such as Alison found that receiving compensation was the “number one barrier to change” in clients she saw. She reasoned that it was difficult for people to move forward in the pain management process while they had a chance of being financially compensated for remaining in high levels of pain.

Researchers have identified the perceived barriers of negotiating a compensation system following workplace injury. Korzycki and Shaw

(2008) noted the tension experienced by injured workers when trying to negotiate the conflicting demands of returning to work while continuing to access health care systems. Briand, Durand, St-Arnaud and Corbiere (2008) concluded that for return to work interventions to be most effective, a number of essential components needed to be in place. These included the centralised coordination of claims, contact between all stakeholders (worker, workplace, health care providers and compensation representatives), and formalised interventions that supported work resumption after injury. They also found that only two of the 11 programs they surveyed met these requirements.

The ensuing emotional repercussion of having a work-related injury were noted in a literature review of the psychosocial impacts of return to work following injury (Eggert, 2010). Eggert found common themes of "frustration, depression, discrimination... obstacles in understanding how the system works and obtaining care" (p. 51) as barriers to rehabilitation. This supports the findings from Dawn's and Willie's narratives, where feelings of bitterness towards the compensation system were expressed. Dawn and Willie spoke at length about the long process of fighting to have their claims recognised and how this continued to influence their perceptions of a "heartless" system. Therapist-participants also noted the "profound" impact of the system on their participants. Leah was forthright in her views about the "conflicting nature of the system" where people needed benefits to survive but were continually scrutinised and treated like a number, which she saw as making them exceedingly vulnerable.

Returning to work is considered the ultimate outcome of both workers' compensation organisations and occupational rehabilitation programs. Due to the time since their injury and their age, return to work for most PMP participants was not a priority. Dawn and Willie did not return to work in the long term, but Sara and Stacey, being considerably younger, did. Evidence-based studies of return to work using an occupational therapy framework have noted the conflicting opinions of insurers and employers regarding readiness to resume work compared to clients with LBP (Paquette, 2008). Paquette found that work readiness was not simply a

matter of physical and performance ability. The work context, particularly cultural (related to disability at work and absence), social (type of insurance and support), spiritual (beliefs about value of work and work ethic), and temporal factors (age and gender, work stability and time to retirement) all influenced the return to work outcome. Age and time factors were also confirmed by the findings from PMP- and therapist-participants in this research.

Studies exploring rates of return to work for people with sub-acute back pain following early intervention in clinical, occupational and case-based interdisciplinary programs found that at 6 months workers at high risk of disability had returned to work at higher rates than high-risk workers receiving conventional treatment (Reme, Hagen, & Erikson, 2009; Schultz et al., 2008). It appeared, however, that return to work was “highly dependent on individual and cognitive factors” (Reme et al., 2009, p. 139) with pain intensity, negative expectations of returning to work and early physiotherapy intervention being negatively attributed. Therapist-participants mentioned often seeing clients long after the onset of their chronic pain and after they had undergone a number of conventional treatments. The majority of PMP participants had experienced chronic pain for several years before being accepted into the PMP. Most had consulted a number of specialists and undergone procedures or other interventions that could inadvertently have reinforced the chronicity of their condition.

7.2.8.4 *The influence of other health professionals (general practitioners and specialists)*

All PMP participants continued to consult GPs as their primary point of health care contact. Over the course of their chronic pain they also consulted a range of medical specialists, allied health professionals and alternative therapy practitioners. The opinions of other health professionals influenced how PMP participants interpreted their pain and how they saw themselves living with pain. They were able to discuss their perceptions of what made a good health practitioner and what did not. Will felt his GP was genuine and took extra care of him when he was

experiencing suicidal thoughts. Maree, like several other participants, established a friendship with her GP which involved socialising out of hours. Sarah saw her GP and physiotherapist as part of her “team” who “battled” for her. Slade, Molloy and Keating (2009) found that feeling connected, having value and having credibility were all seen as positive attributes of health care providers by their participants with chronic LBP. Therapist-participants likewise noted what they believed constituted a good therapeutic relationship for their clients. Health professionals who advocated and supported pain management principles were seen as positive compared to those who doubted or disputed a person’s pain and level of disability. Slade et al. (2009) found that having poor communication, lack of understanding and perceptions of secondary gain were perceived negatively by people with pain consulting health professionals. This was noted by Sarah, Stacey and Rachel, who had seen specialists who were indifferent or thought the pain was all in the person's head. Several studies support the contention that people with pain in general are unhappy with the health care they receive, the lack of diagnosis and lack of effective management beyond medication management (Harding et al., 2005; Parsons et al., 2007; Slade et al., 2009). Holloway, Sofear-Bennett and Walker (2007) found that although most of their participants with chronic pain received various scans and x-rays, these were of limited diagnostic value. They noted that doctors continued “to privilege organic explanations for pain” and devalued chronic pain where the “cause is unknown and treatment of limited value” (p. 1458). They also reported, however, that people with pain believed in an organic cause for their pain and wanted a biomedical diagnosis that could be treated. Some PMP participants such as Bill continued to believe there was something “there” that could be treated with regard to his knee pain, although many specialists had said that nothing further could be done.

Having their pain validated as real was important for PMP participants. Ian described an encounter with a specialist soon after his injury where he was labelled as a “malingerer”. Several other PMP participants reported the same situation when dealing with various health care providers. Therapist-participant Patricia noted the negative connotations her clients

reported after dealing with GPs and specialists. She had seen people who felt they were disbelieved and who thought the health professional was “annoyed” or “angry” with them for taking up their time. She reported that she always reinforced with clients that their pain was real, to validate their experience. Pelonquin (1993) noted the distance that some health professionals established when dealing with a person in pain. Using narratives of participants with pain who experienced negative encounters with health professionals, she found that the use of “brusque manners” and “misuse” of power (p. 830) was a common theme. Bias could be argued here, however, due to the nature of the study. In the present study, Sarah described how “blunt and rude” a specialist had been in his dealings with her. This made her hesitant to consult him again, although he was a leading specialist in the area of one of her health conditions. As GPs remained the most prominent health care professionals consulted in the long term, the importance of their ability to understand chronic pain from both PMP- and therapist-participants’ perspectives was paramount.

7.2.8.5 *The therapist-client relationship*

Establishing rapport and a therapeutic relationship with clients is a basic premise of the therapy process for allied health professionals, including occupational therapists. All therapist-participants within this study noted the importance of having a good relationship with clients if assessment and intervention were to be successful. Establishing rapport was seen as critical by Elizabeth and Kristine. Other therapist-participants used metaphors to convey the type of relationship they created with their clients. Being a “motivator for change”, being an “explorer” and “coach” were all noted as ways that therapists engaged with clients within their practice. PMP participants noted that staff on the PMP were generally “excellent”, although occupational therapists were not singled out for special mention. They were seen as part of the team and evaluated accordingly. Only one PMP participant, Bill, described how members of the team had been “preserving their patch” by setting up perceived barriers between participants and themselves.

Brown (2003) explored chronic pain service users' and occupational therapists' beliefs about the most effective disciplines and treatments for chronic pain as endorsed by both groups. Occupational therapists rated themselves equally important to psychologists, with physiotherapists coming third. Service users, on the other hand, rated occupational therapists as the fourth most important behind physiotherapists, physicians and psychologists. PMP participant narratives did not specifically single out occupational therapists, though they did mention physiotherapy and medical staff. Although participants in Brown's study rated occupational therapy below other professionals, the service users rated occupational therapy interventions such as body mechanics, pacing and graded return to activity in their top four interventions. These results are consistent with some of the findings from PMP participants' narratives, with pacing being the most reported ongoing strategy used (see Section 5.4.1.4). Thus PMP participants valued the strategies imparted by occupational therapists as members of the treating team. Therapist-participants saw the need for establishing good rapport with their clients in order for their assessments and interventions to be meaningful and applied. Although acknowledging that personal and social factors could affect the quality of the relationship, they considered that for intervention to be successful, good rapport was imperative.

7.2.8.6 *Group versus individual approaches*

Strong (1996) found that groups for people with chronic pain took the form of therapy, structured and self-help groups. Since the 1980s, group approaches for chronic pain treatment have been advocated as cost effective for service delivery of psychological, educational and relaxation components of chronic pain programs (Strong & Unruh, 2002). The socially supportive elements of being in a group with other people with chronic pain has been seen to encourage feelings of belonging, reduction in isolation, and promotion of respect for self and others (Martensson & Dahlin-Ivanoff, 2006; Strong & Unruh, 2002). All PMP participants took part in a group-based program. The majority noted the support, motivation and socialisation that being in a group engendered. These aspects were seen as positively supportive of their pain experience. Most therapist-

participants worked within group programs, although some hospital services also offered individual programs. Therapist-participants in private practice or working in the community generally worked individually as sole therapists with clients. The reasons were multifactorial, including lack of resources to run groups or personal preference. Most therapist-participants, however, extolled the virtues of working with groups, with group members “validating” others experiences. Being able to utilise the power and energy of group dynamics was noted as a positive thing. Those therapist-participants who no longer ran groups admitted that their practice was sometimes poorer for this, although there were also benefits in working individually.

Some PMP participants disliked the group focus of the PMP. Either they found a lack of reciprocity within their particular group or their individual needs had not been catered for. These sentiments were also noted by some therapist-participants. “Getting the group mix right” was seen as a major difficulty. Therapist-participants reported group members who dominated or were disruptive in groups and negatively affected all group and staff members. Also the necessity of having one set approach in groups was noted as being too prescriptive at times for clients with diverse individual needs. Flexibility in delivery of individual and/or group approaches was generally supported by therapist-participants.

Studies exploring multidisciplinary group programs have generally been supportive of their use (Martensson & Dahlin-Ivanoff, 2006; Oslund et al., 2009). A report by Access Economics into cost effective pain interventions found that “a coordinated multidisciplinary approach is... the most effective way... to manage chronic pain... and the most cost effective for more disabled chronic pain patients” (Access Economics, November 2007, p. vii). In contrast, in a study of service users’ beliefs about treatment effectiveness by Brown (2003), physiotherapy and modality-specific clinics were given the highest rate of endorsement, above multidisciplinary programs. Even when the use of groups was endorsed, people with chronic pain criticised the content and format of the program provided (Martensson & Dahlin-Ivanoff, 2006). Strong (1996, p. 133) noted that

“one of the problems in determining the efficacy of groups was the frequent use of concurrent modalities”. The combination of self-management strategies and neurosurgical interventions in some treatment settings was seen as conflicting. This occurred in the program with which Matt was involved, where his clients were having medical procedures concurrently with group self-management. Professionally he saw this as a major limitation to effectiveness.

PMP participants in the main enjoyed the group focus, although some participants were equivocal about the experience. Alexandra found that group service delivery was unsuitable for her as “you can’t pigeon-hole everyone in the same hole”. Therapist-participants saw the advantage of being able to tailor PMPs to their clients’ needs. While both saw the value of group approaches, this sometimes came at the cost of meeting individual needs. Some PMP participants tended to enjoy their own company or were particular about who their friends were. For some of those participants, the group setting and being within a fixed program where everyone did everything together was a challenge. Group approaches were seen as conducive to self-management if the group mix was supportive of all group members, social networks were gained and positive group dynamics were achieved.

7.2.8.7 *Having follow-up post-program/lack of resources*

After completion of the PMP all participants returned home with the aim of continuing to strive for pain self-management. Most PMP participants had seen their fitness improve and had better control over their pain after the program. Going back to the “realistic” world, as Stacey termed it, was difficult without the high level of support the PMP offered. PMP participants described “falling in a heap”, “doing it alone” or “being cast off” to detail what happened once they returned home. Processing the large amount of information provided by the program took different amounts of time depending on the individual. Years later, after making initial gains, several participants found that they had deteriorated and their pain increased. Depression, ongoing exacerbation of pain, and the lack of community and personal resources appeared to contribute to this.

Dunn (2010) focused on a life course approach to back pain, looking at risk factors and behaviours in childhood and adolescence and actual onset and progression of the condition. Dunn argued this epidemiological approach could provide a “chain of risk” (events predisposing the individual to back pain) and “accumulation of risk” (accumulation of pain and other risk factors over the life course) (p. 5) that could be used prospectively or retrospectively. Clinically this information could be used to provide early intervention to help prevent the development of long-term chronic pain, or retrospectively it could provide a more comprehensive picture of back pain factors than standard assessment methods. By examining the narratives of PMP participants a number of risk factors can be found that could have predisposed some participants to back pain. Julia suffered ongoing abuse as a child and into adulthood, and as a child was also in a serious accident requiring long-term hospitalisation. She acknowledged that her current severe pain and inability to cope were influenced by past life events. Rachel had a history of problematic family relationships. This, combined with her physical disability, saw her disadvantaged socially, with consequent difficulty forming relationships with others and gaining support. Willie had performed heavy manual labour as a farmer. His injury was the result of a scarfing accident felling trees, a high-risk activity.

Few studies of chronic pain programs examine outcomes beyond a 12-month period (Dunn, 2010). Jensen et al. (2005) identified a lack of quality studies looking at long-term outcomes. Their study explored outcomes (sick leave, early retirement and quality of life) at 3-year follow-up of a multidisciplinary pain program. They found that women in general had benefited more than men from such programs. Their study took into account demographic variables but did not explore coping, adherence to treatment strategies, or other psychological factors. Some therapist-participants offered ongoing review following pain program completion. The PMP, for instance, conducted a formal review at 10 weeks and then up to 12 months. A few programs had no review process and therapist-participants who worked within those programs gave lack of time and

resources as the primary reason. They also acknowledged that lack of evaluation was problematic.

A few programs offered “booster” sessions. These offered a short-term “refresher” to revisit pain management strategies, review exercises and provide support. Although “booster programs” were advocated by both PMP- and therapist-participants, there is a paucity of literature related to this and chronic pain. Similarly, the use of a “buddy” system did not feature in the literature. Some studies focusing on rheumatoid arthritis management and HIV/AIDS management (where chronic pain was also present) (Home & Carr, 2009; Zuyderduin, Ehlers, & van der Wal, 2008) have advocated the use of buddies for ongoing community-based support. A few PMP participants maintained relationships with others from their particular program, while others thought that having a “buddy” to exercise with would be helpful.

Some literature exists advocating the use of chronic pain support groups. In a mixed-methods study, Subramaniam, Stewart and Smith (1999) interviewed consumer-led group members of a chronic pain support group at commencement and 5 months later. Their participants reported a significant increase in activity levels and decreased reliance on health professionals. Arthur and Edwards (2005) used a 10-session psychosocial group program “to foster the development into community-based self-help groups” (p. 169). Their participants with chronic pain and complex psychological histories improved in self-responsibility for pain management. Moreover the satisfaction of being part of an ongoing group once the 10 sessions were completed was motivating for their participants.

Only two PMP participants were actively attending support groups. Both found that being part of a group was restorative, and Maree, due to her own pain experience, was able to impart knowledge to others. Not all studies however, noted only positive aspects of support group attendance. Townsend et al. (2006) reported that some participants with chronic illness justified their decision to not attend support groups as it clashed with their “self-image” of being self-managers (p. 192). Similarly, PMP participant Bill

saw being with “like-minded people” with chronic pain as being detrimental to his coping with pain. Some therapist-participants such as Elizabeth and Louise saw support groups as reinforcing pain for their clients, and thus did not recommend them to their program participants.

Due to the regional/rural location of the PMP, consideration of where participants resided in relation to pain management appears pertinent. Studies of rural chronic pain management programs have shown that such programs can be effective in improving pain management and psychological functioning and reducing disability (Burnham, Day, & Dudley, 2010; Dunstan & Covic, 2007). However the rural/regional setting where the majority of PMP participants resided impacted negatively on ongoing pain management. This was due to the lack of local resources, the travel requirements, and economic factors.

Studies of the incidence of chronic pain in rural and remote areas report similar findings. In a discussion paper on chronic pain in rural Australia, Tollefson and Usher (2006) noted that people in rural/remote areas experienced “higher rates of morbidity and mortality”, higher risk-taking behaviours, and “a lack of health care resources and distance from services” (p. 134). They also found that the “rural personality” also displayed characteristics of “stoicism... independence, self-sufficiency, innovativeness and resilience” (p. 134) which influenced their help-seeking behaviours. Several of these traits were also found in PMP participant narratives, such as Ian’s “growing up tough”, Alexandra’s “being stoic” and Dawn’s “using it or losing it”. Regardless of their personality type, most PMP participants stated that continuing with formal exercise or hydrotherapy would be a good thing but cost, distance or isolation was a hurdle to actually doing it. Interestingly, therapist-participants in general did not comment on access to services, perhaps because of their diverse practice areas, both rural and metropolitan. This may be because interview questions did not focus on service provision post-program, rather on pain program content and pain management. However, as confirmed by PMP participants, access to services post-program was a significant

barrier to ongoing management and thus should be addressed by therapists, especially those in rural/remote areas.

7.2.8.8 *Dealing with people in the community*

Living within the social world continued to provide challenges for PMP participants in the long term. Some participants returned to and increased participation in volunteer roles within the community. Others withdrew from community roles due to ongoing pain and disability. Several participants increased their focus on family, while a few participants resumed paid worker roles. How they were perceived by others within the social world had a large psychological impact on how PMP participants coped day-to-day. All adopted different ways of negotiating social situations, using strategies such as isolating themselves from others and leaving or avoiding social situations that could be problematic. PMP participants' perceptions of how they were seen within the general community were evident in many of their narratives. Dawn spoke about being judged by others, Sarah had been verbally confronted over her use of a wheelchair, Alexandra spoke of the general lack of understanding within the community about what chronic pain entailed, and Ian mentioned the ongoing "stigma" of living with chronic pain.

Stigmatisation is an "issue of disempowerment and social injustice" (Slade et al., 2009, p. 145). It causes people to be judged in a negative way in comparison to others because of being different from the norm. Slade et al. (2009) found that stigma pervaded every aspect of social life for participants with chronic low back pain. They discovered that stigma occurred at a family, friend, community and workplace level, as well as with health care providers and even within their low back pain group. Stigmatisation was both overt and subtle, with participants noting feelings of guilt, blame and judgement by others and the need to appear credible in their pain accounts. Slade et al. also found that the invisibility of back pain created "a barrier to legitimacy" (p. 146) similar to that noted by several PMP participants. Holloway et al. (2007) noted that stigmatisation had a "profound effect on the perceptions, self-esteem and behaviours" (p. 1456) of the participants in their qualitative study. They again found that stigma

permeated the lives of their participants in relationships with significant others, work colleagues and health professionals. Ian looked back with regret at the “friendships that came undone”. Dawn and Sarah found the judgement of others to be personally undermining. Sarah noted that the way others saw her could “tip you from a good day to a bad day”, such was their impact.

7.2.9 Conclusion for Section 4 – Social World

Social factors thus played a significant part in PMP participants’ ongoing pain management. How individuals managed in the long term was influenced by the availability of support and resources and perceptions of themselves in the community. As stated by Alexandra, “I guess it’s the whole experience, not just the pain. It’s how people deal with you, with the pain, the group, the support, everything”.

7.3 Synopsis

Consideration of the above findings (related to self, meaning ascriptions, strategies and the social world) is required to identify factors influencing long-term chronic pain management. Although there is limited explication of some of these factors within research studies, the body of literature on chronic pain attests to the need to address psychosocial, emotional, physical and quality of life needs, while maintaining independence and engagement in occupations of meaning. Townsend et al. (2006) noted that in the process of chronic illness management there is “illness work, everyday life work, biographical work” and “moral work” (p. 186). These “works” interact, and involve working on the management of illness symptoms by the use of various strategies (illness work) and working at maintaining everyday valued activities and life roles such as being a worker and being a mother (everyday life work). They also involve maintaining a sense of continuity with “former selves” (p. 189) by being able to carry out tasks and valued activities. Biographical work refers to reconciling the “trajectory of illness” (p. 186) that encompasses the past, perceived present and future in consideration of the self. It also details the process of moving forward with acceptance of pain as part of everyday life. Moral work involves the personal struggle against the chronic illness

and the need to be perceived as credible to health practitioners. It takes into account the social and cultural aspects of dealing with chronic illness and their implications for a person's perceived identity.

The findings of Townsend et al. (2006) summarise themes similar to those identified as significant in this research. Managing illness by using strategies, participating in valued everyday activities, considering how identity is influenced by past, present and anticipated future views of self, and the ongoing struggle to maintain credibility are all prominent. The types of "work" represented above are reflected in the categories and findings related to the "self", "meaning ascriptions", "strategies" and "social world" within this research. The categories are interconnected, and connected with how the person ultimately lives life with chronic illness. These areas are paramount to consider in the attainment of a semblance of a normal life when living with chronic pain. These factors are now presented and discussed with reference to agentic (active) and victimic (passive) conceptual models influencing chronic pain management.

7.4 Conceptual Models of Agentic and Victimic Factors Influencing Chronic Pain

7.4.1 Introduction

The models in Figures 7.1 and 7.2 illustrate the conceptual factors that emerged from this research. Findings from the narratives of PMP- and therapist-participants were grouped under the categories of the self, meaning ascriptions, strategies and social world. That provided a pragmatic schema of how factors related within each category, but it did not indicate the complex interactions between these areas. As managing pain is an ongoing process, people may at different times move between agentic and victimic ways of viewing their pain, depending on life events. Agentic factors are identified as having an internal locus of control, with responsibility for pain management being dependent on the individual. Victimic factors have an external locus of control, with individuals seeing others as responsible for their pain management. These models therefore

bring together the aspects from the findings that arose as agentic (promoting self-management) under one model, and those noted as victimic (being passive in pain management) under another. A predominance of either agentic or victimic aspects would indicate the likelihood of pain management/non-management. When people retain more agentic features they would fall into the category of self-managers. When people remain stuck in the process of self-management and reliant on others they could be viewed as passive in pain management (victimic).

7.4.2 Background to the Conceptual Models

These proposed conceptual models borrow and build upon theoretical perspectives present in occupational therapy literature. They differ from existing concepts as they are specific to chronic pain management and arose from the findings of this research. There are many conceptualisations around human occupation within occupational therapy and occupational science. Wilcock (1999) proposed (as discussed in the Chapter 2) that *occupation* as a term could be seen as a “synthesis of doing, being and becoming” (p. 1). *Doing* may be seen as “the active part of occupation that is readily observable” (Lyons, Orozovic, Davis, & Newman, 2002, p. 287). *Being* encapsulates being individual, having certain personal abilities and being “true to oneself” (Wilcock, 1999, p. 1). *Becoming* describes the ability to change and grow into the future to achieve “self-actualization” (Wilcock, 1999, p. 1). Within this research, the researcher proposes the aspects of being, knowing, doing and managing as representative of the themes and findings that emerged.

Being: This aspect represents the self/identity. It occurs within time and across time (past, present, future), and does not occur in isolation but as part of belonging to a social world. It takes into account the physical and psychological self in relation to how one sees oneself within the world.

Knowing: This aspect signifies the meaning ascriptions applied to chronic pain. These meanings are derived over time and life experience. The meanings ascribed to pain and management are influenced by others, by attendance at pain programs, by one’s past (from child to adulthood) and

the events that have preceded, included and will continue to include chronic pain.

Doing: This aspect symbolises the active use of strategies, adaptations and techniques that enable people to engage in their life world. Choosing to engage is influenced by one's sense of being and knowing, the meaningfulness of the occupation to the individual, and one's sense of self at being able to "do"

Managing: This aspect denotes the reciprocal characteristics of the above aspects. These aspects interact, with each feeding into and influencing others.

"Being" within this research would appear congruent with Wilcock's (1999) notion of *being* (p. 1). The concept of "doing" would also appear to be compatible with Wilcock's theory. "Knowing" is proposed here as the acquisition of knowledge and meanings ascribed to chronic pain that facilitate doing and being. This knowledge is acquired through life experience, time in pain, interactions with health professionals and interventions sought. "Managing" in this context refers to the ability to continue to engage in life to an acceptable level. Wilcock's concept of *becoming* (p. 1) has resonance within all the above conceptual aspects. Rather than subsume Wilcock's concepts into this research for the sake of existing theory, the alternative framework suggested here was generated from the data and findings. As stated by Lyons, Orozovic, Davis and Newman, (2002) rather than "compromising the data interpretation" (p. 293) by the use of existing models, it is preferable to remain true to the findings that emerge from the data.

To represent the interrelationship of these aspects to chronic pain management, agentic (Figure 7.1) and victimic (Figure 7.2) models are proposed and diagrammatically presented. The language used within the models is dynamic, denoting the relational nature of the conceptual aspects considered. The models are also time contingent (as indicated on the models), as findings from the research indicate that moving through a

process of pain management or non-management is different for everyone.

The models are non-hierarchical, due to their interactive and process-related attributes. However, certain features were consistently seen by both groups of participants as antecedent to moving through the process to self-management or otherwise. “Being” factors, such as having valued roles, being in control and having ongoing support, provided the impetus to move on in the pain process. Losing valued roles, having a history of abuse or severe depression, receiving compensation, or lacking good support were noted as promoting victimic responses to pain. “Knowing” factors, including readiness for change and acceptance of chronic pain, appeared to be precursors to agentic behavioural change. Being unable to change pain-related behaviours and continuing to look for a cure were highlighted as victimic factors, preventing moving forward in the process of pain management. “Doing” is inherent in the agentic model, in which finding different ways and using strategies such as goal setting, pacing and relaxation allow individuals to have a good quality of life. Being unable to use strategies or find other ways is more characteristic of victimic features. As noted in the findings, for some PMP participants the PMP was not deemed the catalyst in establishing pain management but was seen as a negative experience. Even for these participants, however, changes in thinking and in ways of managing pain still occurred to some extent in the long-term. Other PMP participants, although enjoying the program, had up to the time of interview not adopted strategies or ways of thinking about pain (e.g., CBT) from the program. Individuals who self-managed (as demonstrated by findings), showed strong characteristics of adoption of methods and strategies across all agentic categories in Figure 7.1. These factors were also highlighted in therapist-participant narratives of their clients who self-managed pain. Those who maintained valued roles, had good ongoing social support and continued to engage in occupations of meaning were more likely to be self-managers. PMP participants who appeared ambivalent about managing their pain may have had aspects of one or even two of the categories shown in Figure 7.1. However, they maintained an external locus of control. They continued to seek a cure for

their pain or were undergoing further medical procedures to treat their pain. Thus they retained more victimic features from Figure 7.2. For therapist-participants, receiving compensation was highlighted as the main impediment for self-management for their clients. As stated above, a predominance of agentic or victimic factors would predispose the person towards either model.

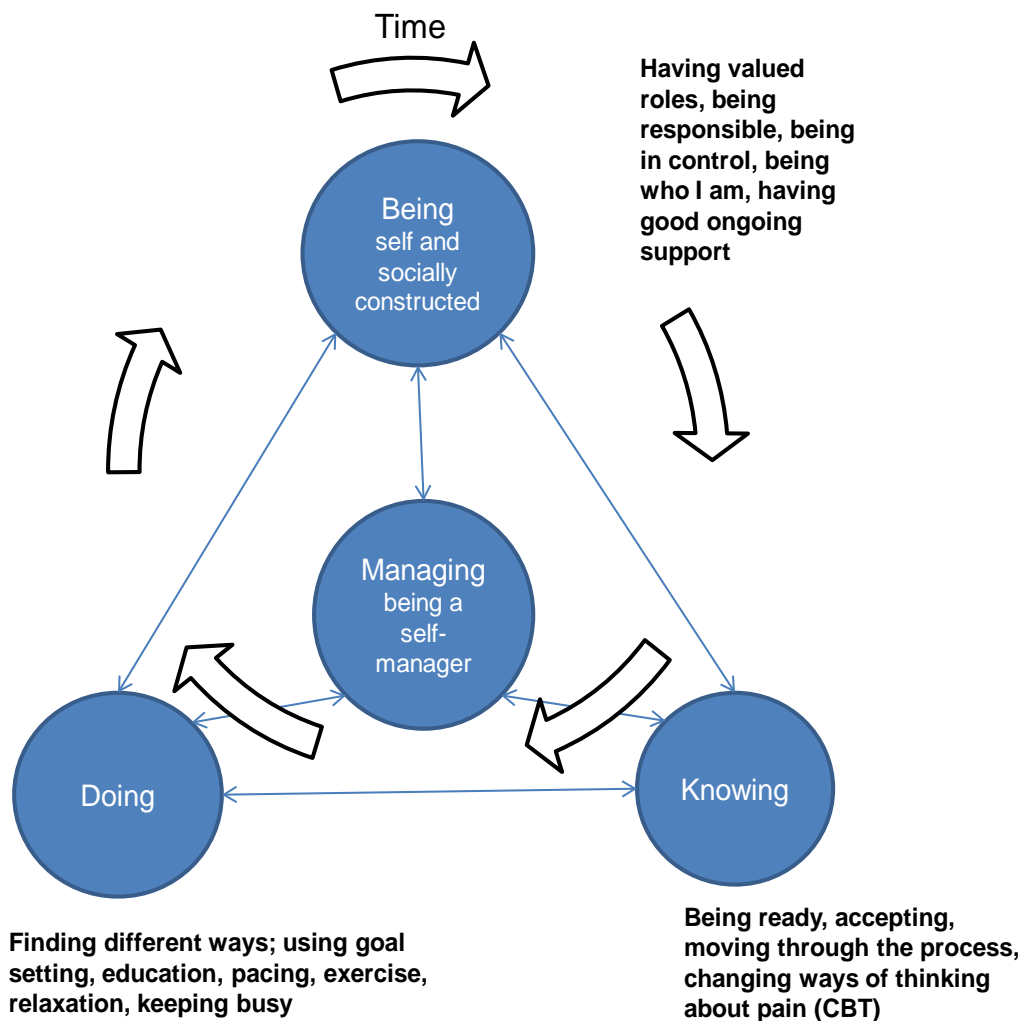


Figure 7.1: Agentic conceptual model. Based on agentic factors noted by PMP- and therapist-participants that influence chronic pain management.

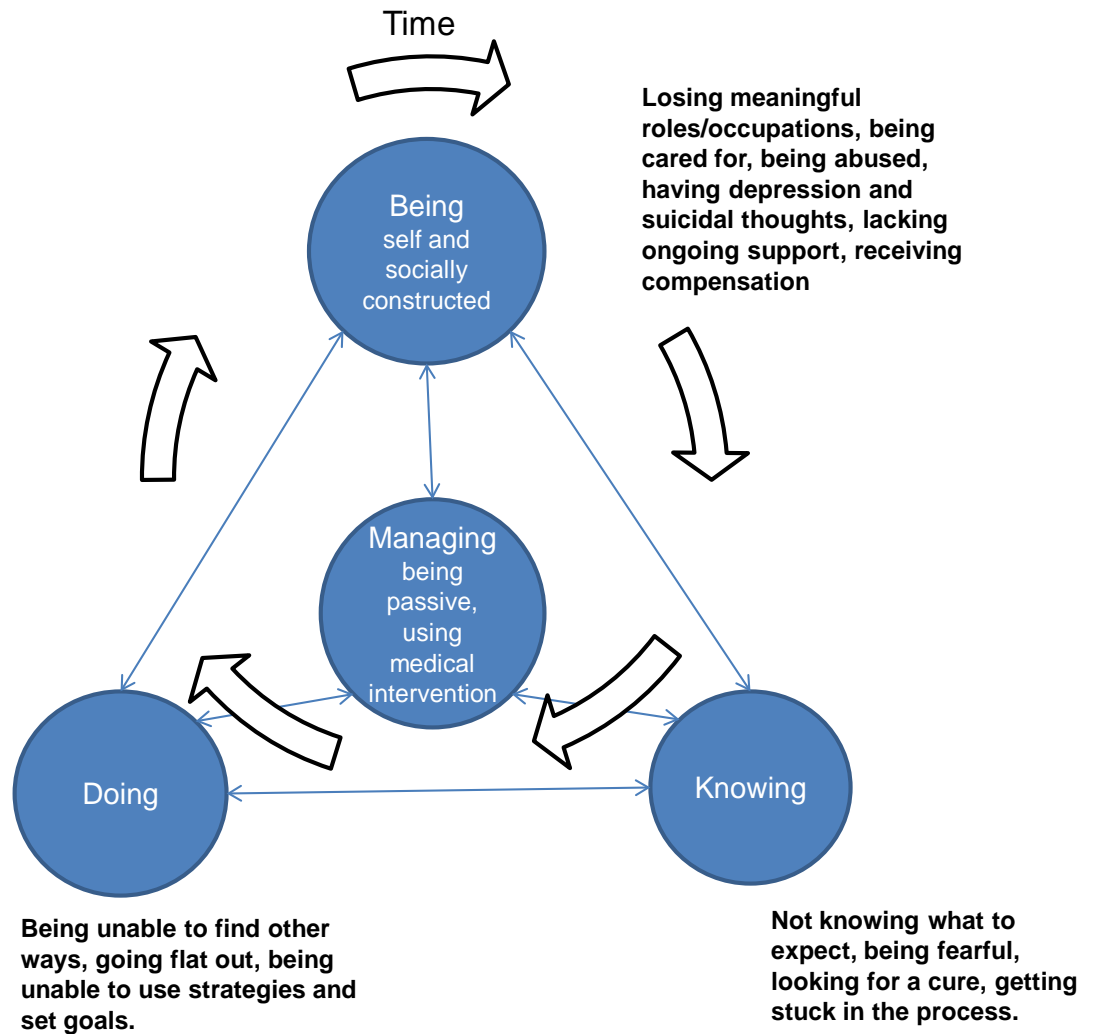


Figure 7.2: Victimic conceptual model. Based on victimic factors noted by PMP- and therapist-participants that influence chronic pain management.

7.5 Implication of Findings for Theory

Occupational therapy has been influenced by theories from a variety of disciplines including social and biomedical sciences and psychology. Theories from these areas have informed occupational therapy practice in chronic pain management. Within the context of this research, implications for theory generated here are applied to qualitative ways of knowing, psychological approaches, occupational science and narrative methods. How these inform knowledge about chronic pain management is explicated.

Rothwell (1998) noted that science does not occur without a specific context, and that qualitative approaches are also a “bringing into light of something that is taking account of its context” (p. 26). Comparison of results between the two groups (PMP- and therapist-participants) demonstrated that both held comparable views of what facilitates long-term pain management. Rothwell noted the quasi-linear approach in quantitative research of theory being generated by research, producing knowledge which is then applied to practice. He considered qualitative knowledge as having a more hermeneutical or circular paradigm, with theory being “as much in the activity as the activity is in theory” (p. 25). This circular or recursive paradigm is exemplified by the approach taken in this thesis. First, the literature reviewed resulted in a conceptual model to guide the questions examined in the research, which in turn influenced the methodology used (narrative inquiry). This method resulted in findings that in turn created new knowledge applicable to chronic pain management. This sequence is consistent with Rothwell’s description of the hermeneutic paradigm with theory informing method, and evaluation of practice generating further refinement of theory.

Frank and Polkinghorne (2010) noted that qualitative methods have been used in occupational therapy for three decades. They asserted that an “informed critical view” (p. 51) is required to move qualitative research from the first to the second generation. The first generation involves an appraisal of methods used in relation to theories and knowledge created. Within this thesis, in-depth analysis of the narratives led to knowledge generation in the form of recognition of common factors that influenced long-term pain management. Factors were considered from agentic or positive (internal locus of control) and victimic or negative (external locus of control) typologies (points of view). These factors related to self/person, meaning ascriptions around pain, strategies used, and the impact of the social world. Using this analytic lens led to the creation of agentic and victimic models related to the ongoing process of pain management. These models positioned the interaction of knowing, doing and being as integral to long-term management of pain. An awareness of these factors

in the process of moving from victim to agent in pain management is proposed as a useful framework to apply to practice.

Moving the results of this thesis to the “second generation” (Frank & Polkinghorne, 2010, p. 51) of qualitative research involves recognition of existing theory and its adaptation and expansion to the knowledge created here. In particular, the following theories are discussed: acceptance theory, psychological flexibility, Wilcock’s model of doing, being becoming (1999) and narrative theory.

Contemporary approaches to chronic pain include the so-called “third wave” (McCracken & Vowles, 2006, p. 90) of psychological approaches, such as acceptance theory and readiness for change, with a move away from operant and cognitive behavioural methods. These traditional methods were challenged empirically as far back as 20 years ago, by questioning the suitability of assuming “patient and treatment uniformity” (Turk, 1990, p. 255). According to Vowles and McCracken (2010), being flexible in the psychological approach taken involves the consideration of “additional processes and modes of coping that might be useful to integrate” into pain management (p. 145), such as acceptance of pain. Accepting pain and readiness for change were dominant findings in the meaning ascriptions of PMP- and therapist-participants about chronic pain management. Having a range of ways of thinking about pain and coping was highlighted in both PMP participants’ and therapists’ narratives as a significant agentic factor in ongoing pain management. “Knowing” therefore relates to people being flexible in ways of thinking about pain, and for therapists, to applying a range of coping strategies and methods. Maintaining awareness of psychologically flexible approaches to chronic pain management is therefore warranted as useful in practice.

Occupational science has identified that engaging in meaningful occupation is critical to wellbeing (Wilcock, 2005). Wilcock (1999) has proposed a model of doing, related to being and becoming, which was considered in this research. Based on the findings in this research, Wilcock’s model was applied and amended specifically for those with

chronic pain to denote the process over time of doing, being *and knowing* as integral to managing pain or otherwise. This research also considered existing models of occupational therapy theory that focus on the transaction between the person, occupation and environment to enable engagement in life (Polatajko et al., 2007). Models like the Canadian Model of Occupational Performance and Engagement (COPM-E) (Polatajko et al., 2007) acknowledge the inclusive nature of personal attributes influencing occupational engagement within a social, physical or cultural context. People with chronic pain value engagement in meaningful and mundane daily life. Being able to engage in “doing” is central to how they see themselves in relation to social roles and personal identity, or “being” within the social world. “Doing” is fundamental to occupational therapy. It is a core belief that doing is directly related to health and wellbeing (Wilcock, 2001). Findings from this research support previous occupational models and propose the conceptual model of “knowing”, “doing” and “being” as relevant to those with chronic pain and to occupational therapists in pain practice.

Narrative theory considers how people perceive themselves in relation to their past, present and future and how aspects of the self are socially constructed within a given context (Polkinghorne, 1988). For PMP participants, with chronic pain, the predominance of a positive or negative present, past and future outlook impacted on the resources they had to bring to ongoing pain management. These temporal elements are included in the agentic and victimic models as an ongoing cyclical process of change. Narrative approaches provide an opportunity for people to “tell the whole story”(Nilsen & Elstad, 2009, p. 51) and for health practitioners to appreciate the “progression of illness through its entire trajectory” (p. 52). Current medical paradigms focus on the presenting symptoms or the “here-and-now” (p.52) story rather than the process. This research proposes that narrative methods and life trajectories are a legitimate way of knowing where people are in the pain management process.

The agentic and victimic models represent a development of theory that synthesises and builds on existing theories to provide a comprehensive

overview of what influences pain management whilst considering individual difference.

7.6 Implication of Findings for Education and Practice

This section addresses the implications of the findings to entry-level occupational therapy education and occupational therapy practice. It considers education, evidence-based interventions, individual and group methods, importance of follow-up post intervention and use of narratives in practice.

In a systematic review of qualitative studies, Parsons et al. (2007) focused on clients' and primary care providers' beliefs and expectations about chronic pain management, and found conflict between the two groups. Divergent views related to difficulties in communication (listening to clients), education (non-adoption by clients or understanding of concepts), and suggested intervention (lack of intervention provided, lack of validation of pain). Parsons et al. advised that to address these differences, changes would be required in "undergraduate and post-graduate education" and "organization and availability of health services" (p. 91). Although their study focused on general practitioners (as primary care providers) within the U.K. National Health Service, Australian research supports their findings. The 2007 report by Access Economics into the economic impact of chronic pain in Australia produced similar findings, including the need for improved education and training in chronic pain for health professionals, as well as increased community awareness.

Occupational therapists working in chronic pain practice have a wide range of practice experience and level of expertise in the area (Brown, 2002). That was also apparent in this research. Occupational therapy undergraduate education may or may not specifically address chronic pain mechanisms and management, depending on curricula. One implication is that graduate occupational therapists working with people with chronic pain might not have up-to-date knowledge to meet the needs of their clientele. Also their awareness of programs for self-management of chronic conditions and chronic pain such as those promoted by Lorig and Holman (1993) and LeFort (2000) may be lacking. Investigating allied

health practitioner knowledge, Mosely (2003) found discrepancies in understanding and imparting pain education to clients. It is apparent that occupational therapy entry-level curricula should provide sufficient education about chronic pain mechanisms and management to prepare therapists for practice.

There is increasing research and discussion about the importance of evidence-based interventions and whether occupational therapists are operating using sound evidence-based practice. Some strategies used by PMP participants and taught by therapists for managing pain have a recognised, if somewhat limited, theoretical base (e.g., goal setting, pacing). Others (e.g., relaxation) are considered contentious, because existing research findings are compromised by lack of uniformity of delivery and method used (Brown & Pinnington, 2007). This research provides anecdotal evidence for the use of certain strategies, while noting the idiosyncratic way they are applied in everyday life (pacing, relaxation, goal setting). People adopt and modify methods that suit their individual lifestyles over time, to assist in pain coping.

In their study of occupational therapists' beliefs about an evidence base for chronic pain intervention, Brown and Pinnington (2007) found that therapists endorsed some treatments more than others regardless of the available evidence. This problem would appear to be long-standing, as Jones, Ravey and Steedman (2000) found that occupational therapists' "knowledge, beliefs and attitudes" (p. 232) about chronic pain lacked a sound evidence base. Within the profession there has also been a lack of congruence between occupational therapists' beliefs about the value of their service and strategies used in practice and those of service consumers (Brown, 2002, 2003). Findings from this research indicated that PMP- and therapist-participants held similar perspectives about what influenced long-term pain management. Although PMP participants did not highlight occupational therapists in particular, their ongoing use of strategies taught by therapists (such as pacing) suggests their perceived value. This could have been influenced by the length of time therapists had been in practice and specialising in this field. All therapist-participants

in this research had practised in chronic pain practice for at least 3 years. Several therapist-participants had undertaken postgraduate study or researched in the area of pain management. Most therapists felt that they had a positive contribution to make in assessment and intervention for their clients. Several therapist-participants acknowledged, however, that they did not regularly evaluate their programs and effectiveness of interventions. One therapist, Matt, wondered if his program made any difference to clients and, as it did not use measures to evaluate effectiveness, he was unsure of short- or long-term outcomes.

The results of this thesis would support the contention, based on prevalence and health care costs alone, that occupational therapists require current pain knowledge, as they will most likely encounter chronic pain in any practice setting. Education should focus on awareness, understanding and promotion of methods of chronic pain management. Research into methods of pain management from qualitative and quantitative perspectives is also warranted to support the use of these methods by occupational therapists and to provide a sound evidence base.

The Access Economics report (2007) supported a coordinated multidisciplinary approach to pain that takes into account psychological and functional interventions. It also saw the need for integrated in/outpatient services, but this has not been implemented in the existing health care system. The results of this research provide evidence to support the use of multidisciplinary pain programs that address group and individual needs in the short- to long term. The research indicated that the value of group interventions varies from person to person. Not all people appear suited to a group-based approach. Addressing chronic pain in a way that acknowledges a person's needs, knowledge, values and beliefs is therefore warranted. This supports the importance of the "knowing", "doing" and "being" aspects of the conceptual model proposed in this chapter.

Findings from this research showed that many PMP participants felt “cast adrift” after the completion of the PMP. The expectation that program participants would develop their own support networks was largely unfounded, because of lack of available community resources, problems of finance, and personal factors. Some therapist-participants reported being unable to follow-up clients actively due to lack of time and resources. Thus, long-term community-based support is lacking in both metropolitan and regional areas. Having suitable available support could assist individuals to manage in the long term when returning to the community.

Within occupational therapy practice, the clinical encounter is critical to establishing an authentic relationship with the client (person). Being person-centred is a core value of the profession, where the person is provided with the opportunity to engage actively in the therapy process. This involves autonomy and choice, partnership between the therapist and the individual, responsibility of both parties, and enablement of the individual (Law et al., 1995). Person-centred care is about placing people (including their family and carer/s) at the centre of their health care, with their needs and wishes seen as paramount (National Aging Research Institute, 2006). This thesis supports the use of narrative methods as a way of being person-centred by allowing people to share their story, be it positive or negative, as a way of exploring their ongoing condition.

The use of narrative as a therapeutic method has been explored by Frank (1995) and Kleinman (1988), both of whom noted the restorative power of narrative in making sense of illness or disease. Frank (2005) discussed the role of narrative in clinical care and proposed four premises of narrative medicine, namely that: (a) any medical worker can have a healing presence; (b) people experience stories of disease and pain; (c) stories can take care of people; and (d) this occurs when they evolve out of caring relationships.

Narrative approaches using life story work have gained recent research interest in the fields of medicine, nursing and allied health (Bingley, Thomas, Brown, Reeve, & Payne, 2008; Crogan, Evans, & Bendel, 2008; Gray, 2009). These approaches have been used in palliative care, elder care, developmental disability and chronic illness management. Narrative has been described as a “key communication strategy”, “clinical counselling strategy, an information gathering strategy and a teaching tool” (Gray, 2009, p. 258). McKeown, Clarke and Repper (2006), in a systematic review of life story work in health and social care, found that life stories could be used “as a basis for individualised care, improve assessment” (p. 237) and to improve relationships between health care providers and carers. They did conclude, however, that use of the methods was immature and that the literature rarely focused on “patient and carer views” (p. 237). Crogan et al. (2008) used storytelling as a clinical intervention for patients with cancer. They found that those assigned to the storytelling group had decreased stress and anxiety levels and improved pain and coping. Unlike many cancer treatments, storytelling was non-invasive and addressed patients’ psychosocial issues. This research, although using narrative as a data gathering tool only, evidenced the power of people sharing their pain or practice story. One PMP participant, Julia, found that telling her story acted as “therapy” when she was limited in her ability to use strategies around coping. Other PMP participants commented on how far they had come in their pain journey after being debilitated by pain and depression. The ability to reflect and share their stories in a voluntary capacity provided a restorative element, particularly as most participants noted that in dealings with health professionals they were required to legitimise their pain stories to be socially and culturally accepted. Therapists also enjoyed the opportunity to relate stories that reflected on their pain practice and particular case scenarios.

As noted by Garro and Mattingly (1998, p. 1), “stories can provide a powerful medium for learning and gaining understanding about others”.

Within the chronic pain literature a growing body of studies explores the use of narrative to understand the pain experience (Bullington et al., 2003; Keponen & Kielhofner, 2006; Peolsson et al., 2000; Richardson et al., 2006). Using narrative within practice is advocated as a way of getting in touch with the client, beyond the objective measures most usually employed in chronic pain practice. Narrative approaches were selected as the method of choice in this research, because generating stories gave rise to a deeper understanding of the pain experience. As evidenced within this research, people with pain wanted to share their story. In busy practice settings, however, particularly if cognitive behavioural methods are used, the pain story is often delegitimised in favour of dialogue around coping and positive thinking. Giving credence to the pain story authenticates the individual's pain experience. Thus this research proposes using narrative approaches as an adjunct to psychologically flexible methods in practice as an area for further study.

Acceptance and readiness for change have been found to be positive indicators of movement forward in the process of pain management (McCracken, 1998; McCracken et al., 2005; Vowles & McCracken, 2008). Within this research, acceptance and readiness factors were also common to the stories of both PMP- and therapist-participants. Having a level of acceptance about the long-term nature of chronic pain and implementing strategies enabled PMP participants to engage in valued roles and occupations. Acceptance and readiness were also seen as critical by therapist-participants to moving forward in the process of pain management. Using narrative methods to gauge acceptance and readiness for change prior to undertaking pain programs could provide more in-depth data on which to base decision making about the right time to participate in pain programs. Using narratives in addition to existing measures would provide a subjective dimension that could capture the subtle temporal aspects of moving through the pain process that are difficult to capture using quantitative measures alone. This has been demonstrated in medical, nursing and allied health literature, where narrative has been used to enhance assessment, negotiate clinical care in

response to grief and loss, and promote inclusive decision making for clients and their families (Gray, 2009; Keady, Ashcroft-Simpson, Halligan, & Williams, 2007; McKeown et al., 2006). The use of narrative approaches to gauge where the person is in the pain process is proposed as an area for future research, particularly when acceptance and readiness for change were significant findings here.

7.7 Conclusion

The next chapter situates the importance of the study in relation to knowledge about chronic pain. Recommendations for occupational therapy practice are stated, as are research issues encountered. Self-reflection on the research process and future research directions are also discussed, and conclude this thesis.

CHAPTER 8: CONCLUSION – REFLECTIONS AND RECOMMENDATIONS

8.1 Introduction

This thesis has identified factors associated with long-term pain management for people post-pain management intervention. This has been considered from the perspectives of participants of a 3-week PMP and of occupational therapists working in chronic pain practice. This final chapter considers the following: impact/importance of the study; recommendations for occupational therapy practice; limitations of the study; self-reflection as a researcher; and recommendations for future research in this area.

8.2 Impact/Importance

In Australia, chronic pain is third only to cardiovascular disease and musculoskeletal conditions in terms of health expenditure (Access Economics, November 2007, p. 51). In 2007, loss of productivity, burden of disease and disability support contributed to an estimated cost of \$34.3 billion in Australia alone (Access Economics, November 2007). The prevalence and health care costs of chronic pain have been noted in many parts of the Western world (Aegler & Satink, 2009; Dean, Smith, Payne, & Weinman, 2005; Oslund et al., 2009). Addressing chronic pain effectively within health service provision and within the community in general therefore appears to be imperative.

Management of chronic pain has moved away from a biomedical to a biopsychosocial approach as a way of “understanding how suffering, disease and illness are affected by multiple levels of organization from the societal to the molecular” (Martensson & Dahlin-Ivanoff, 2006, p. 985). To be cost effective, many chronic pain programs are delivered in a group context. The majority of these programs use cognitive behavioural methods to change people’s thinking about chronic pain and coping (Jensen et al., 2005). The effectiveness of group programs has been

demonstrated in some functional domains such as depression and quality of life (Vowles & McCracken, 2010), but findings about aspects such as pain severity have been equivocal (Sullivan et al., 2009). Chronic pain is a subjective experience mitigated by many factors, including personality type, behaviour, social support, gender, and influence of health care interventions (Ashghari & Nicholas, 2001; Jensen et al., 2005; Richardson et al., 2007).

Qualitative research, which considers the subjective experience of those living with chronic pain, has increasingly been identified as providing empirical evidence across a number of personal dimensions. These dimensions include people's beliefs about pain, its impact on engagement in occupations, and experiences of attending biopsychosocial chronic pain programs (Keponen & Kielhofner, 2006; Parsons et al., 2007; van Huet et al., 2009). Few studies have examined the impact of chronic pain beyond 12 months post-chronic pain intervention (Jensen et al., 2005; van Huet et al., 2009). There is little research addressing how people live with chronic pain on an ongoing basis. In this thesis I aimed to add to knowledge about long-term pain management. I considered the perspectives of those who experienced chronic pain and the occupational therapists who worked in chronic pain practice. Research seeking the viewpoints of both groups within the same study is also limited (Brown, 2003). Again, this is an issue this thesis aimed to address. Often, as illustrated in Chapters 5 and 6, the findings resonated between the PMP participants and therapists. This was particularly the case in regard to themes of acceptance of pain, readiness for change, engagement in meaningful roles and occupations, influence on identity, and social support. There was some dissonance between and within the two groups, however, in perceptions of which aspects of pain programs were helpful. These aspects included the effectiveness of cognitive behavioural methods and of various strategies such as relaxation and exercise, and the lack of evidence noted by some therapist-participants to support the use of various strategies (e.g., goal setting). Tangible outcomes supporting pain interventions were also lacking, with several programs/practice areas failing to use outcome measures to

evaluate post-program intervention. The implications of these findings were discussed in the preceding chapter (Sections 7.5, 7.6) from both theory and practice perspectives.

This research highlighted that chronic pain is an ongoing experience. As evidenced by this research, the value of chronic pain interventions is influenced by the person, their thinking about pain, strategies used and social support. It is important that programs and interventions meet individual needs, are evidence-based and are evaluated on merit. Pain management is also time contingent and dependent on where the person is in the pain process. Being agentic or victimic in pain management influenced whether the person moved forward or was stuck in the process. Providing appropriate ongoing support post-intervention is limited in current treatment paradigms. Returning to the community and having access to good social support and resources was found to be imperative to long-term management in this research. The following section details recommendations based on the findings for occupational therapy and chronic pain practice.

8.3 Recommendations for Occupational Therapy and Chronic Pain Practice

The following recommendations for occupational therapy and chronic pain practice were derived from the findings:

- Qualitative approaches using narrative methods are suitable ways of exploring a person's chronic pain experience. Exploration of how narrative methods can be incorporated into occupation therapy practice is warranted.
- Analysis of narratives can identify whether agentic or victimic factors are predominant in the person's narrative. These could be applied in conjunction with standardised assessment methods, in determining pain acceptance and readiness for change.

- Flexibility in applying psychological approaches to chronic pain, rather than applying one method only, may best meet the needs of individuals. This can be achieved by incorporating mindfulness approaches into chronic pain practice as is currently occurring in Australia.
- Although certain strategies (e.g., pacing) were helpful for most PMP participants here, no strategies were universally endorsed. Therefore being competent in and providing a range of evidence-based strategies is indicated in chronic pain practice to meet individual needs. For many strategies no current evidence base exists and therefore recommended strategies rely on future research into their efficacy.
- Routine evaluation of the outcomes of pain programs and occupational therapy interventions would enhance the evidence base of programs and interventions currently provided. This would appear mandatory in supporting the current focus on evidence-based practice in health care.
- Promotion and provision of ongoing support from family, friends and within communities for people with chronic pain in the long term is indicated. Promoting sustainability of support within communities needs addressing.

Clinical application of these recommendations has implications on therapists' time available within programs, education into emerging treatment approaches at an undergraduate to post-graduate level and research to establish/support the evidence base for the recommendations. A consideration of future research recommendations is addressed in Section 8.6.

8.4 Research Issues Encountered

Within any research process, problems are encountered, whether quantitative or qualitative approaches are used. In the exploration of human experience both methods can involve methodological, conceptual and practical conundrums.

One methodological issue commonly cited when qualitative research is used is its limited generalisability across groups. As qualitative research aims for a deeper understanding of a phenomenon, being able to generalise findings to others was not the aim here. Transferability is, however, assumed in quantitative research. Curtin and Fossey (2007, p. 92) have asserted that transferability should apply to qualitative research if “detailed descriptions” of participants are provided to enable “the reader to make comparisons with other individuals and groups”. It can be argued that through introducing the participants and providing detailed stories, comparison to other individuals in similar circumstances can be made.

Conceptual limitations within qualitative research centre on issues of representation, trustworthiness, and power within research relationships (Cohn & Lyons, 2003; Curtin & Fossey, 2007). Within this research the perspectives of past participants of a chronic PMP and of therapists working in chronic pain settings were represented. Narrative accounts from both groups were used as data for analysis, using narrative inquiry to elicit themes of factors contributing to ongoing chronic pain management.

A potential limitation to representation could have been that Stage 1 participants were sourced from one PMP only. However as explained in Section 3.6.2.1, this was done for reasons of accessibility to participants for me the researcher and for the uniformity of chronic pain information that had been provided to those PMP participants. The lack of inclusion of family members/carers of people with chronic pain or members of the broader community who have not experienced chronic pain could be seen as a restriction on representation. That, however, was not the purpose of this study. I aimed to embody the perspectives of people with pain and of occupational therapists who work with such people. It was noted that between the Stage 1 and Stage 2 participants comparable results were found in the value of acceptance, readiness for change, engagement in meaningful occupations and roles, and having good social support. But not all results were similar. When taking into account individual perspectives regarding treatment programs and strategies, areas were highlighted that

could provide directions for the future development of PMPs. These areas are discussed in Section 8.5.

The range of therapist-participants interviewed included therapists considered early-career practitioners and others considered elite in terms of years of experience. Their perspectives could therefore differ appreciably, depending on level of knowledge and practice experience. This mix is representative of the profession, which is predominantly female, has a younger median age than other allied health professions and a higher turnover rate (Allied Health Professional Workforce Planning Group, 2002).

In terms of trustworthiness, elements of “thick description, triangulation, member checking, collaboration, transferability and reflexivity” (Curtin & Fossey, 2007, p. 88) are seen as indicative of authenticity in qualitative studies. The use of thick descriptions is evident in the findings chapters (Chapters, 4, 5 and 6). Condensing the narratives was difficult while ensuring that the *in vivo* language of participants and the richness of the data were retained. Researcher triangulation was achieved through transcripts being analysed by me and the two supervisors at that time. Data triangulation was obtained by seeking perspectives from two groups, PMP participants and therapists. Member checking occurred by sending interview summaries to all participants, which allowed them “to read, comment on and contribute to the findings” (Curtin & Fossey, 2007, p. 92). Follow-up interviews also occurred with all PMP- and some therapist-participants. This provided the opportunity to clarify meanings and misconceptions and also allowed time for participants to reflect on questions asked in previous encounters. Collaboration, whereby the researched become part of the research process in terms of informing design and analysis, did not occur in this study, which could be seen as a limitation. However the authenticity of the narrative encounter was evident from the in-depth sharing of personal information, the insights provided and the positive messages given to the interviewer about the value of the

interview process. The final element of trustworthiness, reflexivity, is discussed in the reflections on the research process (Section 8.4).

Interpretive research designed to understand human experience must respect the integrity of the research participants. Issues of power within the research relationship need to be acknowledged. Power relates to being heard, being represented, and having one's contribution matter in the research process. However power can also potentially "oppress others, reproduce inequality, or minimise the perspective of others" (Cohn & Lyons, 2003, p. 40). To address issues of power within this research the following were implemented: (a) PMP participants were informed that the researcher did not belong to or represent the PMP; (b) PMP participants chose the venue for their interviews, which in the main was the person's place of residence; (c) therapist-participants were made aware of the researcher's background in chronic pain practice and of previous research conducted; (d) therapist-participants chose the venue for interview, either in their practice setting or in the community; and (e) both groups were provided with summaries of transcripts for comment, addition or deletion of information. Moreover, the core values of the occupational therapy profession promote person-centred practice that respects equality, justice, dignity and truth for the people seen in practice. I value these core principles and thus they were taken into account when I engaged in the storytelling process with PMP- and therapist-participants.

Even when the above features are taken into account, some PMP participants might have perceived me as representing the PMP. This could have influenced the findings from the research. Therapist-participants might have felt that their programs required justification in the approach and strategies used. This also could have influenced their answers, as most saw few limitations within their current practice. Only one therapist-participant was critical of his particular pain program overall.

The use of evidence-based practice in occupational therapy is widely accepted across the profession (Lin, Murphy & Robinson, 2010). Allocation of allied health care expenditure is dependent on outcomes, and occupational therapists are increasingly responsible for providing evidence that their services are useful and cost effective for their clients. Positivist methods of research that have been seen as “best evidence” (Carpenter, 2004, p. 3) are being challenged in clinical practice. This has been witnessed in the “theory–practice gap” (Welch & Dawson, 2006, p. 227) that exists when trying to apply objective knowledge to subjective human experience. Recognition of the need for greater methodological diversity means that qualitative methods are becoming increasingly valued as forms of evidence. In acknowledging issues of transferability, representation, trustworthiness and power, a conscious endeavour is made to attain transparency in the research process. That has been the intention in this thesis. This research contributes to and strengthens existing research into chronic pain management by representing the perspectives of both PMP- and therapist-participants. The processes applied to the research aimed to ensure that the findings can contribute to current epistemology.

8.5 Reflections on the Research Process

Reflexivity involves “the conscious examination of the position of the researcher within the research” (Whalley-Hammell, 2004, p. 15). As the researcher, I was an active participant in the research, influencing the process and entering relationships with participants having assumed values and beliefs. Acknowledging bias is critical to qualitative research. Lather (1986) argued that it is impossible in any research process to avoid self-interest or unconscious bias. She advocated processes of inquiry that involved “negotiation, reciprocity and empowerment” to achieve “research as praxis” (p. 257). I was aware of my views about chronic pain management, gained from working in the area over many years. I was also aware of the tension I experienced in practice when programs in which I worked did not meet the needs of those who attended them. This might have affected questions asked in the narrative process and could

have influenced participants, particularly those who held similar views. Participants could choose not to answer questions and were reminded of this during interviews if sensitive matters arose. I was also aware at times that some participants had views that differed markedly from mine. Reflective listening was therefore required to ensure that information was interpreted as intended by participants, not by me assigning meaning to it. Some narrative encounters were noted in my journal as difficult due to the sensitivity of the material imparted, and the beliefs, values and personality of the participants. Debriefing and journaling these encounters enabled me to reflect on the experience and provided a context for considered interpretation based on the rigorous process of data analysis. Participants were encouraged to talk freely about issues of concern or interest that might not have been directly related to the research. Although this meant that some information gathered was not of direct relevance to the research (e.g., significant details about Bill's book), it allowed participants to share parts of their life stories that had particular importance to them. This may have resulted in the position stated by most PMP participants that the process of reflection on their pain experience had in some way been emancipatory.

Epistemic reflexivity has been proposed by Kinsella and Whiteford (2009, p. 249) as "reflexivity that can be used to critique and contribute to our disciplinary knowledge". They proposed a "conception of practice knowledge that is informed by evidence yet based on... wise practice". This thesis has proposed implications for theory and for training and practice as well as recommendations for occupational therapists working in chronic pain, based on knowledge generated from the research. Occupational therapists' beliefs and values are based on social models of health that enable emancipatory action for their clients. Wise practice therefore mandates that these beliefs and values be reflected in the service that therapists provide and the evidence base from which "knowledge-producing practices" (p. 257) are sourced.

8.6 Implications for Further Research (Recommendations)

Future research directions that arose from this thesis include the following:

- Exploring individual versus group chronic pain program participation
- Discovering the benefits of narrative as a way of providing care within the therapeutic relationship and as a tool to facilitate intervention in occupational therapy practice specific to chronic pain
- Investigating the value of using psychologically flexible approaches that include acceptance of pain rather than using a single coping method (i.e., CBT)
- Continuing research into strategies commonly used within pain management programs, such as pacing, goal setting, relaxation, and engagement in meaningful occupation
- Conducting further research into the long-term impacts of living with chronic pain across a longer time frame (i.e., 5 years or more)
- Investigating the value of provision of booster programs and longer term follow-up for people post-chronic pain intervention.

8.7 Closing Message

The ultimate goal of any research process is the production of an “insightful, relevant and responsive piece of work” (Goodfellow, 1998, p. 115). This research thesis has provided an opportunity for people with chronic pain, and occupational therapists who work with them, to voice their perspectives about what influenced pain management in the long term for them. The stories people have shared of living with pain every day are a testament to their ability to manage difficult life circumstances. They hoped that sharing their stories would in turn help others who find themselves in similar circumstances.

I have been privileged to hear the stories from both groups and to represent their perspectives within this thesis.

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Appendix A: Information letter and consent form for Stage 1 participants



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 1825
Telephone: +61 2 9351 9209
Facsimile: +61 2 9351 9197

INFORMATION STATEMENT

STUDY TITLE: "AN EXPLORATION OF THE OCCUPATIONAL SELF IN OCCUPATIONAL ROLE PERFORMANCE FOR PEOPLE WITH CHRONIC PAIN"

You are invited to participate in a research study looking at how living with chronic pain influences the things that you do everyday.

You have been invited to participate in this current study because you were a previous participant in a study conducted between the Wodonga Regional Health Service and Charles Sturt University, entitled *An exploration of the relationship between self-efficacy and occupational performance for people with chronic pain*, whilst you were involved in the Pain Program.

We are again seeking your assistance to participate in exploring how you are living with your pain now.

This study will involve two 1½ hour interviews. This will take the form of asking you questions about your current pain, what you do over a typical day and how the pain may influence what you do.

You can choose to be interviewed at one of the following locations that best suits you:

- An interview room at the Albury campus of Charles Sturt University;
- Your place of work; or
- Your home.

It is planned that these interviews will be audio-tape recorded, then typed out. You will receive a typed summary of the interview for your comment and approval for use in the study.

All information will be strictly confidential and no personal identifying information will be used during interviews or in the typed interview content. All typed interviews and tape recordings will be stored in a locked filing cabinet by one of the researchers for seven years. After this time the typed interviews will be shredded and the tapes erased. Data gathered during the study may be published in appropriate professional journals or presented at professional conferences in the future. In any publication or presentation, information will be presented in a way so that you cannot be identified.

You are able to withdraw from this study at any time if you wish, without an explanation being required.

If you agree to participate in this study, please complete the attached consent form with a contact phone number and return it in the reply-paid envelope attached to:

Helen van Huet
School of Community Health
Charles Sturt University
PO Box 789
ALBURY, NSW 2640.

Ph: (02) 6051 6746
Email: hvanhuet@csu.edu.au

This study is being conducted to meet the requirements for the Masters of Applied Science (Occupational Therapy) by Helen van Huet under the supervision of Dr Ev Innes of the School of Occupation and Leisure Sciences, at The University of Sydney.

If you have any additional questions or would like to discuss the study further please contact Helen van Huet on (02) 6051 6746 or Dr Ev Innes on (02) 9351 9209.

Any complaints about the conduct of this research can be directed to the Manager for Ethics Administration, Gail Briody, University of Sydney on (02) 9351 4811 or email: gbriody@mai.usyd.edu.au

Thank you for your consideration in participating.

Helen van Huet, BAppSc(OT)
MAppSc(OT) candidate (USyd)
Lecturer
School of Community Health
Charles Sturt University
Tel: (02) 6051 6746

Dr Ev Innes, PhD, AccOT
Senior Lecturer
School of Occupation & Leisure Sciences
Faculty of Health Sciences
The University of Sydney
Tel: (02) 9351 9209



CONSENT FORM

STUDY TITLE: "AN EXPLORATION OF THE OCCUPATIONAL SELF IN OCCUPATIONAL ROLE PERFORMANCE FOR PEOPLE WITH CHRONIC PAIN"

1. I,, agree to participate as a participant in the study described in the attached subject information statement.
2. My contact telephone number is
3. I acknowledge that I have read the Subject Information Statement, which explains why I have been selected, the aims of the study and the statement has been explained to me to my satisfaction.
4. Before signing the consent form I have been given the opportunity to ask any questions and have received satisfactory answers to any questions I have asked.
5. I understand that I can withdraw from the study at any time.
6. I agree that the research data gathered from the results of the study may be published, provided that I cannot be identified.
7. I understand that if I have any questions relating to my participation in this research, I may contact Helen van Huet on (02) 6051 6746, who will be happy to answer them.
8. I acknowledge a receipt of a copy of this consent form and the subject information statement.

Participant's Name

Signature

Date

Witness's Name

Signature

Date

REVOCAION OF CONSENT

I hereby wish to withdraw my consent to participate in the research described above.

Participant's Name

Signature

Date

The section for revocation of consent should be forwarded to:
Helen van Huet, School of Community Health, Charles Sturt University, PO Box 789, ALBURY 2640.

Dr. Ev Innes
Senior Lecturer
School of Occupation & Leisure Sciences
The University of Sydney
Tel: (02) 9351 9209

Helen van Huet
Lecturer
School of Community Health
Charles Sturt University
Tel: (02) 6051 6746

Appendix B: Information letter and consent form for Stage 2 participants



The University of Sydney

School of Occupation and Leisure Sciences

Faculty of Health Sciences
College of Health Sciences

Cumberland Campus C42
East Street (PO Box 170)
Lidcombe NSW 1825
Telephone: +61 2 9351 9209
Facsimile: +61 2 9351 9197

INFORMATION STATEMENT

STUDY TITLE: "AN EXPLORATION OF THE OCCUPATIONAL SELF IN OCCUPATIONAL ROLE PERFORMANCE FOR PEOPLE WITH CHRONIC PAIN-CLIENTS' AND THERAPISTS' PERSPECTIVES"

You are invited to participate in a research study exploring occupational therapists perceptions of clients who experience chronic pain. This study is Stage 2 of previous research that focussed on clients perceptions of identity and role performance related to their occupations when living with chronic pain. The clients in the previous study had been participants in a cognitive-behaviourally based pain management program.

You have been invited to participate in this current study because you are working in a chronic pain management in- or out- patient program that utilises a cognitive-behavioural framework as part of the pain management process. We are seeking your assistance to look at what strategies/factors influence clients' ability to manage their pain and the impact of cognitive-behavioural methods on this. We will also be seeking your experiences of when clients most benefit from participation in pain management programs.

This study will involve in-depth interviews of occupational therapists working in chronic pain programs. The time commitment is expected to be two 1½ hour interviews that can be performed at your place of work, by phone or at the Albury-Wodonga campus of Charles Sturt University. You will be asked questions about the pain program in which you work, the clients' who utilise your program and the factors which predicate success for those clients.

It is planned that these interviews will be audio-tape recorded, then transcribed. You will receive a typed summary of the interview for your comment and approval for use in the study.

All information will be strictly confidential and no personal identifying information will be used during interviews or in the transcribed interview content. All transcribed interviews and tape recordings will be stored in a locked filing cabinet by one of the researchers for seven years. After this time the transcribed interviews will be shredded and the tapes erased. Data gathered during the study may be published in appropriate professional journals or presented at professional conferences in the future. In any publication or presentation, information will be presented in a way so that you cannot be identified.

You are able to withdraw from this study at any time if you wish, without an explanation being required.

If you agree to participate in this study, please complete the attached consent form with a contact phone number and return it in the reply-paid envelope attached to:

Helen van Huet
School of Community Health
Charles Sturt University
PO Box 789
ALBURY, NSW 2640.

Tel: (02) 6051 6746
Email: hvanhuet@csu.edu.au

This study is being conducted to meet the requirements for a Doctor of Philosophy degree by Helen van Huet under the supervision of Dr Ev Innes of the School of Occupation and Leisure Sciences, at The University of Sydney, and Professor Gail Whiteford, School of Community Health, Charles Sturt University.

If you have any additional questions or would like to discuss the study further please contact Helen van Huet on (02) 6051 6746 or Dr Ev Innes on (02) 9351 9209.

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@mail.usyd.edu.au (Email).

Thank you for your consideration in participating.

Helen van Huet, BAppSc(OT)
PhD(OT) candidate (USyd)
Lecturer
School of Community Health
Charles Sturt University
Tel: (02) 6051 6746

Dr Ev Innes, PhD, AccOT
Senior Lecturer
School of Occupation & Leisure Sciences
Faculty of Health Sciences
The University of Sydney
Tel: (02) 9351 9209



CONSENT FORM

**STUDY TITLE: "AN EXPLORATION OF THE OCCUPATIONAL SELF IN
OCCUPATIONAL ROLE PERFORMANCE FOR PEOPLE WITH CHRONIC PAIN-
CLIENTS' AND THERAPISTS' PERSPECTIVES"**

1. I,, agree to be a participant in the study described in the attached Subject Information Statement.
2. My contact telephone number is ... * **Please complete**
3. I acknowledge that I have read the Subject Information Statement, which explains why I have been invited to participate. The aims of the study and the statement have been explained to me to my satisfaction.
4. Before signing the consent form I have been given the opportunity to ask any questions and have received satisfactory answers to any questions I have asked.
5. I understand that I can withdraw from the study at any time without penalty.
6. I agree that the research data gathered from the results of the study may be published, provided that I cannot be identified.
7. I understand that if I have any questions relating to my participation in this research, I may contact Helen van Huet on (02) 6051 6746, who will be happy to answer them.
8. I acknowledge a receipt of a copy of this consent form and the Subject Information Statement.

Participant's Name

Signature

Date

REVOCAION OF CONSENT

I hereby wish to withdraw my consent to participate in the research described above.

Participant's Name

Signature

Date

The section for revocation of consent should be forwarded to:
Helen van Huet, School of Community Health, Charles Sturt University, PO Box 789, ALBURY
2640.

Dr. Ev Innes
Senior Lecturer
School of Occupation & Leisure Sciences
University of Sydney
Tel: (02) 9351 9209

Helen van Huet
Lecturer
School of Community Health
Charles Sturt University
Tel: (02) 6051 6746

Appendix C: Ethics approvals



The University of Sydney

NSW 2006 Australia

COPY

Human Research Ethics Committee
www.usyd.edu.au/ethics/human

Manager:

Gail Briody

Telephone: (02) 9351 4811

(02) 9351 4474

Facsimile: (02) 9351 6706

Email: gbriody@mail.usyd.edu.au

Rooms L4.14 & L4.13 Main Quadrangle A14

Human Secretariat

Telephone: (02) 9036 9309

(02) 9036 9308

(02) 9351 4474

Facsimile: (02) 9036 9310

Email: r.todd@reschols.usyd.edu.au

02 December 2004

Dr E Innes
School of Occupation and Leisure Sciences
Faculty of Health Sciences
Cumberland Campus – C42
The University of Sydney

Dear Dr Innes

I am pleased to inform you that the Human Research Ethics Committee at its meeting on 22 November 2004 approved your protocol entitled **"How the occupational self is perceived within occupational role performance for people living with chronic pain"**

Details of the approval are as follows:

Ref No.:	11-2004/4/7862
Approval Period:	November 2004 – November 2005
Completion Date of Project:	31 December 2007
No. of Participants:	12
Authorised Personnel:	Dr E Innes Ms H van Huet Ms A Hillman Professor G Whiteford

To comply with the *National Statement on Ethical Conduct in Research Involving Humans*, and in line with the Human Research Ethics Committee requirements this approval is for a 12-month period. At the end of the approval period, the HREC will approve extensions for a further 12-month, subject to a satisfactory annual report. The HREC will forward to you an Annual Progress Report form, at the end of each 12-month period. **Your first report will be due on 30 November 2005.**

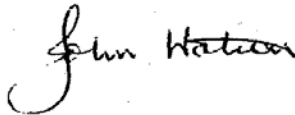
Conditions of Approval Particular to this Project

- (1) Amend the Participant Information Sheet: Page 2 of 2, penultimate paragraph: Delete "Gail Briody" and "or email: gbriody@mail.usyd.edu.au".
- (2) Amend the Consent Form: Remove witness section.

Conditions of Approval Applicable to all Projects

- (1) Modifications to the protocol cannot proceed until such approval is obtained in writing. (Refer to the website www.usyd.edu.au/ethics/human under 'Forms and Guides' for a Modification Form).
- (2) The confidentiality and anonymity of all research subjects is maintained at all times, except as required by law.
- (3) All research subjects are provided with a Participant Information Sheet and Consent Form, unless otherwise agreed by the Committee.
- (4) The Participant Information Sheet and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee.
- (5) The following statement must appear on the bottom of the Participant Information Sheet. ***Any person with concerns or complaints about the conduct of a research study can contact the Manager, Ethics Administration, University of Sydney, on (02) 9351 4811.***
- (6) The standard University policy concerning storage of data and tapes should be followed. While temporary storage of data or tapes at the researcher's home or an off-campus site is acceptable during the active transcription phase of the project, permanent storage should be at a secure, University controlled site for a minimum of seven years.
- (7) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely



**Associate Professor J D Watson
Chairman
Human Research Ethics Committee**

Encl. Information Statement
Consent Form
Interview Guide

Cc: Ms Helen van Huet, PO Box 786, Albury NSW 2640

Wednesday, December 22, 2004

Ms Helen van Huet
School of Community Health
CSU
PO Box 786
Albury
NSW 2640



Study Number 2004/37

Dear Ms van Huet

I refer to your application for Greater Murray Area Health Service Ethics Committee approval to undertake a research project Occupational self, occupational role performance and chronic pain.

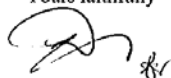
The application was considered by the Committee at their meeting on 16/12/2004 and approval has been given to proceed with the project. Please note the requirements for data maintenance as set out in the National Statement.

Please note that approval for this research is on the basis that the researchers accept responsibility for conducting the study in accordance with the principles contained in the National Statement on Ethical Conduct in Research Involving Humans, the Privacy Act and any other legal statutes. The National Statement can be accessed on <http://www.nhmrc.gov.au/publications/humans/ccontents.htm>

In order to ensure that any research undertaken within the Health Service complies with our ethical standards, it is our policy to allocate a member of staff to act as research monitor. The Director of Public Health will fulfill this role with respect to your study and you are asked to keep him/her fully informed on the progress of the research and any problems that may arise.

It is noted that the date for completion of the study is 31/12/2007 and the GMAHS Ethics Committee requires that you provide them with a final report detailing the methodology and your compliance with the record keeping sections of the National Statement. *Interim reports on the progress of the study should be made on an annual basis with the first of these being due on 31/12/2005.*

Yours faithfully



Dr. Paul Curtis
Director of Clinical Services

AREA OFFICE POSTAL ADDRESS: LOCKED MAIL BAG 10 WAGGA WAGGA NSW 2650
63 JOHNSTON STREET WAGGA WAGGA. PHONE: (02) 6933 9100 FAX: (02) 6933 9104
WEBSITE: www.gmahs.nsw.gov.au



The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee

www.usyd.edu.au/ethics/human

Senior Ethics Officer:

Gail Briody

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Human Secretariat

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(02) 9351 4474

Facsimile: (02) 9036 9310

Email: roslyn.todd@usyd.edu.au

bdleon@usyd.edu.au

COPY

18 July 2006

Dr E Innes
School of Occupation and Leisure Sciences
Faculty of Health Sciences
Cumberland Campus - C42
The University of Sydney

Dear Dr Innes

I am pleased to inform you that the Human Research Ethics Committee at its meeting on 11 July 2006 approved your protocol entitled **"The occupational self in occupational role performance for people living with chronic pain: Clients' and therapists' perceptions"**

Details of the approval are as follows:

Ref No.:	07-2006/9375
Approval Period:	July 2006 – July 2007
Authorised Personnel:	Dr E Innes Ms H van Huet Professor G Whiteford

The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans*. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

The project is approved for an initial period of 12 months with approval for up to three (3) years following receipt of the appropriate report. **Your first report will be due on 31 January 2007.**

Conditions of Approval Applicable to all Projects


(1) Reporting of Serious Adverse Events

Researchers should immediately report anything to the Human Research Ethics Committee which might warrant review of ethical approval of the protocol, including:

- Serious or unexpected adverse effects on participants;

- Proposed changes in the protocol or any other material given to the participants in the study must be known prior to being actioned, including participant information and consent forms; and
 - Unforeseen events that might affect continued ethical acceptability of the project.
- (2) Modifications to the protocol cannot proceed until such approval is obtained in writing. (Refer to the website www.usyd.edu.au/ethics/human under 'Forms and Guides' for a Modification Form).
 - (3) The confidentiality and anonymity of all research subjects is maintained at all times, except as required by law.
 - (4) All research subjects are provided with a Participant Information Sheet and Consent Form, unless otherwise agreed by the Committee.
 - (5) The Participant Information Sheet and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee.
 - (6) The following statement must appear on the bottom of the Participant Information Sheet. ***Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811.***
 - (7) The standard University policy concerning storage of data and tapes should be followed. While temporary storage of data or tapes at the researcher's home or an off-campus site is acceptable during the active transcription phase of the project, permanent storage should be at a secure, University controlled site for a minimum of seven years.
 - (8) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely



**Associate Professor J D Watson
Chairman
Human Research Ethics Committee**

Cc: Ms Helen van Huet, School of Community Health Sciences, Charles Sturt University, Albury,
PO Box 786, Albury NSW 2640

Appendix D: Sample questions for Stage 1 participants

Sample questions for Stage 1 PMP Participants.

- What roles do you have in your life right now?
 - Qualifying question: Could you tell me a bit about your life right now? (self and roles)
- What do you do over a typical day/week? (activities and tasks related to routines)
 - Qualifying questions: What activities do you enjoy doing?
 - How does your pain impact on what you do each day/week?
- Can you tell me about your childhood? (social, cultural environment)
 - Qualifying question: When you were growing up, how did your parents react when you were in pain? (cultural beliefs)
- Could you tell me about how you came to be on the PMP? (social environment)
 - Qualifying question: Could you tell me about how you developed chronic pain (self)?
- Could you tell me about the PMP? (social, physical environment)
 - Qualifying questions: Could you tell me what you did on the program?
 - What did/didn't you enjoy on the program?
- What was the overall message you got from the PMP about how to manage your pain? (program approach, cognitive-behavioural methods)

Appendix E: Examples of Reflexive Journal entries

Dawn - 3. B.P. 8/6/05.

Boy, what a lady.

She reminds me of a tender - never lets go.

She has so many ideas - speaks in sayings - motifs.

Lots seems to come from her dad → he seems to have been very important in her life - main person.

She seems to have developed traits from family - never give in etc.

Strength → a word that describes her & wants to help others, helps herself by keeping in front of the pain.

lots of anger over Worcester.

- Says she never experienced loss - a bit ambivalent about this I think

What about I (husband)? very close supportive of each other. She is

'pragmatic' - I think she would be strong in most situations a 'doer' - my

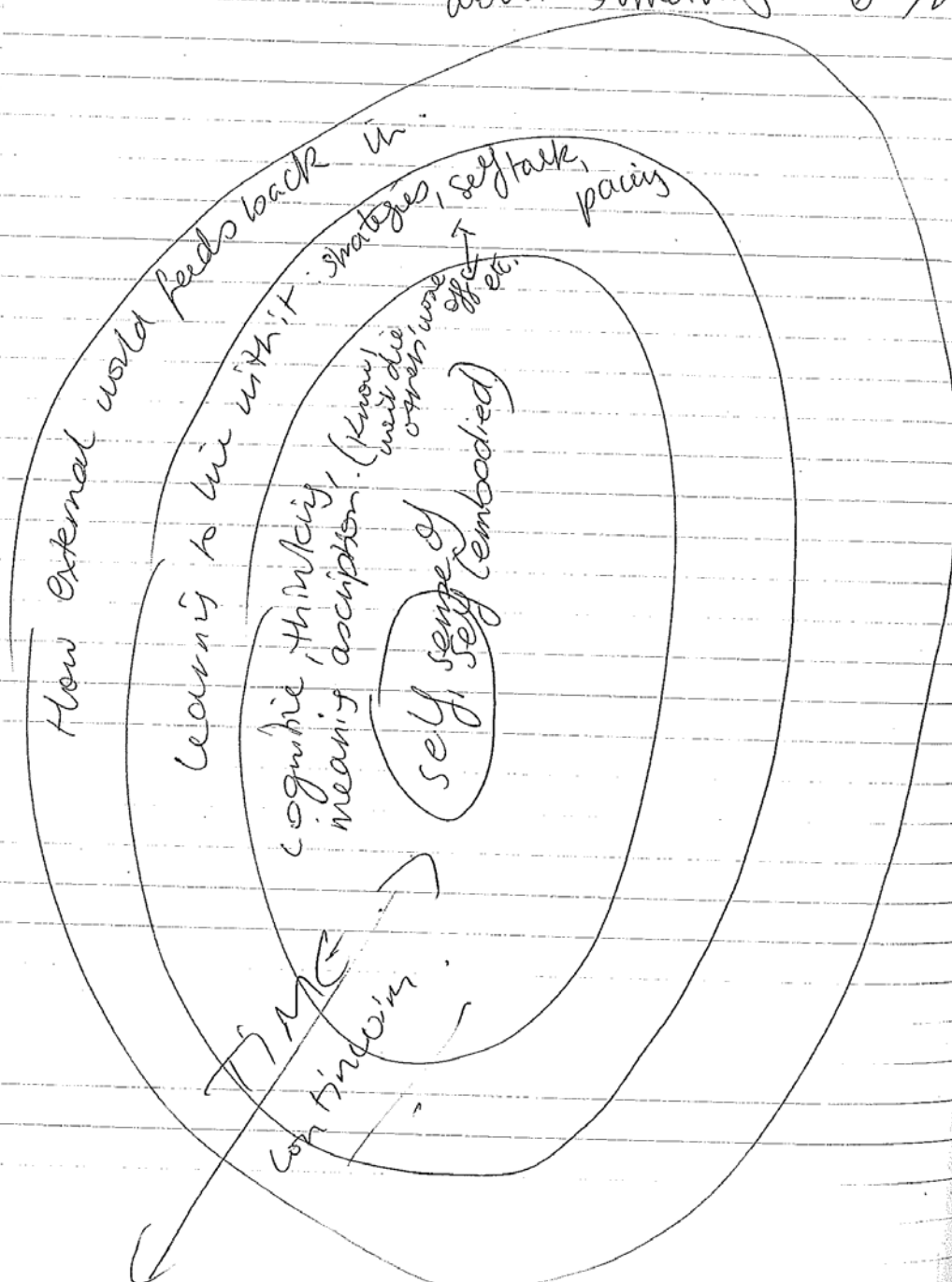
words not hers.

She uses lots of key terms in her everyday speech - adapting ^{idea} occupy
= keeping busy, doing, managing, malingering → says she was definitely never this.

~~has~~ I feel she has been very honest with me. A privilege to have talked to her!

Very neat house - polished floors - sits on floor to do this!

Stories are about something. Final key element



MIND MAP METHODS

