

The involvement of significant others within a chronic pain management programme: The views of programme participants and significant others

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Catherine Swift

A handwritten signature in black ink, appearing to be 'C. Swift', written in a cursive style.

6.4.2012

Acknowledgements

The saying “no man is an island” (John Donne, n.d., Career and later life, para. 2) aptly describes my experience of writing this thesis. From the outset my research has been inspired by the families that I have worked with and my questions could never have been answered without the participants who willingly shared their stories with me.

The journey of writing this thesis has been marked by highs and lows, tears and excitement. There were numerous times when I questioned why I ever decided to enrol in a Masters and dreamed of the day that my thesis would be submitted and my evenings would once again be my own. Reaching the end of this journey has been a triumph, and one that I could not have achieved without the unconditional support of my husband, who was always there to give me an encouraging hug, act as a sounding board and ensure that I had space to work.

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Finally, this research would not have been possible without the approvals of the: Northern Y Ethics Committee, AHDB Research Review Committee and ADHB Maori Research Review Committee.

Abstract

The dynamic relationship which is widely recognised to exist between a person's pain and their social environment provides a strong argument for the inclusion of significant others e.g. friends and family, in chronic pain management programmes. To date research concerning the involvement of significant others in chronic pain management programmes has been dominated by a quantitative approach, with a focus on comparing the effectiveness of programmes with and without the involvement of significant others. What is missing from the literature is research illuminating the perspectives of those with pain and significant others about the involvement of friends and family in pain management programmes.

This study utilised a qualitative descriptive methodology to investigate the question: "What are the views of individuals who have participated in a Family Day, delivered as part of the 3 week multidisciplinary chronic pain management programme at The Auckland Regional Pain Service (TARPS), on the involvement of significant others within the programme?"

The purpose of this research was firstly to investigate whether the theoretical rationale for involving significant others within a programme is supported in the views shared by those with pain and significant others. Secondly, to provide TARPS with feedback on their service and this may in turn identify opportunities to enhance programme delivery. Thirdly, the findings will contribute to the body of knowledge that informs the delivery of pain management services in general.

Semi-structured phone interviews were held with eight people who volunteered to participate in this study after attending a Family Day at TARPS. Conventional content analysis of the interview data resulted in the emergence of two themes: Firstly, the involvement of significant others in the programme is important so that everyone is on the same page about pain and its management and secondly, the involvement of significant others in the programme is important so that significant others have the opportunity to access information and support. These views reinforce what is already known about the psychosocial dimension of pain and lend support for the theoretical rationale which is commonly used to justify the involvement of significant others in a pain management programme.

The findings also extend existing knowledge about the involvement of significant others in a pain management programme in three ways. Firstly, they highlight a wish for significant others to be directly involved in the programme, rather than via media such as the internet. Secondly, the findings point to the importance of involvement finding a balance between what is feasible for significant others and beneficial for all, and thirdly the need for the involvement of children in the programme to be carefully considered.

To my knowledge this is the first study that has sought to ascertain views on the involvement of significant others in a chronic pain management programme, from the perspective of those with pain and significant others. For those involved in the delivery of pain management services, the findings from this research highlight the urgent need for research into *when* and *how* significant others, including children, are involved within programmes.

Chapter One – Introduction to the Study

Introduction

This qualitative descriptive study explores the views of eight people who participated in The Auckland Regional Pain Service (TARPS) Family Day, which occurs on the final day of their 3 week multidisciplinary chronic pain management programme. Specifically, participants were asked to share their views on the involvement of significant others in the programme. Of the eight participants, four had pain and four were significant others.

The involvement of significant others in chronic pain management programmes is guided by theories regarding the role that a person's social environment e.g. their family and friends can play in their experience of chronic pain. Over the years a large body of knowledge has been developed about both the psychosocial dimension of pain and the role of multidisciplinary or interdisciplinary programmes in its management. What is missing from the literature is research illuminating the perspectives of those with pain and significant others about the involvement of friends and family in pain management programmes.

The purpose of this research is three fold. Firstly, to investigate whether the theoretical rationale for involving significant others within a programme is supported in the views shared by those with pain and significant others. Secondly, to provide TARPS with feedback on their service, and this may in turn identify opportunities to enhance programme delivery. Thirdly, the findings will contribute to the body of knowledge that informs the delivery of pain management services in general.

Chronic pain refers to pain which has been experienced for longer than 3 months, is due to a non-life threatening cause, has not responded to currently available treatment and may continue for the remainder of an individual's life (Dysvik, Natvig, Eikeland, & Lindstrøm, 2005; Unruh, Strong, & Wright, 2002). It should be noted that chronic pain can also be experienced as a symptom of a disease process e.g. cancer or rheumatoid arthritis, however the focus of this study is on pain which might have commenced following injury, surgery or without an identifiable origin, such as in the case of fibromyalgia.

Chronic pain is understood to arise from a complex interaction between medical, psychological and social factors (Gatchel, 2004), with the ‘best’ treatment outcomes achieved through a biopsychosocial approach (National Pain Summit Initiative, 2010; Scascighini & Sprott, 2008). Pain management programmes are typically designed to address the biopsychosocial aspects of pain through multi or interdisciplinary input and are consistently recognised as the most effective form of intervention for chronic pain (Dopson, 2010; Scascighini & Sprott, 2008).

The ‘social’ component of the biopsychosocial framework is concerned with the relationships that an individual has with those around them, especially family and friends (Kerns & Otis, 2003; Lewandowski, Morris, Burke Draucker, & Risko, 2007). Within this study the term ‘significant others’ will be used to refer to those family and friends that an individual with chronic pain defines as their key sources of social support¹. Over the last 30 years, the impact of pain on an individual and also their significant others has received increasing recognition, as has the role that interpersonal relationships can have in shaping an individual’s experience of pain. This understanding has translated into awareness about the importance of involving significant others in the assessment and treatment of chronic pain (Lewandowski et al., 2007). Accordingly, a Family Day is included in the 3 week multidisciplinary programme at TARPS.

Officially established in 1990, TARPS is a hospital based, multidisciplinary service, which provides acute and chronic pain management services to the greater Auckland region (Rowe, 2009). The multidisciplinary team at TARPS includes: Anaesthetists, a Clinical Nurse Specialist, an Occupational Therapist, an Otolaryngologist, a Psychiatrist, Physiotherapists, Psychologists, a Rheumatologist, Postgraduate Trainees (Registrars) in Rheumatology, and Pain Fellows (Healthpoint, n.d.). The team uses a client centred biopsychosocial approach, with intervention based around Cognitive Behavioural Therapy (Rowe, 2009). The overall aim of the TARPS programme is not to cure pain (although some people may experience a welcome reduction in their pain as a result of attendance) but rather to support people to achieve a better quality of life in spite of their pain (Dopson, 2010).

¹ In some situations throughout this thesis, the term ‘significant others’ will be replaced with ‘family’ to facilitate the flow of a sentence.

One of the services provided by TARPS is a 3 week multidisciplinary chronic pain management programme (See Appendix 1 for an overview of the programme). Nine programmes are run every year, with approximately 6-11 people in each group. Those attending the programme have a wide range of pain conditions, including back pain, headaches and complex regional pain syndrome (CRPS). There is no official age criterion for attending the programme, however people admitted to the programme are typically in their adult years (D. Bean, personal communication, September 16, 2011). Prior to admission, those with pain attend a pre admission clinic, at which their significant others are welcome. During the 3 weeks, issues relating to significant others are discussed with programme participants by means of several group sessions and on the final day they are encouraged to invite their significant others to a Family Day. During the Family Day those attending are provided with education on the programme and chronic pain (See Appendix 2 for an example timetable of the Day).

“In my mind the family day has been ‘forever’. It’s been part of our thinking from the start of running programmes that family involvement was vital. The challenge has been to find ways of doing it that were effective and useful to the patients and their families...” (Dr B. Large, personal communication, May 5, 2011).

The importance of involving significant others in the delivery of interventions for chronic pain is supported by numerous studies, which described how pain can affect, and is affected by interpersonal dynamics (e.g. Snelling, 1994). While theories have helped to explain the complex relationship between an individual’s social environment and their experience of pain and have guided interventional approaches with families (Lewandowski et al., 2007), to my knowledge no research has yet explored how those with pain and their significant others would like significant others to be involved in chronic pain management programmes. Such research represents a valuable opportunity to learn from those with pain and their significant others, and this knowledge may provide valuable direction for the design and delivery of programmes.

Having introduced the study I will now provide a context to this research, by describing the evolution of my own interest in chronic pain and in particular, the involvement of significant others in chronic pain management programmes. I will then focus the discussion on the incidence and management of chronic pain in New Zealand, while also drawing on various initiatives and strategies currently in circulation, to clearly outline the relevance of my research to healthcare in New Zealand. I conclude with an

explanation as to why the involvement of significant others in pain management programmes is of relevance to occupational therapy and an acknowledgement of the assumptions with which I commenced this study.

My interest in this area of research

In 2004 I graduated as an occupational therapist and accepted a position at QE Health, a specialist rheumatology and chronic pain management service in Rotorua. During my time at QE Health I had the great fortune to work with some truly inspirational staff and clients and the more I learned about pain, the more I wanted to learn. Since leaving QE Health I have worked in two other multidisciplinary pain management services – one in New Zealand and the other in Australia. My role within all three services had been to support clients to develop strategies to minimise the impact of pain on their participation in personally meaningful daily activities.

The level of family involvement offered by each of the three services had varied from no formal involvement, to a structured family forum. However, the significance of family involvement within a programme was not something that I had given consideration to, until 2009 while working within the Independent Management of Pain through Activity and Cognitive Therapy (IMPACT) pain management programme. The IMPACT programme was run through Greenslopes Private Hospital in Brisbane, Australia and was held two days a week, for a total of five weeks. The multidisciplinary programme included a half day family forum, at which significant others could access support and obtain information regarding chronic pain. Programme participants were strongly encouraged to invite their significant others to the forum and while the feedback from those who attended was typically very positive, acceptance of the invitation was consistently low i.e. typically only 2 or 3 programme participants would have significant others represented. As there were usually 6-10 people in each programme, this represented at best, the involvement of significant others in 50% of cases.

The decision to involve significant others in the IMPACT programme and the design of the forum had been driven by members of the team, as part of efforts to address pain from the recommended biopsychosocial approach (Scascighini & Sprott, 2008). However, the more that I worked with clients and their significant others, the more I

began to question whether we were involving significant others in a way that was truly meeting their needs. In search of answers I turned to the literature hoping to find some published guidelines regarding the “best” way of involving significant others within programmes. My search, although extensive, including databases such as CINAHL, ProQuest and PubMed proved fruitless. There were numerous articles citing the benefit of multidisciplinary programmes for chronic pain and many others acknowledging the impact of chronic pain on family functioning. Interestingly however, research findings were inconsistent about the benefits of including significant others within pain management programmes. I was unable to locate an explanation for this inconsistency but did note wide variation in the extent to which significant others were involved within chronic pain management programmes and queried whether this may have contributed to the inconsistent findings. For example, some programme descriptions did not talk about family involvement at all, whereas others talked about a one-off family session and still others described family involvement to be a requirement for the entirety of the programme. I was also unable to locate any research exploring the views of those with pain or their family members, regarding the involvement of significant others in a multidisciplinary pain management programme. For example, there were no perspectives on how significant others wanted to be involved in programmes or what information families felt that they would find useful. Since developing an interest in this area of research I have returned to New Zealand and it is within the New Zealand context that I have based this research.

Chronic pain and its management in New Zealand

One in six New Zealanders over the age of 15 years are reported to experience chronic pain, with prevalence rates positively correlated with increasing age and lower socioeconomic status (Dominick, Blyth, & Nicholas, 2011). What this figure does not take into account is the impact that chronic pain has on those around the individual i.e. their significant others. Depending on the individual’s geographical location and the circumstances surrounding the onset of their pain, intervention may be provided through their GP or another community based provider such as a physiotherapist. Alternatively an individual may be referred on to a specialist pain management service. There are three specialist pain management centres in New Zealand (TARPS being one of these)

and numerous other community teams providing services through the Accident Compensation Corporation (ACC)².

The role that strong community systems play in health is acknowledged by a number of initiatives supported through the New Zealand government. The New Zealand Health Strategy provides a framework for the delivery of the country's healthcare services (Ministry of Health, 2000b). This strategy sits alongside the Disability Services Strategic Plan for July 2008 to June 2010 (Ministry of Health, 2008) and three more recent documents, Whānau Ora: Report of the Taskforce on Whānau Centred Initiatives (Ministry of Social Development, 2010), Whānau Ora: Transforming our Futures (Ministry of Health, 2011) and Alleviating the Burden of Chronic Conditions in New Zealand (Connolly et al., 2010). Together these documents stress several things, firstly the need to empower families to self manage their health by assessing and addressing not only the needs of an individual but their significant others as well. Secondly, the need to involve individuals, their families and their communities from the beginning of service design, to ensure that services are providing the most appropriate care. Thirdly, these documents highlight the importance of moving away from a health professional centred system, to a patient/family centred system, in which families enter an active partnership with health care professionals, with respect to decision-making, treatment and care (Simons, Franck, & Roberson, 2001).

To date there are no strategies or documents in New Zealand which directly guide health services for chronic pain. However in 2010, such a document was released in Australia. The National Pain Strategy: Pain Management for all Australians (National Pain Summit Initiative, 2010) "is the first comprehensive initiative in Australia – and worldwide – which sets out to improve the assessment and treatment of all forms of pain" (National Pain Summit Initiative, 2010, p. v). The need to consider significant others in the management of chronic pain is clearly highlighted in the strategy's mission statement: "To improve quality of life for people with pain and their families, and to minimise the burden of pain on individuals and the community" (National Pain Summit Initiative, 2010, p. v). The clinical question under enquiry in this research attempts to embrace the essence of the documents outlined above, as it is concerned with clarifying the support needs of families, by asking individuals with pain and significant others for

² The Accident Compensation Corporation (ACC) provides comprehensive, no-fault personal injury cover for all New Zealand residents and visitors to New Zealand (www.acc.co.nz).

their views on the involvement of significant others within a pain management programme. Because the findings from this study will be used to provide TARPS with feedback about their service, and will in turn possibly identify opportunities to enhance programme delivery, the intent of this study also aligns with national efforts to involve families in the design and delivery of health services.

Responsibilities as a researcher

The aim of qualitative descriptive research is to remain close to the data and provide a comprehensive summary of an event or experience, rather than to make interpretations about its meaning (Milne & Oberle, 2005; Sandelowski, 2000). However, any report of an event will always be dependent on the “perceptions, inclinations, sensitivities, and sensibilities of the describer” (Sandelowski, 2000, p. 335). Central to the integrity of a study is the researchers ability to “interrogate their own beliefs and feelings in the same way as they will interrogate those of the participants”. The purpose of this is to identify the biases and influences that they may bring to the research (Carpenter & Suto, 2008, p. 128).

I entered this research as a practicing occupational therapist, with an interest in the management of chronic pain. As outlined by Carpenter and Suto (2008), undertaking research as a practitioner can facilitate the interview process through the possession of background understanding about a situation e.g. the language used. However, entering research as a practitioner can also raise challenges. Firstly, practitioners must learn how to negotiate a research rather than a therapeutic relationship with participants. This requires listening to each participant’s story without the intent of offering an explanation or intervention. Secondly, the process of data collection and analysis can be shaped by assumptions and perspectives about rehabilitation, which have been gained through practice. Any pre-existing assumptions can restrict a researcher’s receptiveness to the information shared by the participants and thus the ability to fully understand the complexity of the situation under investigation.

Reflexivity or conscious reflection is the process of making explicit the opinions, assumptions and perspectives that can influence the way in which a researcher collects and analyses data (Carpenter & Suto, 2008). The process of reflection should continue

throughout the research process to ensure that the quality of the findings is preserved (Carpenter & Suto, 2008).

I commenced this process of reflection with a presupposition interview, designed to raise my awareness about any assumptions, beliefs or biases that I might be carrying into the research. The interview identified the following; firstly, while I did not have a clear idea about what I might find from this research, I was to a large degree drawing on my own experience in the IMPACT programme when hypothesising what the experiences of those going through the TARPS programme might be. Secondly, I developed awareness that this might be the first time that significant others had had a chance to talk about their experiences and that this opportunity had the potential to elicit a number of emotions for them. Richardson, Ong and Sim (2007) encountered this situation when they interviewed the family members of individuals with chronic pain. They shared their experiences to highlight the delicate nature of interviewing the relatives of an individual with a hidden condition such as pain, especially where the family may have previously encountered queries around the legitimacy of their relative's pain. Thirdly, through the process of engaging in the presupposition interview I developed a greater appreciation for the role adjustment that families may need to undergo following a programme and the challenges that navigating these changes might present. Finally, I realised that I held a belief that participation in the Family Day would foster communication about pain management between those affected and their significant others. A more realistic expectation might be that attendance at the Family Day would increase understanding, but that this may not necessarily lead to better communication. As described by Richardson et al. (2007), families communicate through a shared understanding of the world, which develops over time and in response to a complex and dynamic process of negotiation. "The invisible nature of chronic widespread pain, coupled with the desire, neither to talk about it nor to show it, exacerbates the potential for misunderstanding in implicit negotiations within the family" (Richardson et al., 2007, p. 360).

Why an occupational therapist?

One of the questions that I am asked frequently when I tell people about my research is, "what is the relevance for occupational therapy?" Occupational therapists believe that health and wellbeing are directly influenced by competent and adaptive participation in

personally meaningful daily activities (Hagedorn, 2000). Challenges to a person's participation in daily activities may come from the environment (physical or social), within the individual or from the activity itself (Hagedorn, 2000). When an individual has chronic pain, his or her participation in daily activities can become ruled by pain, which in turn impacts on those around them (Lewandowski et al., 2007; Snelling, 1994). To date the impact of chronic pain on a persons' participation in daily occupations has been investigated (e.g. Fisher et al., 2007), as have the views that occupational therapists hold about intervention options for chronic pain (Brown, 2002). The use of occupational interventions such as art therapy for chronic pain has also been studied (Henare, Hocking, & Smythe, 2003). No research has yet been undertaken by occupational therapists regarding the involvement of significant others within chronic pain management programmes, which is the focus of this study.

Within pain management services occupational therapists are involved in supporting individuals to acquire the skills they need to minimise the impact of pain on their lives. For an individual to achieve this goal they must be able to successfully transfer the skills learned within a programme to their home context. This generalisation inevitably requires changes within the family (Riemsma, Taal, & Rasker, 2003). The dynamics within families are complex and it cannot be guaranteed that change will be welcomed by significant others (Hudgens, 1979). The intimate, dynamic relationship between an individual, their environment and the context of an activity means that occupational therapists must work with clients *and* their significant others to achieve therapeutic goals (Dickie, Cutchin, & Humphry, 2006). In the context of a chronic pain management programme, involving significant others by way of a family session provides a forum for educating significant others about pain and stimulating ideas as to how they can continue to support their loved one with pain following the programme. This study is therefore relevant to occupational therapists working within multi or interdisciplinary pain management teams, as it offers insight on how those with pain and their significant others would like significant others to be involved within a programme.

Conclusion

The aim of this qualitative descriptive study is to fill a gap in current research, by investigating whether the commonly used theoretical rationale for involving significant

others in a chronic pain management programme, is supported in the views shared on the matter, by those with pain and significant others. The specific question under investigation is “What are the views of individuals who have participated in a Family Day, delivered as part of the 3 week multidisciplinary chronic pain management programme at The Auckland Regional Pain Service (TARPS), on the involvement of significant others within the programme?” By asking this question I would like to gain insight into areas such as: How do individuals with chronic pain feel about the involvement of their significant others in the programme e.g. do they feel that their involvement added benefit to the programme, and if so how? Then conversely from the significant others, how do they feel about being involved in the programme, for example, did they feel that there was enough involvement and what benefits did they experience as a result of their participation. The information gathered in this research will provide TARPS with feedback about their service and possibly identify opportunities to enhance programme delivery. Secondly, the findings will contribute to the body of knowledge that informs the delivery of pain management services in general. Finally, the interest that this research has on exploring the views of those with pain and significant others about programme, also aligns with national health efforts to involve families in the design and delivery of health services.

In this chapter I have provided background to the question under investigation in this study and discussed its relevance for both healthcare in New Zealand and occupational therapy practice. In chapter two I will provide a review of the literature and in chapter three outline my research methodology. Chapter four contains the findings of the study and finally in chapter five I discuss the results which have emerged.

Chapter Two – Literature Review

Introduction

Pain is a normal human experience, which in many cases is only ever short lived (National Pain Summit Initiative, 2010). However, for those affected by chronic or persistent pain, its presence can become disabling (National Pain Summit Initiative, 2010). Over the last few decades the prevalence and effects of chronic pain on individuals and the communities in which they live has received increasing recognition. This has been thanks to several large scale studies such as ‘Chronic pain in Australia: A prevalence study’ (Blyth et al., 2001) and the ‘Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment’ (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). These studies have highlighted the need for chronic pain to be made a priority area for research and health care funding around the world. New Zealand is no exception, with the most recent research on the prevalence of chronic pain concluding that “chronic pain represents a major health issue” for the country (Dominick et al., 2011, p. 63).

The biopsychosocial nature of chronic pain has generated interest in its aetiology and management from a diverse range of researchers and clinicians. As such, a vast and ever growing body of literature exists about the subject of chronic pain. My particular focus of interest in this study, is the involvement of significant others within chronic pain management programmes. As a means of gaining insight into this area I have founded my research on the TARPS, 3 week multidisciplinary pain management programme. In this chapter I will firstly describe the process that I used to locate relevant literature for this study and secondly outline the findings of my search.

The process of my literature search

I commenced my literature search by looking for any guidelines that might have been published regarding the involvement of significant others in chronic pain management programmes. There is no shortage of literature on chronic pain and its management, for example, searching the terms ‘chronic pain’ and ‘programmes’ using the ProQuest database reveals 162, 913 articles. Due to its reputation, I chose to begin my search by accessing the website for the International Association for the Study of Pain (IASP). Established in 1973, the IASP is recognised as “the leading professional forum for science, practice, and education in the field of pain” with more than 7,000 members in

126 countries (IASP, 2011, Background section, para. 3). The Australian and New Zealand Pain Societies are two chapters of the 85 that constitute that IASP (IASP, 2011). Freely accessible from the IASP website are resources for professionals, patients and academics. These include guidelines on a range of topics, one of these being 'Recommendations for pain treatment services'. This document differentiates between Multidisciplinary Pain Centres, Clinics, and Practices and advocates for a high standard of practice in all settings. No guidelines are provided within this document regarding the involvement of significant others in programmes, however the importance of treatment being aimed at improving physical and psychosocial functioning is stressed.

Next, I conducted a wider search of the IASP website using the phrase 'family + pain management programmes'. This search directed me to literature acknowledging the impact of pain on significant others and awareness that they too benefit from opportunities to learn skills which help them to cope with the effects of pain on their lives. One of these articles was by Keefe, Somers and Kothadia (2009). They briefly comment on two approaches that have been used to involve significant others in intervention for chronic conditions such as arthritis and depression but did not reference any studies exploring these approaches for chronic pain of unknown origin.

Unable to locate the information that I was looking for on the IASP website, I then searched the websites of the New Zealand Pain Society and the Australian Pain Society, using combinations of the following terms: 'guidelines', 'family', 'spouse', 'family involvement', 'pain programmes', 'programmes' and 'programs'. When my search for guidelines regarding the involvement of significant others in pain management programmes continued to be unsuccessful, I broadened my investigation to a wider review of the way in which significant others were being conceptualised within the literature on chronic pain and its management. I approached this aspect of my search by accessing the following databases: PubMed, ProQuest and CINAHL. I chose these databases for the extensive access they offer to articles published by a broad range of international authors. To search these databases I used combinations of the following terms: 'chronic pain', 'pain', 'chronic pain management', 'programmes', 'programs', 'family involvement', 'family', 'spouse', 'occupational therapy' and 'guidelines' and 'multidisciplinary chronic pain management programmes'. Finally, I entered combinations of these terms, plus the word 'blogs' as internet searches, using the Google search engine. I chose to include blogs in my search, to identify any personal

accounts that had been written by those with pain or their loved ones, about their experiences, especially their involvement in a chronic pain management programme.

My research spanned approximately 2 ½ years, beginning in 2009. I periodically repeated the above searches to ensure that I remained up to date with developments in the literature. During this period I was also made aware of relevant articles and publications through my daily clinical practice, conversations with my research supervisors, membership of professional organisations such as the New Zealand Association of Occupational Therapists and the New Zealand Pain Society, and subscriptions to online publications such as Te Pou and the Long-Term Conditions Bulletin (available from <http://www.tepou.co.nz/> and <http://www.healthnavigator.org.nz/newsletter-registration/> respectively). Although Te Pou is concerned with mental health research and workforce development in New Zealand, both Te Pou and the Long Term Conditions Bulletin have a common interest in improving healthcare in New Zealand, through the sharing of knowledge and resources. While not all the literature that I accessed through these latter sources were directly related to chronic pain, they did allow me to gain an appreciation for how the involvement of significant others in healthcare was being discussed nationally and how their inclusion was being structured within intervention programmes for other chronic health conditions such as depression. The information I gathered through these sources thus helped to provide justification for my research in the context of New Zealand healthcare. Secondly, it also gave depth to my literature review, by creating the opportunity for a comparative discussion regarding the knowledge that has been developed in other related fields, about interventions involving significant others.

Two things became very clear early in my search; firstly the absence of information regarding how families want to be involved in chronic pain management programmes and secondly, the challenge of how to refer to ‘family’ or to those people that an individual with chronic pain might consider to be their key social supports. The term ‘social support’ is recognised to be a complex and multifaceted concept (Williams, Barclay, & Schmied, 2004). Over the years the concept of social support has been extensively studied; however due to its complexity, researchers and academics are yet to agree on a definition (Williams et al., 2004). As such, Williams et al. (2004) argued that the concept of social support should be defined by the context, to ensure the best fit. I noted while conducting the literature review for this research that the terms ‘family’ or

‘spouse’ were most commonly used in the literature. The 3 week multidisciplinary programme at TARPS also concludes with a ‘Family Day’, to which friends and family members are invited. However, from a research perspective, use of the term ‘family’ is fraught with difficulty, as it requires defining a family (Fitzgerald, 2004; Snelling, 1994). The term ‘family’ will inevitably mean different things for different people and for various reasons it cannot be automatically assumed that an individual will identify family members as their key sources of support (Fitzgerald, 2004). Rather, key supports may be flatmates, neighbours, friends or members of a local community group to name just a few (Widmer et al., 2008). For the purpose of this study, the term ‘significant others’ has been used to describe those people that an individual with chronic pain defines as their key sources of social support.

As a biopsychosocial phenomenon, it can be expected that individuals in every culture will experience the effects of pain differently, depending on the norms, practices and beliefs of their family and community (Sturkenboom, Dekker, Scheppers, van Dongen, & Dekker, 2007). In some cultures independence is valued, while in others, society is structured around a framework of interdependence (Sturkenboom et al., 2007). As a Western based researcher I have chosen to present the findings of my literature search from the stand point of an independent worldview, beginning with an overview of what is known about the impact of chronic pain on the individual immediately affected, before extending my discussion outwards, to include significant others and finally their involvement in chronic pain management programmes.

In the remainder of this chapter I will present the findings of my literature search and discuss their significance under the headings: ‘Impact of pain on the individual’, ‘The ripple effects of pain’, ‘Intervention for chronic pain’, ‘The theory guiding interventions for those with pain and their significant others’, ‘How significant others are being involved in interventions for pain’, ‘Styles of involving significant others in interventions’, ‘The outcomes achieved when significant others are involved in interventions for pain’, ‘The perceptions of significant others regarding the content and purpose of interventions for pain’, ‘The involvement of children in chronic pain management programmes’, ‘The views on inclusion that have been shared by significant others caring for a loved one with mental illness’ and ‘Conclusion’.

Findings of the literature search

Impact of pain on the individual

Pain is a normal, albeit unpleasant emotional and sensory experience, which exists to protect the body from harm and/or further damage (National Pain Summit Initiative, 2010). Typically the experience of pain equates to a behavioural response such as moving a hand from a hot plate or resting an injured limb. In such situations pain is referred to as acute and resolves with or without intervention over days or weeks (National Pain Summit Initiative, 2010). However, in the case of chronic pain, or pain that persists without explanation, the sensation of pain does not equate to harm (National Pain Summit Initiative, 2010). If a person does not understand that hurt can occur without harm, their confidence and ability to freely engage in all aspects of daily life may become compromised, through an avoidance of activities that they fear will aggravate their pain or cause further damage (Dopson, 2010; Morris, 2004; Scascighini & Sprott, 2008). This decrease in activity further restricts their ability to engage in daily activities, through deconditioning, fatigue and an overall reduction in activity tolerance (Dopson, 2010).

Over the last 10 years, three large scale population studies — two in Europe (Breivik et al., 2006; Fricker, in association with Mundipharma International Limited, 2003) and one in Australia (Blyth et al., 2001) have provided data on the prevalence of chronic pain and its impact on people's lives. Each of the European studies involved over 46,000 participants across 16 countries, while the Australian study included 17,543 residents from New South Wales. In all three studies computer assisted telephone interviews were used to collect the data. Both Blyth et al. (2001) and Breivik et al. (2006) reported using random sampling to recruit participants however, Breivik et al. (2006) used only listed phone numbers, whereas Blyth et al. (2001) used a random digital dialling method. In contrast, it is not stated in the study by Fricker, in association with Mundipharma International Limited (2003) how participants were recruited. While involving a smaller sample, the use of random digital dialling by Blyth et al. (2001) does strengthen their study, as it ensured that all residents had an equal probability of being contacted. This is of importance, as those who choose not to be listed may represent a different demographic of the population.

Once potential participants had been contacted by interviewers in the two European studies, they were screened for chronic pain using a predetermined definition. This screening method acted as a means of ascertaining the prevalence of pain in the general population and those that satisfied the selected definition for chronic pain were then invited to participate in an in depth interview about the effects of the pain on their life. An initial screening process was not used by Blyth et al. (2001) but they did ask participants to state if they had chronic pain, based on a predetermined definition. All three studies defined chronic pain differently; however there was only a slight variation in the wording between the studies by Breivik et al. (2006) and Fricker, in association with Mundipharma International Limited (2003). The findings from the three studies are also presented in different ways and this, together with the absence of a consistent definition of chronic pain makes a direct comparison of the findings challenging. What all three studies do confirm is the large impact that pain has on people's lives. Forty percent of those surveyed in the study by Fricker, in association with Mundipharma International Limited (2003) reported that pain had an impact on their daily activities, with the study by Blyth et al. (2001) showing that those aged 20-24 were proportionately more likely to report interference with their daily activities due to pain. Sleep was identified as the most common area of difficulty by participants in the study by Breivik et al. (2006) and 32% reported that they were no longer able to work outside their home due to their pain (Breivik et al., 2006).

Emotional distress in the form of anxiety, anger, resentment, frustration and helplessness are experienced by many people as they attempt to deal with the challenges and changes that pain imposes on the way that they live their lives (Adams & Field, 2001; Adams, Poole, & Richardson, 2006). Studies have shown that roughly 20% of those with chronic pain have also been diagnosed as having depression (Breivik et al., 2006; Fricker, in association with Mundipharma International Limited, 2003) and in Australia, 20% of those with chronic pain have contemplated suicide (Stollznaw Research, 2010). Further, 5% are reported to have attempted to commit suicide due to their pain (Stollznaw Research, 2010). It is not clear from the data provided in that study whether this figure on attempted suicide is in addition to the 20% who have contemplated suicide. At highest risk of committing suicide are men under the age of 66 years, who come from low income households (Stollznaw Research, 2010). The source of these latter figures comes from an online survey involving 2,511 Australians. While the sample had been designed to represent the Australian population e.g. male to female

ratio, it cannot be overlooked that the participants were self selected i.e. they had agreed to be part of an online panel for a small incentive. Secondly, the participants had all been recruited through email or online marketing methods and thus the survey may not reflect the views of those who do not use, or are not confident using the internet.

The major sources of stress amongst those with chronic pain have been examined by Dysvik et al. (2005). While their chosen assessment tool restricted the focus of their investigation to a one week period (i.e. participants were asked to comment on the week prior to completing the tool), their findings showed that for 58% of participants, family life and social activities were the main sources of stress. A further 9% identified work or studies as their main stress, with the remaining 38% identifying their own health.

Psychosocial variables play a significant role in the development of chronic pain and frequently outweigh the biomechanical variables or physiological processes from which the pain may have originated (Gouche, 2003; Linton, 2003). This understanding has been well demonstrated in a prospective, longitudinal study by Carragee, Alamin, Miller and Carragee (2005). For five years they followed 100 participants with persistent, non-disabling, mild back pain, who were at risk of developing degenerative disc disease (e.g. people reporting no functional limitations or use of medication to manage their pain at the time of recruitment). Their results showed that it was psychosocial rather than structural variables that most strongly predicted the development of disability arising from lower back pain (e.g. absences from work and healthcare visits). These findings build on the conclusions reached in an earlier literature review by Linton (2000), who had examined 37 prospective studies concerning back and neck pain and also found that psychosocial variables were linked to the transition from acute to chronic pain and typically had more influence on the development of disability arising from back pain than biomedical or biomechanical factors.

The ripple effects of pain

Within the literature a number of papers have been published looking at the effects of chronic pain on a family system. Although Kerns and Otis (2003) criticized many of these papers for being descriptive as opposed to theory driven and explanatory in nature (the absence of theory also more recently raised as an issue of concern by Martire, Helgeson, & Saghafi, 2010), the findings from these studies clearly demonstrate that chronic pain can have a significant impact on the way in which a family functions

(Lewandowski et al., 2007; Snelling, 1994). Illness and response to illness has been described by Sturkenboom et al. (2007) as a “dynamic, continuously interactive social process” (p. 324). For this reason it is important to remember when considering how a family has, or might have been affected by the presence of pain, that the experiences and perceptions of the person with pain may well vary from those around them (Lewandowski et al., 2007).

A qualitative study by Snelling (1994), which although nearly 20 years old is still being referenced, described the multiple ways in which pain can affect a family. Often an individual with chronic pain will become physically and emotionally dependent on others. Within a marital partnership this can result in the relationship shifting from a foundation of equality, to dependence, as one partner assumes care for the other and adjustment occurs in household roles. Sometimes this means one partner having to take on roles that he or she does not enjoy, taking time off work or declining advancements at work to care for their spouse. Similarly, contact with relatives and friends can decrease because social invitations are declined, as life becomes increasingly focused around minimising a loved one’s pain. Further strains in a relationship can arise through a reduction in sexual expression due to changes in the way that partners view each other or the pain experienced during intercourse. Pain can also affect a parent’s relationship with his or her children, through reduced tolerance for their play and the inability to spend time together on activities. Finally, a child can begin to mimic the pain behaviours of their parent e.g. choosing to spend time in bed (Snelling, 1994). The knowledge that pain affects both the individual and their significant others highlights the importance of incorporating family and friends into pain management programmes but in ways which are acceptable for the individual with pain so as to avoid adding to their sense of lost independence and emotional distress.

How significant others respond to an individual’s expression of pain can lessen or exacerbate the pain problem (Snelling, 1994). Research has shown that significant others typically consider pain to be a physical problem and that they attend to a variety of verbal and non-verbal cues, such as movement and facial expression, when estimating their loved one’s pain (Johansen & Cano, 2007; Sturkenboom et al., 2007). Unfortunately, the findings from the study by Snelling (1994) suggested that in most cases the responses and coping strategies used by partners are “ineffective and pointless” (p. 545) and exacerbate the individual’s pain. For instance, while perceived

social support has been found to buffer the daily effects of pain on an individual's mood (Stanos & Houle, 2006), the adoption of solicitous behaviours by significant others can discourage independence (Sharp & Nicholas, 2000). Equally, those with partners who are overly critical or punishing can demonstrate poor psychological adjustment and more maladaptive coping (Keefe et al., 1999). The responses displayed by significant others can arise through confusion about the pain and what a loved one can or cannot do (Johansen & Cano, 2007; Sharp & Nicholas, 2000). Indeed, uncertainty about the pain that a loved one is experiencing is a commonly reported concern amongst significant others and often underscores a sense of helplessness and hopelessness about how to support their loved one and what the future will hold (Lewandowski et al., 2007).

The need for the effects of pain on significant others to be routinely addressed as part of a comprehensive approach to the assessment and management of chronic pain has been repeatedly emphasised for many years (e.g. Ahern & Follick, 1985; Lewandowski et al., 2007; Sharp & Nicholas, 2000; Snelling, 1994). Evidence suggests that the spouse (a husband or a wife) of an individual with pain is at greater risk of developing psychological disorders, especially depression, than those in the general population (Bigatti & Cronan, 2002; Lewandowski et al., 2007; Schwartz, Slater, Birchler, & Atkinson, 1991). The reported rates of depression amongst significant others vary in the literature, with one paper stating that up to 83% of spouses experience "significant depressive symptomatology" (Lewandowski et al., 2007, p. 1022). Unfortunately this article does not define significant depressive symptomatology or clearly identify where this information was sourced to allow further investigation. By contrast an earlier study reported that 28% of spouses experienced at least mild depressive symptoms, as identified by a score of 10 or greater on the Beck Depression Inventory (Schwartz et al., 1991). Half of the 29 participants in that study also reported fatigue, sleep disturbance, irritability, decreased efficiency and decreased libido. Those findings were consistent with another larger study by Flor, Turk and Scholz (1987), which also used the Beck Depression Inventory and found that 26% of spouses experienced a significant level of depression.

Efforts to provide more up to date statistics on the rates of depression amongst significant others in this literature review proved unsuccessful for two reasons. Firstly, while researchers have remained interested in how pain affects significant others, the focus of research regarding depression and psychological distress in general, has moved

towards understanding it in the context of a couple's interactions and other similar areas (e.g. Johansen & Cano, 2007). Thus, rates of depression are not always directly reported. Secondly, variation in the type of assessment used to measure psychological distress and the way in which findings are reported makes a comparison about depression rates challenging. What is clear from the literature is that not all significant others experience depression and the risk of a spouse developing depression is most heavily influenced by how well the individual with chronic pain is coping with their pain — especially how they deal with any associated anger that they may experience and the spouse's own sense of life control and marital satisfaction (Flor et al., 1987; Lewandowski et al., 2007; Schwartz et al., 1991).

How a family typically responds to daily stressors will also determine how individual members adapt to the presence of chronic pain and the impact that pain has on the way that a family functions i.e. pain does not negatively impact on all families (Kerns & Otis, 2003; Snelling, 1994). Adjustment can take time and with time distress can decrease (Bigatti & Cronan, 2002). Learning what helps and hinders significant others, including children, to adapt to the presence of chronic pain and then integrating this knowledge into chronic pain management programmes offers a valuable opportunity to enhance the wellbeing of significant others. Preserving the wellbeing of significant others and ensuring that their response to the pain is not driven by distress or uncertainty also represents a means of enhancing the support that they can provide to a loved one with pain. Ultimately, knowledge of what helps and hinders significant others to adapt, has the potential to enhance the effectiveness of pain management interventions (Bigatti & Cronan, 2002; Sharp & Nicholas, 2000; Snelling, 1994).

Intervention for chronic pain

Multidisciplinary or interdisciplinary chronic pain management programmes are globally acknowledged within the literature as the most effective intervention for those with chronic pain (e.g. Dopson, 2010; Okifuji, 2003; Scascighini & Sprott, 2008). Such programmes are typically delivered to small groups of approximately 8-10 people with pain at a time, but may also be provided individually (Dopson, 2010; Scascighini & Sprott, 2008). Most commonly programmes are based around a biopsychosocial approach, with the intent being to support each individual to learn how to live with their pain, through the acquisition of coping skills, continued participation in meaningful activities and lifestyle modification (Dopson, 2010; Scascighini & Sprott, 2008; Strong, 2002). Wide variation exists in the way that programmes are delivered (Okifuji, 2003).

In some situations individuals will participate in an intensive, 2-3 week residential programme, whereas other programmes may be run for 5-12 weeks, as day- or home-based services (Okifuji, 2003). There is debate around which mode of delivery is the most effective but the absence of evidence supporting the effectiveness of one mode over another suggests that different programmes will suit different individuals (Okifuji, 2003). It has also been recommended by Okifuji (2003) that future research efforts need to focus on not just whether a particular programme is more effective than another but what interventions work best for which individuals and by what means of delivery. This applies to the way in which significant others are included within chronic pain management programmes.

The theory guiding interventions for those with pain and their significant others

Over the last several decades Family Systems Theory, Operant Behavioural Theory and Cognitive Behavioural Theory have played influential roles in explaining how families respond to pain and directing lines of intervention for families who struggle to adapt to its presence independently (Kerns & Otis, 2003; Lewandowski et al., 2007). According to Family Systems Theory, the family is viewed as a complex system that resists change and seeks homeostasis through rules governing the behaviour of members (Kerns & Otis, 2003; Lewandowski et al., 2007). Pain can come to fulfil many purposes within a family, sometimes becoming the most influential factor binding members together (Lewandowski et al., 2007). While pain can strengthen the bond between people, it can also act to separate those involved from their community and reinforce dependency on one another (Lewandowski et al., 2007). As such it cannot automatically be assumed that efforts by an individual to manage their pain in a different way e.g. following a pain management programme, will be welcomed or accommodated by their significant others (Lewandowski et al., 2007; Schwartz et al., 1991). An understanding of Family Systems Theory is therefore valuable for those providing interventions for chronic pain, as it indicates that the whole family needs to undergo change if the individual is to successfully gain the skills required to manage their pain (Hudgens, 1979; Kerns & Otis, 2003; Moore & Chaney, 1985).

Arising from Family Systems Theory, Structural Family Therapy is recommended where the interactions between an individual with pain and their significant others are founded upon unresolved conflict, resulting in features such as poor communication and rigidity (Lewandowski et al., 2007). For example a couple with unresolved marital

issues may find it easier to focus their anger towards the pain that one of them is experiencing and the ineffectiveness of medical interventions, rather than dealing with their interpersonal conflict (Lewandowski et al., 2007). The aim of Structural Family Therapy is to change the structure of the family system, by altering the governing interpersonal dynamics, through open communication and conflict resolution (Lewandowski et al., 2007).

The second approach, Operant Behavioural Theory posits that behaviours are learned and may be retained or rejected based on the feedback that an individual receives from significant others (Kerns & Otis, 2003; Lewandowski et al., 2007). The focus of Operant Behavioural Therapy is therefore to teach significant others how to acknowledge a loved one's pain but in a way that reinforces wellness rather than pain behaviours (Kerns & Otis, 2003; Lewandowski et al., 2007). Operant Behavioural Therapy has been widely criticised for neglecting to address the reasons that may be motivating both an individual's pain behaviours and the responses of significant others. By contrast, the goal of Cognitive Behavioural Therapy (which draws from Cognitive Behavioural Theory) is to support those with pain and their significant others to understand, and where necessary restructure the way that they appraise the meaning of the pain and consequently respond to the challenges it places on daily life (Kerns & Otis, 2003; Lewandowski et al., 2007). Within Cognitive Behavioural Theory, the experience of success is considered to be an essential part of reinforcing learning and developing an individual's self efficacy in relation to managing the pain (Kerns & Otis, 2003; Lewandowski et al., 2007).

All three theories imply that the involvement of significant others within a chronic pain management programme will enhance the outcomes achieved and accordingly have been cited as rationale for the inclusion of significant others in programmes for a number of years. For example, in 1985 Moore and Chaney stated that the three most commonly provided rationale for involving significant others in programmes are, firstly to ensure that those with pain and their significant others can be jointly supported to restructure their interactions away from a focus around pain i.e. change together (an example of Family Systems Theory). Secondly, so that significant others can access support to address any distress that they may be experiencing in relation to the effect that pain is having on their life and learn how to cope with its presence (an example of Cognitive Behavioural Theory). Thirdly, because significant others can intentionally or

unintentionally play a role in reinforcing unhelpful pain behaviours, thus they need to be familiar with the skills that their loved one has learned during the programme, so that they can continue to provide appropriate support at home e.g. encouraging their loved one to engage in normal daily activities versus undertaking activities for them. This latter rationale can be considered as an example of Operant Behavioural Theory but may also involve a Cognitive Behavioural approach to assist significant others to address the underlying thoughts or beliefs which may be motivating their responses.

In more recent years authors have continued to advocate for the inclusion of significant others within programmes, due to the recognised influence of a person's social environment on their adaptation to chronic pain but also, so that significant others can access their own support (Martire, 2005). Unfortunately, despite the existence of theoretical arguments regarding the value of involving significant others in intervention and ongoing work in this field, I was unable to find conclusive evidence demonstrating that the involvement of significant others in chronic pain management programmes translates to superior outcomes over a patient orientated approach i.e. programmes without the inclusion of significant others (Kerns & Otis, 2003; Moore & Chaney, 1985). Neither is there any evidence of how the involvement of significant others in a programme is experienced by either the individual with pain or significant others.

In 2003, Kerns and Otis expressed their concern that advancements in knowledge about the impact of pain on individuals, their significant others and interpersonal dynamics had not resulted in "the development of efficacious family interventions" (p. 80). They attributed the limited progress to the absence of robust research but also the fact that chronic pain does not have a predictable effect on how a family functions. This latter comment highlights the intrinsic challenge that researchers face when attempting to find an effective intervention for a highly diverse client group i.e. one intervention will not work for all (Okifuji, 2003). Similarly, the multifaceted, complex and idiosyncratic nature of pain seems to suggest that individualised rather than group based input for those with pain and their significant others may be more effective in supporting change (Martire, Schulz, Keefe, Rudy, & Starz, 2007; Okifuji, 2003). This suggestion has the potential to create a dilemma, as the current trend is towards group based pain management programmes due to their cost efficiency (Dopson, 2010; Okifuji, 2003).

How significant others are being involved in interventions for pain

What became evident through the process of my literature search was the lack of clarity regarding how those with pain and their significant others *want* significant others to be involved in pain management programmes and how they *are* actually being involved. Gouche (2003), Scascighini and Sprott (2008), and Stanos and Houle (2006) all discussed the common goals and treatment modalities of multidisciplinary programmes but none of these authors addressed the inclusion of significant others in treatment. Scascighini and Sprott (2008) also stated that the majority of programmes are aimed at improving pain management from the individual's perspective. In those articles that did describe the inclusion of significant others, the style of involvement varied from full to part participation in the programme. For example, a four week residential programme described one afternoon session for friends and family. During this session family and friends were provided with information on the programme and discussion occurred as to how they could support their loved one with pain following the programme (Dopson, 2010). By contrast, an outpatient couples programme described by Moore and Chaney (1985) involved those with pain and their spouse attending eight sessions together. These sessions were held twice a week, for two hours. Throughout the course of the programme, couples were provided with information on chronic pain. They were then supported within the group setting to identify ways in which pain had negatively impacted on their lives and shown how to use problem solving and goal setting tools to make desired changes. Couples were also taught pain management strategies such as relaxation, as well as techniques to enhance communication and manage conflict, thus minimising the risk of pain associated with stress. Between each session homework tasks were set to help couples practice the discussed skills. As a final example, another outpatient programme described couples attending five, monthly, couples' therapy sessions (i.e. they were not part of a group). Each session lasted 1-2 hours and was structured about a Family Systems approach, with interventive interviewing used as the main therapeutic method (Saarijärvi, 1991).

Styles of involving significant others in interventions

The considerable variation that exists regarding the way in which significant others can be involved within intervention programme has received attention in the mental health literature (Baucom, Shoham, Mueser, Daiuto, & Stickle, 1998). This attention has resulted in the definition of three distinct styles of involvement: partner assisted interventions, disorder specific interventions and general couples therapy (Baucom et al., 1998). These three styles may be used separately or in combination (Baucom et al.,

1998). The differentiating feature between these approaches is the degree to which intervention focuses on interpersonal issues (Martire, 2005). In the first approach (partner assisted interventions) the significant other is taught how to support the individual to adopt new or change existing behaviours e.g. to go for a walk each day (Baucom et al., 1998; Keefe et al., 2009; Martire, 2005). By contrast, disorder specific interventions focus on the interpersonal dynamics between individuals and their significant others. Specifically, this approach focuses on how the parties involved in a relationship interact and ways in which this interaction may be maintaining and/or exacerbating an individual's health concern (Baucom et al., 1998; Martire, 2005). The third approach (general couple's therapy) is concerned with not only interactions that may directly relate to an individual's experience of pain but also addresses wider relationship issues which may be indirectly affecting an individual's wellbeing (Baucom et al., 1998). This classification system has been adopted within the chronic pain literature and of the three approaches, partner assisted and disorder specific interventions have been identified as the two favoured means of involving significant others in programmes (Keefe et al., 2009; Martire, 2005; Martire, Helgeson, & Saghabi, 2010).

The outcomes achieved when significant others are involved in interventions for pain

Spouse assisted intervention has been investigated by Keefe et al. (2004), for patients with persistent osteoarthritic knee pain. Where the work by Keefe et al. (2004) and another study by Martire et al. (2007) differ from many others, is that they also assessed the outcomes achieved by the significant others who attended the intervention programme (Martire, 2005; Martire et al., 2007). The results from these two studies indicate that even though an individual with pain may not gain advantage from programmes involving their significant others, inclusion can have benefits for significant others, in the form of stress reduction and greater confidence that their partner can cope with their pain (Keefe et al., 2004; Martire et al., 2007). Spouses who had been involved in a programme were also found to adopt less critical attitudes towards the individual with pain (Martire et al., 2007). Although these studies report on pain arising from osteoarthritis, their findings have important bearing for chronic pain arising without clear origin. Firstly, the findings highlight the importance of not merely judging the merits or effectiveness of a programme by the outcomes achieved by an individual with pain (Martire et al., 2010). Secondly, and perhaps more importantly, the findings raise important ethical issues regarding the potential for the involvement of

significant others to be associated with harm. Involvement was only identified by Martire et al. (2007) to have resulted in a reduction of stress for female spouses, a result that was sustained at a 6 month follow up. By contrast, the stress levels experienced by husbands increased.

My ability to compare the findings achieved by Martire et al. (2007) was hindered by the fact that I was only able to locate one other article which described a pain management programme and included outcome measures concerning the psychological wellbeing of significant others as a consequence of their involvement. This article was by Eccleston, Malleson, Clinch, Connell and Sourbut (2003), and described an adolescent, interdisciplinary cognitive behavioural therapy programme which required an adult family member to accompany the adolescent with pain. Unlike Martire et al. (2007), Eccleston et al. (2003) found that psychological distress decreased in significant others as a consequence of inclusion. However it should be noted that the majority of adolescents were accompanied by either a mother (77.2%) or a grandmother (5.3%). The remaining adolescences were accompanied by their father or stepfather (12.3%), or both parents (5.3%). As the outcome measures used to gauge distress were reported collectively for family members rather than being gender specific, it is not possible to gain a clear picture as to whether a gender specific difference occurred. There was also no control group with which to compare whether the outcomes achieved by the adolescents with pain would have been any different to those that did not have an adult family member present. The absence of a control group was another point of difference to the study by Martire et al. (2007), who found that those with osteoarthritis accompanied by a significant other did not show as much improvement in the areas of pain severity or physical function as those who attended the programme alone. However, it should be noted that all those with osteoarthritis in the study by Martire et al. (2007) were reported to have experienced similar improvements in terms of their ratings of self efficacy. This is noteworthy, as self efficacy has been identified as an important outcome indicator of an individual's adjustment to, and management of pain (Keefe et al., 2004; Riemsma et al., 2003).

The finding that those with pain can experience worse outcomes when accompanied by a significant other was certainly not a common theme amongst the literature that I located, but has also been reported by Riemsma et al. (2003). They examined the effects of significant other involvement in programmes for rheumatoid arthritis and found that

those with pain experienced a decrease in their self efficacy that they could manage symptoms such as fatigue, depression and frustration and also experienced an increase in their fatigue levels as a result of the involvement of a loved one. These findings regarding self-efficacy differ from Martire et al. (2007) but may possibly be explained by the different ways in which the two diseases (rheumatoid arthritis and osteoarthritis) affect people. Looking at the literature it is clear that not all people experience negative effects from the involvement of significant others (e.g. Lewandowski et al., 2007). Viewed collectively, the information contained within the literature highlights the urgent need for research regarding the involvement of significant others within programmes, as it has not been clarified what factors contribute to positive or negative outcomes from their inclusion. If such information was known, interventions could be targeted in an informed and appropriate manner.

The perceptions of significant others regarding the content and purpose of interventions for pain

All but one of the articles that I located on the theme of significant others and their involvement in interventions for chronic pain were quantitative. Quantitative research by its very nature does not allow for the meanings and views of participants to be explored beyond the preconceived responses researchers make available to participants (Milne & Oberle, 2005). Thus, what is missing from the literature is descriptive information about the involvement of significant others in chronic pain management programmes, from the perspectives of those with pain and their significant others e.g. reports of how significant others have found their involvement in a programme. The one qualitative study that I did find was a pilot study involving face to face interviews with the family members of nine women of Moroccan or Turkish decent, who had a range of pain conditions (Sturkenboom et al., 2007). All the women had or were receiving some form of intervention for their pain but this varied from contact with a doctor and one other discipline, to participation in a comprehensive rehabilitation programme. Four of the participants had recently been discharged from the service and the other five were still receiving input. The initial intention of the authors had been to learn how family members perceived the health, treatment and care of a relative with chronic pain, however the authors reported participants to have talked very little about the rehabilitation that their loved one was or had been receiving. All but two of the participants were also described as having a very limited awareness of the aims or content of the rehabilitation programme that their loved one was engaged with. Many expressed the opinion that rehabilitation was something that happened ‘there’ at the

hospital without association to activities within the home. Most also considered that their role in the care of their loved one with pain was to provide practical support, such as assistance with domestic tasks, so that the individual could rest and avoid further damage. Further, many participants shared a belief that activities such as going to the doctor was a sign that the individual was taking responsibility for seeking a cure for their pain, whereas this action might be considered by professionals to represent the adoption of a passive role in treatment (Sturkenboom et al., 2007).

In Western culture independence and autonomy are valued. This value translates to health care, with an expectation that significant others will instinctively facilitate independence in their loved one with pain (Sturkenboom et al., 2007). The findings by Sturkenboom et al. (2007) serve as a clear reminder that independence is not valued by all cultures and even within Western families, beliefs and values around the roles of significant others in the care of a loved one with pain may vary. New Zealand is a multicultural society (Dominick et al., 2011) and the comments by Sturkenboom et al. (2007) signal the need for the aims and interventions used when addressing the psychosocial element of chronic pain to be culturally responsive.

Prior to attending a pain management programme, an individual may have tried multiple other treatments without success (Dopson, 2010; Sturkenboom et al., 2007). In cases where an individual had experienced pain for more than two years, family members in the study by Sturkenboom et al. (2007) were not reported to be hopeful of an improvement. This lack of optimism may explain in part, why the relatives of only three out of nine individuals with pain were involved in their intervention programme. What is not clear from that, or any other study, is how significant others would like to be involved in the intervention that their loved one with pain is receiving. Sturkenboom et al. (2007) commented on the absence of literature regarding the perceptions that family members have about their involvement in pain management programmes. They stressed the need for further research into the factors which influence the involvement of significant others in intervention and also the identification of strategies regarding how significant others can best be involved.

The involvement of children in chronic pain management programmes

When describing the involvement of significant others in a chronic pain management programme, articles only typically discussed the inclusion of a spouse or partner (e.g. Keefe, et al., 2004; Martire et al., 2007; Saarijärvi, 1991). Some papers did talk about

family and friends being invited to attend a general session as part of the programme (e.g. Dopson, 2010), however I did not locate any research specifically discussing or investigating approaches for the inclusion of children, even though the possible effects of pain on children are well acknowledged (Bustin & Hughes, 2009; Chun, Turner, & Romano, 1993). Focus group interviews with individuals who have pain, prior to commencing a residential pain management programme, have shown that one of the key wishes for those who are parents, is that programme attendance will enable them to restore parenting roles and regain relationships with their children (Bustin & Hughes, 2009). Interestingly, participants in this study did not talk about a wish for their children (or other significant others) to be involved in the programme but rather their wish was to improve themselves for the benefit of their children (Bustin & Hughes, 2009). The fact that children are affected by pain but in potentially different ways to a spouse e.g. taking time off school to care for a parent with chronic pain (Bustin & Hughes, 2009), indicates that they too may need support, which might be different than that required by an adult. It has been suggested by Bigatti and Cronan (2002) that ensuring that a spouse has the skills to cope effectively with their partner's pain, will in turn enable them to share those skills with their children. Once again, I found no studies investigating this proposal in the pain literature.

The views on inclusion that have been shared by significant others caring for loved with mental illness

Looking outside the field of chronic pain, guidelines for the involvement of significant others in intervention is available within the mental health literature (Ministry of Health, 2000a), as is research concerning the views that significant others hold regarding their involvement in the rehabilitation of a loved one. A recent report regarding the needs of carers in culturally diverse communities (Multicultural Mental Health Australia, 2004), provides clear evidence that although there is often very little family involvement, relatives wish to be involved in the treatment a loved one is receiving for their mental health. Specifically, all the family members in that report indicated that they wanted to remain informed of what was happening, to have their input valued, and to be involved in the decision making for their relative. A lack of communication was described by family members to leave them feeling as though they were not valued, listened to or supported (Multicultural Mental Health Australia, 2004).

One way of involving significant others in the rehabilitation of a loved one is through the provision of education. Prince (2005) interviewed 246 individuals with

schizophrenia three months after hospital discharge and found that interventions that were designed to provide family members with education about mental illness were less valued than those aimed at assisting family members to practice and acquire the skills required to cope with daily challenges. Although the aforementioned documents are set in the context of mental health, both mental ill-health and chronic pain are long term conditions which involve significant others making adjustments to support the loved one who is immediately affected. It is therefore possible that those who are supporting a loved one with chronic pain may also desire greater involvement with intervention services, so that they can acquire the practical skills necessary to manage associated daily struggles. To the best of my knowledge, research exploring the views that significant others hold about their involvement in chronic pain management programmes has not yet been undertaken but could usefully inform the support offered to significant others as part of programmes.

Conclusion

Over the last several decades knowledge about the aetiology and prevalence of chronic pain has grown, as has understanding regarding its effects on an individual, their significant others and interpersonal relationships. It is now widely accepted that interventions offered for chronic pain cannot neglect to address an individual's social environment, as friends and family have been shown to play a significant role in an individual's experience of pain. Equally however, it is recognised that pain can have a huge impact on the wellbeing of significant others and in turn their ability to provide support. Accordingly, the involvement of significant others in programmes is common, however this literature review has highlighted the absence of research investigating whether the theoretical rationale for involving significant others within a programme is supported by the views of those with pain and significant others. In fact some studies even suggest that involvement might place some with pain and/or their significant others at risk of harm or disadvantage.

Wide variation currently exists regarding the extent to which significant others are involved in programmes and the treatment aims associated with their participation. This variation is understandable given the absence of guidelines regarding the involvement of significant others in programmes and may well explain the observed variation in the outcomes reported as a consequence of their involvement. Adding to the challenge of

involving significant others within a programme is the need to be responsive to cultural diversity. Restoration of independence in an individual with pain is the primary aim for many pain management programmes. This approach may not align with all cultural practices, suggesting that significant others may have very different expectations of a programme to those of the team providing it and this may contribute to poor participation rates by significant others.

To date, research regarding the involvement of significant others within programmes has largely been quantitative in nature and the approaches used to involve significant others driven by theory. This literature search has indicated several areas of much needed research relating to the involvement of significant others in chronic pain management programmes. The focus of the study reported here is to build on calls by Sturkenboom et al. (2007) for research into the involvement of family and friends in intervention programmes for chronic pain and to this end, those with pain and significant others who attended the Family Day at TARPS, were asked to share their views on the involvement of significant others in the programme. It is hoped that the findings from my research will stimulate discussion within pain management teams regarding how, and with what intent significant others are involved in programmes.

Chapter Three – Methodology

Introduction

This study used a qualitative descriptive research design to examine the question: “What are the views of individuals who have participated in a Family Day, delivered as part of the 3 week multidisciplinary chronic pain management programme at TARPS, on the involvement of significant others within the programme?” In this chapter I will explain why a qualitative descriptive methodology was selected, describe the ontological and epistemological underpinnings of this methodology and address the ethical issues which were considered pertinent to the study. Secondly, I will describe the participants, the recruitment process, and the methods of data collection and analysis. Finally I will outline the strategies that were used to ensure rigour.

Selecting a qualitative descriptive methodology

Qualitative research or inquiry is an umbrella term which encapsulates a number of different research methodologies – of which, qualitative description is one example (Schwandt, 2000). In contrast to a ‘method’, which gives specific detail regarding the techniques used to collect data, a ‘methodology’ provides an overall description of the processes and procedures used to address a particular research question (Hansen–Ketchum & Myrick, 2008; Ponterotto, 2005; Willig, 2001). All qualitative research is concerned with the in-depth exploration of the meanings, perspectives and views that individuals ascribe to a particular experience (Beaulieu, 2007; Meadows, 2003; Pitney, 2004). However the varying methodologies differ in their objectives and the kind of knowledge they aim to produce (Willig, 2001). A qualitative approach was considered to be ideally suited to the focus of this research, which was to explore the views held by individuals with pain and significant others, about the involvement of significant others within the TARPS, chronic pain management programme.

A qualitative descriptive approach was selected for this research, for two reasons. Firstly, the research question under investigation is seeking to explore ‘what’ is happening in the TARPS programme or more specifically ‘what’ those who have participated in the Family Day think about the involvement of significant others in the programme. Qualitative description is very useful for exploring ‘what’ questions associated with practice, as it yields a comprehensive summary in everyday language of what is happening in a particular setting or within a group of individuals (Artinian,

1988; Milne & Oberle, 2005; Sandelowski, 2000). The second reason for the selection of a qualitative descriptive approach was that the intended audience for this research are multi or interdisciplinary team members working within pain management programmes. Each member of a team has his or her own language and understanding of the world, which is shaped by his or her professional background (McCallin & McCallin, 2009). Given the diversity of the intended audience, the uncomplicated presentation of information yielded by a qualitative descriptive approach was deemed an advantage for the communication of findings.

Evaluating the findings produced by a study and determining whether it has met its objectives requires a clear understanding of three things: the paradigm within which the researcher was operating and the ontological and epistemological position anchoring the particular methodology (Willig, 2001). From the outset, the way in which a research question is framed and investigated is determined by the researcher's beliefs and assumptions about the world; this interpretive framework is referred to as a 'paradigm' (Denzin & Lincoln, 2000). There are a number of paradigms, for example positivist, post positivist, constructivist and critical-ideological (Denzin & Lincoln, 2000; Ponterotto, 2005). No one paradigm is considered to be the ultimate truth but rather each provides a different insight into a particular aspect of life and accounts for individual differences in the way that people view the world (Babbie, 2007). This study is founded in a constructivist paradigm. Constructivism recognises that reality is complex, constructed and subjective (Ponterotto, 2005; Schwandt, 2000). Obtaining the "truth" (Sandelowski, Davis, & Harris, 1989, p. 77) requires a commitment to naturalistic inquiry or studying an event in its natural state and in a way that allows access to people's interpretations of that event (Galvin, 2005; Sandelowski, 2000). This means that there is no pre-selection or manipulation of variables, or prior commitment to any one theoretical viewpoint and unlike other qualitative approaches, inference through interpretation is limited with qualitative description (Sandelowski, 2000; Sandelowski et al., 1989).

The kind of assumptions that a researcher holds about the world, the nature of reality and thus what there is to know about it, refers to their ontological position (Hansen-Ketchum & Myrick, 2008; Willig, 2001). Ontological assumptions can be classified as realist or relativist (Willig, 2001). Realism takes the perspective that reality is objective and contained by laws which can be explained through cause and effect relationships

(Willig, 2001). Relativism by contrast embraces the notion that reality is subjective and thus the accounts of a particular experience will vary between participants depending on their perception of the event in question (Willig, 2001). Accessing these personal accounts for the purposes of research requires a commitment to the use of methods that enable participants to share their interpretations and perceptions of an experience (Hansen–Ketchum & Myrick, 2008; Willig, 2001). Research emanating from a relativist assumption also varies from realism in that it does not aim to direct change but may lay the foundations for it (Hansen–Ketchum & Myrick, 2008). In keeping with a constructivist paradigm, this research is based in a relativist perspective.

What can be known and the relationship between the knower (participant) and the researcher is defined by an epistemological position (Guba & Lincoln, 1994; Ponterotto, 2005). This position is not independently generated but shaped by the ontological position (Guba & Lincoln, 1994). This study is anchored in relativism and in line with this view, the epistemological position is transactional and subjective (Guba & Lincoln, 1994). Within this epistemological assumption it is not considered possible for the researcher to be an objective observer but rather the findings are created from the interaction between the researcher and the participant (Guba & Lincoln, 1994). It is also acknowledged that both the researcher and participant may perceive and therefore describe the experience differently, without either being wrong (Willig, 2001).

To summarise – this study uses a qualitative descriptive methodology, which is anchored in a constructivist paradigm, relativist ontology and a subjective and transactional epistemological viewpoint. In the remainder of this chapter, I will describe the methods that I used to collect and analysis the data.

Ethics approval

TARPS is based at the Greenlane Clinical Centre (Auckland) and sits within the services provided by the Auckland District Health Board (ADHB). Accordingly, this study proposal was reviewed and approved by both the ADHB Research Review Committee (14.9.2011) and ADHB Maori Research Review Committee (17.8.2011) (Appendices 3 and 4 respectively). Full ethics approval was received from the Northern Y Regional Ethics Committee on the 8th of September, 2010 (Appendix 5). Recruitment of participants only begun once full ethics approval had been granted. Prior to

submitting any of the ethics applications, my research proposal was reviewed and approved by the Faculty of Health and Environmental Sciences Postgraduate and Research Committee on 26 February 2010 (Appendix 6).

Achieving ethics approval involved demonstrating my familiarity with relevant legislation and describing how these were to be reflected in my research. All health related research undertaken in New Zealand is governed by the principals contained within The Health Information Privacy Code 1994 (Privacy Commissioner, 2008), Code of Health and Disability Services Consumers' Rights 1996 (Health and Disability Commissioner, 2009) and The Treaty of Waitangi. The purpose of these documents is to protect the rights of research participants in three ways. Firstly, by ensuring that they are fully informed about the study; secondly, that they give voluntary consent to participation and thirdly, by ensuring that their respect and dignity is maintained, and their safety is preserved throughout their participation. Participants who feel that their rights have been breached in any way are able to make a complaint to the Health and Disability Commissioner.

To be fully informed

It is the responsibility of the researcher to demonstrate that he or she has taken all reasonable steps to ensure that participants and those considering participation are fully informed about the purpose of the study and what their participation will involve. This information includes, but is not limited to how any information that they give will be gathered, stored, used and then destroyed at the end of the study. Participants must also be aware of their rights, such as how they can withdraw from the research and to whom they can complain if they feel any of their rights have been breached (Health and Disability Commissioner, 2009; Privacy Commissioner, 2008). The methods used within this study to ensure participants were informed included: a group presentation, written information in the form of an information sheet (Appendix 7) and the opportunity for individual discussion with myself (the researcher).

Give voluntary consent to participation

Voluntary consent means the absence of coercion (Health and Disability Commissioner, 2009). Participants not only need to be fully informed but they also need to be provided with adequate time to consider the information before being required to give their consent (Health and Disability Commissioner, 2009). From the outset of recruitment for this study, all participants were made aware that their participation was entirely

voluntary and their decision to participate or not, would in no way affect the care that they or their loved one received from TARPS. Two levels of consent were obtained from participants. Firstly, because I was not a member of the TARPS team, those who expressed an interest in participating in the study on the Family Day were asked to provide their written consent to be contacted after completion of the programme; the purpose of this contact being to review if they were happy to be interviewed (Appendix 8). Secondly, consent was obtained from each participant prior to the initial interview (Appendix 9). A time period of approximately two months separated the point of initial contact i.e. the point at which an expression of interest was obtained and the initial interview. This time period ensured that participants had time to consider their consent.

Maintenance of respect, dignity and preservation of safety

All research participants have the right to be treated with respect and in a manner that preserves their dignity and safety (Health and Disability Commissioner, 2009). This right extends beyond respect for an individual's cultural beliefs and values, to the careful consideration of how information shared by participants will be managed to ensure that their confidentiality is preserved (Health and Disability Commissioner, 2009; Privacy Commissioner, 2008). Finally, participants must be made fully aware of any potential risks or adverse side effects that may occur as a consequence of their involvement (Health and Disability Commissioner, 2009). In this study strategies such as scheduling interviews at mutually arranged times and storing hard copies of information in a locked filing cabinet and electronic files in a password secure computer were used to demonstrate respect and maintain dignity. It was not expected that participants would experience physical or emotional harm as a result of their involvement; however participants were provided with a free phone number for the researcher and advised that they could use this at anytime following the interview, should their participation trigger feelings of distress at a later date. In the event that any of the participants had expressed distress, they would have been placed in contact with appropriate support and the TARPS team notified. Also, during the course of the interview, every effort was made to alleviate any discomfort associated with the interview process e.g. through the use of humour.

The Treaty of Waitangi

The Treaty of Waitangi is the founding document of New Zealand and encapsulates the principles of partnership, protection and participation (McClintock, Mellsoy, & Kingi, 2011; Te Pou O Te Whakaaro Nui, 2009). At the outset of the study it was expected that

at least 1-2 participants would identify as Māori and I arranged cultural supervision in anticipation of this. The purpose of cultural supervision was to ensure I had the appropriate guidance to uphold the principles within The Treaty. Only one person identifying as New Zealand Māori expressed an interest in the study but unfortunately they were not able to proceed to an interview due to illness within the Whānau³.

Execution of design

Selection of participants

Purposeful sampling was used to access “information rich cases” (Patton, 2002, p. 243), who were able to inform the research question and to ensure that maximum variation was achieved within the sample (Meadow, 2003; Patton, 2002; Sandelowski, 2000). The aim of maximum variation is to capture and reflect the common themes that exist within a diverse group (Patton, 2002). Purposeful sampling was deemed most appropriate for this study for two reasons. Firstly, this study was examining an area for which there is limited existing knowledge, thus it was of benefit to gather a range of views. Secondly, chronic pain is not discriminatory about who it affects. New Zealand is a multicultural country (Dominick et al., 2011) and this is reflected in the participants who attend TARPS i.e. programme participants vary in terms of age, race, culture, religion and location of pain etc.

At the outset of the study it was estimated, in consultation with my supervisors, that 8-12 participants would be required to explore the common and unique manifestations of the research question under investigation, to data saturation i.e. the point at which additional interviews do not generate new information (Patton, 2002; Sandelowski, 2000). To be included in the study, a participant needed to be a person with pain who had completed the 3 week pain management programme at TARPS and had one or more significant others present at the Family Day. Or alternatively, they had to be a loved one who had attended the entire Family Day. Programme participants whose significant other(s) did not attend the Family Day were excluded from the study, as were those whose loved ones did not stay for the full Family Day. These exclusion criteria were established in order to focus on the experiences of those who had shared the full experience of the Family Day with at least one significant other. However, if an

³ Whānau is a Māori-language word for extended family

individual with pain volunteered to participate in the study, their significant other was under no obligation to participate and vice versa.

The nature of qualitative research and the use of interviews to obtain in-depth insight into the experiences of participants, necessitates that the researcher and participant can converse with relative ease. Despite the multicultural backgrounds of those attending the TARPS programme (K. McCallum, personal communication, March 22, 2010), it was not felt necessary to stipulate that individuals needed to speak English, the language in which I am fluent, in order to participate in the study. This decision was made following discussion with my supervisors and based on the assumption that all potential participants would be fluent in English, as evident by their participation in the TARPS programme which is delivered in English.

Recruitment

A Family Day is held on the last day of the TARPS, 3 week multidisciplinary pain management programme. I, as the researcher, was granted permission from the TARPS team to attend as many Family Days as needed to recruit the required number of participants. Recruitment stopped when it became evident that data saturation had been achieved during the interviews. The flexibility offered by the TARPS team was vital to the study, as it was not possible to know from the outset how many individuals on any one Family Day would express an interest in participating in the study or how many of those would continue on to an interview. In total I attended three Family Days between October 2010 and March 2011. The first was in October 2010, the second in November 2010 and the third in March 2011; the first two of these programmes occurred consecutively.

At each Family Day I was provided with an opportunity to address attendees — introducing myself and the nature of the study. This address took appropriately 5 minutes and was held during the first session of the Family Day, at which a member of the TARPS team provided attendees with an overview of chronic pain and the self management focus of the programme. During all the presentations I made it known to attendees that I would be present for the remainder of the Day, to answer any questions about the study and to gather expressions of interest. Although my initial presentation was brief, many people approached me at different times during the course of the Day to ask more about the study, with some then offering their participation. Those people who expressed an interest in participating were asked to provide contact details, demographic

information and written consent for me to contact them appropriately two months after the Family Day, to ascertain if they remained available to participate in an interview (Appendix 8). The two month gap between the receipt of an expression of interest and re-contact was selected following discussion with my supervisors. This timeframe was intended to provide individuals with a chance to settle back into their daily routines following the programme and thus facilitate reflection on the family component of the programme during their interview.

Recruitment rates between the three programmes varied. On the first two Family Days, nine and six people respectively expressed an interest in participating in the study; this represented the majority of attendees on each of the Days. By contrast only one person from the third Family Day expressed an interest. I understood from the TARPS team that there had been trouble with group dynamics throughout the third programme, resulting in one participant leaving in the second week. These challenging dynamics possibly reflected the low recruitment from the third Family Day. Another point of difference between the three groups, which may have accounted for the variation in recruitment, was that participants in the first two programmes had been advised prior to the Family Day that I would be joining the group for the Day and also given a copy of the Information Sheet by a member of the team. The final group that I addressed had not been advised that I would be attending the Family Day, as staff had been distracted with the management of group dynamics. While only those with pain in the first two programmes had been advised that I would be attending the Family Day, it is possible that they shared this information with their significant others before the Family Day and this advance knowledge may have made people more willing to participate.

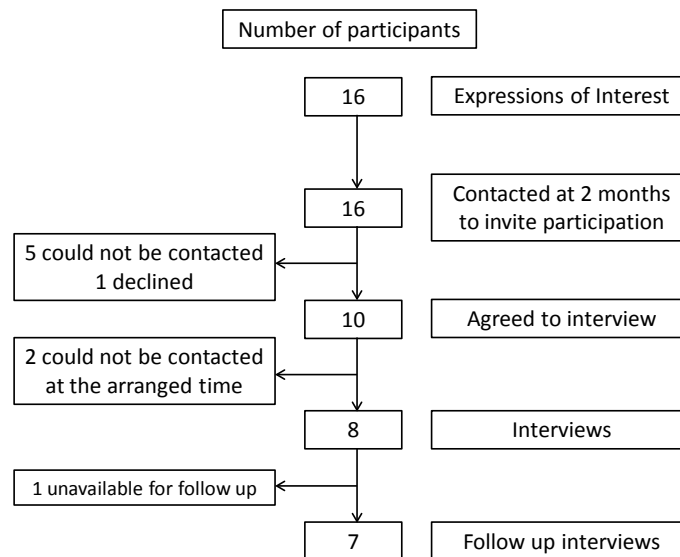
When the collected demographic data was reviewed, wide variation was observed amongst those who had expressed their interest in participating in the study. This variation was observed over a range of characteristics such as age, ethnicity and the length of time that a person had been living with pain or supporting a loved one with pain. Because my aim had been to achieve maximum variation in my sample, all those who had expressed an interest in participating were sent an Information Sheet and a Consent Form exactly two months after the Family Day (Appendices 7 and 9 respectively). This information was posted to all but three people who had provided email details as their preferred method of contact. Those that had provided postal details were also sent a prepaid envelope in which to return their Consent Form, in the event

that their preference was for a phone interview. The posted information also included a cover page reminding prospective participants about the details of the study and priming them for my call (Appendix 10).

Approximately one week after the letter or email had been sent, I attempted phone contact with the 15 participants who had provided a number and re-emailed the remaining participant who had only provided email details. The purpose of the contact was to confirm that the letter or email had been received, provide the individual with any further information they required about the study and confirm availability to participate in an interview. If those who had given a phone number could not be reached after several attempts, a text message was sent if a mobile number had been given. In the message people were asked to reply if they remained keen to participate in an interview. In total three follow up text messages were sent to participants who could not be contacted by phone, however none resulted in people wishing to participate in an interview. The one participant who had only provided her email details did not respond to the first or second email that I sent, the second asking her to contact me if she would like to proceed with an interview and I attempted no further contact.

After confirmation was received that a participant was happy to proceed to an interview, a mutually arranged time was scheduled to ensure the least disruption to their other commitments. Of the 16 people I contacted, 10 agreed to an interview, however when I contact two of the participants at the arranged interview time, there was no answer and attempts to re-contact the participants proved unsuccessful. Thus, a total of eight phone interviews were held. A summary of the recruitment process is shown in Figure 3.1.

Figure 3.1 Flow Diagram of Study Recruitment



Consent process

Participants were given the option of a phone or face to face interview but all elected to have the interview over the phone. If a participant had not received the Information Sheet and Consent Form when contact was achieved, these documents were resent with a prepaid envelope to enable the participant to return the signed Consent Form prior to the interview. Likewise, individuals who had initially provided only an email address were posted a Consent Form and asked to return it prior to the interview. As I was a distance student working from home, it was arranged that all return envelopes would be addressed to my supervisors, who would in turn forward the forms on to me. This decision was made to preserve my own privacy and similarly all email communication with participants occurred via my student email address.

The wish of all the participants for a phone interview did in some cases create challenges around the return of the Consent Form prior to interview. For example, for those interviews that occurred over the Christmas and New Year period, receipt of the form was delayed because of the public holidays. In consultation with my supervisors it was arranged that if the written consent had not arrived prior to the interview, the participant would be asked to confirm that they had posted their Consent Form. Those who gave that confirmation and were happy to participate were then interviewed. Those who when contacted at the arranged interview time, stated that they consented to the

interview but had not signed and returned their Consent Form, were guided by the researcher through the contents of the Consent Form and asked to confirm their consent verbally. They were then asked again if they could return a signed copy of the Consent Form at their earliest possible convenience. All verbal consents were included in the interview transcript and confirmed by my supervisors. In all but two cases, the participant's written consent arrived within a week of the interview having been completed. In the two cases where the written consent was never received, a record was kept of the participants' full verbal consent.

Data collection

I participated in the entirety of three Family Days, with the purpose of gaining expressions of interest for my research. My participation also allowed me to gather valuable information, in the form of observations, about the general dynamics of each group and how each Family Day ran. Observations typically describe the things that one can see, hear and or touch, and can be reported from an etic or emic perspective (Babbie, 2007). An etic perspective refers to the views of an outsider rather than that of someone who was directly involved in the event, which would provide an emic or insider perspective (Babbie, 2007). Both perspectives offer advantages and disadvantages but they do not have to be mutually exclusive so that a researcher can move between the two or hold both simultaneously (Babbie, 2007). I attended the Family Day as an outsider (having never met the group before), however I participated in all the activities undertaken by each group and was in a similar position to the significant others who were joining the group for the first time. Thus, my observations could be considered to reflect in large part an etic perspective but also an emic one to a small degree. Having shared in the experiences of each Family Day meant that when I later interviewed participants and they referred to a particular aspect of the Day, I was able to relate to the information in a way that would otherwise not have been possible.

Interviews

Semi-structured phone interviews were conducted with each of the eight participants. Once all participants had been interviewed and initial themes identified, all were re-contacted and invited to participate in a shorter follow up interview. Of the eight participants, seven were available for a follow up interview (Figure 3.1). The purpose of the follow up interviews were to clarify details gathered during the first interview and check the emerging findings with participants (Hsieh & Shannon, 2005).

A semi-structured, rather than structured or unstructured interview format was selected to ensure that key topics of interest were explored in each interview, while also allowing the emergence of new themes and concepts (Meadows, 2003). In the tradition of qualitative description, questions were structured to elicit the 'Who', 'What', 'Where', 'How' and 'Why' views of participants (Sandelowski et al., 1989) (Appendix 11). The interviewing techniques suggested by Patton (2002) were also used as a framework to facilitate effective interviewing throughout the study e.g. use of singular questions and the timely use of feedback to encourage the interviewee to continue to provide information.

The first interview for all participants occurred between 2½-4 months after they had attended the Family Day. The key factor accounting for the 1½ month interview variation was the Christmas/New Year holiday period, which understandably saw many of the participants involved in holiday activities and wishing to delay the interview. The length of each of the initial interviews varied from 15-76 minutes, with the average time being 38 minutes. An interview template was used for all the initial interviews (Appendix 11). This template provided me with a framework for the interviews, by reminding me of the areas that I wished to explore with each participant. However, the way that I worded each question and the order in which I asked them varied between the participants, in response to the issues that they raised. Thus, to an observer, the initial interviews would have appeared much like a conversation, with natural variation occurring in what each participant wished to share.

Follow up interviews occurred 2-8 months after each participant's initial interview and ranged from 5-33 minutes in duration. The average length of a follow up interview was 19 minutes. The scheduling of the follow up interviews was determined by three factors. Firstly, by my own need to juggle part-time study around work and home life. Secondly, after conducting follow up interviews with five of the participants, I deliberately chose to delay re-contacting the final three participants so that I had an opportunity to process the information that I had gathered and clarify the questions that I wanted to ask. Unfortunately once contact was attempted with these final three participants, only two were available for a follow up interview. Thirdly, variation in the timing of the follow up interviews occurred because recruitment took place over a 6 month time period and it was necessary to delay the follow up interviews until all the initial interviews had been completed. The observed variation in the duration of each of the follow up interviews

occurred because during the first few, I invited participants to comment on my overall findings. This was done as a means of checking whether the participants felt that I had accurately captured the views that had been expressed about the involvement of significant others in the programme. For example, I asked participants questions such as, “A strong theme that seems to have come through all the interviews, is that it is important for significant others to be involved in the programme so that everyone can be on the same page – what do you think about this?” As the follow up interviews progressed and with consistent support articulated from participants for my findings, I chose to become more focused in the questions that I was asking. Thus, in the final two follow up interviews I continued to use a semi-structured interview format but asked the participants more specific questions, as a means of clarifying points that had arisen in previous interviews. For example, “Is knowledge about where families can go for more support after the programme important?” and for significant others specifically, “Some of the other, significant others have described feeling that attendance at the Family Day helped them to achieve a greater level of acceptance about the pain of a loved one and this in turn has helped them to support their loved one to make change – has this been your experience?” Where necessary and appropriate, the participants were asked to provide further information regarding their responses. As with all the participants, these final two participants were also provided with an update on the themes that were emerging from the interviews.

Recording and transcription processes

Each of the interviews were recorded digitally and saved using Adobe Soundbooth CS3, Version 1. All initial interviews were then transcribed verbatim. To ensure transcription occurred in a timely manner, some of the recordings were transcribed by one of two typists, both of whom signed a confidentially agreement (Appendices 12 and 13). All interviews were transcribed within two weeks of the interview being completed, with the exact timeframe dependent on the typists’ other commitments and the number of interviews she was required to complete at any one time. Following consultation with my research supervisors it was decided that follow up interviews would be recorded but only transcribed if they contained new or additional information that would illuminate the study question. Consequently, extracts from three of the follow up interviews were transcribed by myself after each of the recordings had been reviewed.

Confidentiality

Files were created for each participant and included transcripts and a log of all communication. To maintain participant confidentiality each file was coded (e.g. R1). This coding system was generated as each expression of interest was received. As not all those who expressed an interest went on to an interview, the codes reflected in the final participant group are not consecutive. The coded files were stored with all other material associated with the research, in a locked filing cabinet only accessible to me. Any information stored on the computer was password secured. Digital recordings of the interviews were deleted after the transcription had been checked for accuracy. All participants were reassured from the outset of the research that the information that they provided during interviews would not be disclosed to members of the TARPS team; participants were however made aware that the overall findings of the research would be shared with TARPS.

Phone interviews

At the outset of this study it was not expected that all participants would select a phone rather than face to face interview. Relatively little has been written about the use of phone interviews in qualitative research, as face to face interviews have traditionally been considered to be the most effective method of gathering data (Holt, 2010; Sturges & Hanrahan, 2004). The commonly expressed concern with phone interviews is that absence of visual cues compromises the quality of gathered data (Holt, 2010; Sturges & Hanrahan, 2004). This concern and general hesitance to use phone interviews has however been firmly challenged by several authors.

Sturges and Hanrahan (2004) compared the quality and quantity of data gathered through phone and face to face interviews with 43 participants – 21 selecting face to face interviews and 22 phone interviews. When the responses obtained from both groups of participants were reviewed, it was found that the “nature and depth of responses did not differ substantially by the type of interview” (p. 112). In addition participants were asked how they felt about the interview mode that they had chosen. All participants responded that they had been satisfied with their chosen method and that they had felt able to express themselves freely during the interview. The participants also reported their appreciation at being able to choose the interview mode. Amongst those who requested a phone interview, convenience was the most commonly reported reason, along with the degree of anonymity it provided. To maximise recruitment Sturges and Hanrahan (2004) do however suggest that, as was done for this

research, initial contact occurs face to face so that potential participants are informed of the study and invited to participate in person.

Holt (2010) also found phone interviews to “produce rich, detailed data: conversations lasting between 21 minutes and three and a half hours” (p. 117). Like Sturges and Hanrahan (2004), Holt (2010) invited participants to feedback on their experience of the phone interview, with most reporting it to have been positive. Holt (2004) did not comment directly about those whose experience may not have been as positive but did describe phone interviews to create distinct challenges for both parties (the interviewer and interviewee), particularly those associated with the management of uncertainty. For example, how the interviewer should let the interviewee know that they are still there and listening without dominating the conversation. Comments such as this highlight that specific skills are demanded of a researcher when conducting phone interviews but these can be overcome with practice. While careful not to suggest that phone interviews are suited to all research, Sturges and Hanrahan (2004) and Holt (2010) encourage researchers not to dismiss this mode of interviewing before considering the benefits it has to offer. Besides being a safe and cost effective way of gathering data (Sturges & Hanrahan, 2004), Holt (2004) stated that phone interviews help researchers “to stay at the level of the text” (p. 115) during data analysis, through the absence of contextual information that the researcher might have otherwise gathered from an interview in a participant’s home. This comment is of particular relevance, as it suggests that phone interviews fit well with the intent of the qualitative descriptive methodology used in this study i.e. to remain close to the data (Sandelowski, 2000).

One question that I was often asked by my colleagues when discussing my research, was how I could be sure of the information that a participant was sharing with me during their interview i.e. how I knew that they were not being coached through the interview by a spouse who was in the same room. At no time during any of the interviews did I feel that participants were constrained from sharing information by the presence of other members in their household. For example, participants made comments such as *“I just have to get everyone to agree...[that I can do the interview now]...so that I can go somewhere where I can hear you”* and before answering a question about her partner another participant asked for confirmation that *“this is confidential right?”*

Data analysis

Conventional content analysis was used to identify the core themes contained within the data (Hsieh & Shannon, 2005; Patton, 2002). Conventional content analysis is one of three distinct approaches to content analysis (Hsieh & Shannon, 2005). All three forms of content analysis are considered to offer a dynamic and flexible way of developing knowledge about the human experience (Hsieh & Shannon, 2005). As an approach, content analysis lends itself well to qualitative descriptive research, as both adhere to a naturalistic paradigm i.e. both share the aim of going no further with the data than to present a descriptive summary of the event in question, in a way that is most suited to the audience for which it was written (Hsieh & Shannon, 2005; Sandelowski, 2000). Of the three approaches to content analysis, conventional content analysis was selected for this study. This approach was selected because of the three possible approaches, it has been identified as the most appropriate for research designed to describe phenomenon for which there is limited existing literature (Hsieh & Shannon, 2005).

Process of data analysis

The process of conventional content analysis is described by Hsieh and Shannon (2005) and I drew on their guidelines, along with feedback from my supervisors, to direct the analysis of the data. The process of analysing the data began immediately after each interview, as I reflected on the information that each participant had shared. My immersion in the data continued as I re-listened to each interview several times, either while typing up the transcript or checking an interview typed by my transcriber. This process enabled me to gain an overall sense of the information shared in each interview and begin reflecting on the way that it might relate to the data gathered in other interviews. I then read each transcript line by line and made a summary note or word in the margin as a way of coding the content of the corresponding data. At the same time I highlighted any recurring words, phrases and/or themes appearing in the transcript. Once completed, I listed all the summary notes and words that I had made on a piece of paper, along with the words that I had highlighted for each transcript. At the same time I also made notes about my initial impressions of the key themes contained within each transcript.

The aim of the data analysis was not to compare the experiences of an individual with pain to that of their significant other(s). Rather, the data gathered from individuals with pain and the significant others was analysed collectively, to draw out key themes about

the involvement of significant others within the TARPS programme. Thus, the next step of the analysis involved collectively reviewing the lists that I had made for each transcript and then organising the codes contained within each list into meaningful clusters under emerging themes and their sub-themes. The process of data collection and analysis occurred simultaneously. This allowed for ongoing modification of codes and themes and ensured their best fit with the data (Hsieh & Shannon, 2005; Sandelowski, 2000). Open coding was used throughout the analysis and where possible, words or phrases that had been used by the participants were used to name themes and codes (Hsieh & Shannon, 2005; Patton, 2002; Sandelowski, 2000). At the point of data saturation, four themes had emerged and I titled these: 'Support and the importance of having someone there', 'Sharing the journey of a pain management programme', 'A look in' and 'Down the track'. These themes were very broad and encompassed multiple sub-themes. Initially I was drawn to the sequential appeal of being able to present the emerging themes around a framework which reflected before, during and after the programme. However, while using such a framework was intuitively appealing, I quickly realised when I began the process of developing brief descriptions for each, that using a temporal approach placed me at risk of not answering my research question. This was because I was starting to tell a general story about the participants views on the programme, rather than their views on the involvement of significant others.

Through the process of discussion with my supervisors and numerous rounds of analysis, I reorganised the coded data and refined my themes and sub-themes. As the central meaning of each of the themes became clearer, I refined my description for each. I also refined the extracts that I had chosen from the coded data to support each description, so that only those that I felt best conveyed the theme or sub-theme remained (Hsieh & Shannon, 2005). After several phases of refinement, I re-contacted participants to gain their views on the accuracy of the emerging themes and sub-themes (Hsieh & Shannon, 2005). I also used this opportunity to clarify information that individual participants had shared with me during their initial interview and to seek their views on comments that may have been raised by one or two of the other participants. This process enabled me to further refine my themes and sub-themes and was especially useful in situations where extracts of the data appeared to sit within more than one sub-theme or theme. Similarly, sub-themes containing comments from only one participant were then developed to incorporate the views of other participants, integrated into another sub-theme or removed altogether. The process of refining concluded in

consultation with my supervisors and once a comprehensive description of the participants' views on the involvement of significant others in the programme had been achieved (Sandelowski, 2000). The details of the analysis and refinement process that I used to write up each theme are presented in an overview contained within Appendix 14.

Throughout the process of recruitment, data collection and then analysis, I maintained a journal. In this journal I reflected on topics such as things that had gone well (or not) during the recruitment process and my thoughts on how I could modify things for the next time that I attended a Family Day. Similarly, I used my journal to reflect on my interactions with participants during the interviews and the struggle I encountered at one stage to remain in the role of a researcher, rather than a therapist. As themes began to emerge through the process of the analysis, I reflected on these in my journal. I also discussed concerns that I experienced midway through the analysis that my own feelings were influencing the way that I was interpreting the data. As a result of this concern I re-read the transcripts and adjusted my analysis accordingly.

Preserving rigor

A shared concern for all researchers – whether using a qualitative or quantitative approach, is demonstrating the quality of their findings (Pitney, 2004). While quality is determined through 'reliability' and 'validity' in quantitative research, 'trustworthiness' is discussed in qualitative research (Pitney, 2004). Trustworthiness describes the degree to which "the findings are an authentic reflection of the personal or lived experiences of the phenomenon under investigation" (Curtin & Fossey, 2007, p. 89). A second measure of trustworthiness is the researcher's ability to remain true to his or her chosen research approach, in the case of this research, qualitative description. A critical part of establishing trustworthiness is the provision of a rich description of the research process, so that the reader is able to develop a clear picture of what was done, why it was done and the findings (Curtin & Fossey, 2007). Trustworthiness is constructed from four components: credibility, dependability, transferability and confirmability (Finlay, 2006).

Credibility refers to the degree to which a study achieves its purpose (Milne & Oberle, 2005). The purpose of this study was to explore the views of people who had

participated in the TARPS Family Day. For a study's credibility to be determined, evidence must be provided that participants had freedom of speech. Secondly, the voices of participants must be heard in the presented findings, and thirdly, it needs to be demonstrated that the views of participants have been accurately represented (Milne & Oberle, 2005). The strategies used to meet the requirements of credibility in this study included purposeful sampling and recruitment from several programmes to ensure that a range of views were captured. Semi-structured interviews were also used to create a forum whereby participants could share their views in their own words. During the interviews I probed for clarification as required to ensure that I had fully understood each participant's views and I continued with data collection until saturation occurred. All the themes that emerged through the process of data analysis were checked with participants for accuracy and supported by quotes to allow readers to assess for themselves whether the findings truly capture what was reported to be occurring (Pitney, 2004). Finally, I communicated with my supervisors throughout the research, allowing me to access regular feedback on my emerging findings and the processes that I was using. This objective feedback provided another means of monitoring my research and ensuring that it was conducted in an appropriate manner (Hsieh & Shannon, 2005; Pitney, 2004).

Transferability refers to the degree to which research findings can be applied or generalised to other contexts (Curtin & Fossey, 2007; Trochim, 2006). In keeping with the tradition of qualitative research, this research makes no claims about the ability of the findings to be generalised to other settings. Instead all efforts have been made in the first three chapters of this thesis to provide readers with a detailed description of the research context, so that they can determine the relevance of study findings to their own practice area (Curtin & Fossey, 2007; Pitney, 2004). The transfer of responsibility from the researcher to the reader, when determining relevance of findings to other settings is another point of difference with quantitative research, where transferability is often used as a measure of validity (Curtin & Fossey, 2007).

Dependability is used to determine the consistency of findings (Pitney, 2004). Because qualitative research is concerned with human experience, which is rarely if ever static, dependability in the context of qualitative research is determined by whether the findings are reasonable based on the collected data, rather than whether findings can be reproduced by another (Pitney, 2004). Member checking, inclusion of verbatim quotes,

regular supervision, rich descriptions of the methodology and journaling through the research process have been recommended as ways of evidencing dependability (Pitney, 2004) and were strategies which I adopted in this research.

Between the initial and follow up interviews consistency was observed in the information shared by individual participants and this can also be taken as evidence of dependability. All the follow up interviews were conducted at least two months after the initial interview had been completed, but despite this time gap participants were observed to remain consistent in their views regarding the involvement of significant others in the programme. For example, in his initial interview, one participant had expressed a strong wish for families to be pointed in the right direction for more resources following the programme. At the outset of his follow up interview (6½ months later) he apologised that although he could remember having the initial interview, he could not remember what it was that we had talked about. During the conversation that followed, he again expressed strong feelings that it was important for families to be pointed in the right direction for more resources following the programme. When I later reviewed his follow up transcript alongside the one obtained from his initial interview, his comments were almost identical.

Confirmability addresses the issue of how it can be assured that findings reflect the experiences and views of participants, rather than those of the researcher (Curtin & Fossey, 2007). Researchers bring with them a multitude of conscious and unconscious assumptions, expectations, values and beliefs, which influence their emotional and behavioural responses throughout the research process (Finlay, 1998; Savin-Baden & Fisher, 2002). These responses can, in turn sway the direction of findings, by shaping the information sought from participants and its analysis (Finlay, 1998). Rather than attempting to deny the presence of bias, Curtin and Fossey (2007), Finlay (1998), and Savin-Baden and Fisher (2002) advocate transparency in the research process. Transparency requires strategies to create awareness. Reflectivity has been identified as a valuable method by which researchers can identify the factors that may have impinged on data collection and analysis, through the process of continual, critical evaluation (Curtin & Fossey, 2007; Finlay, 1998; Savin-Baden & Fisher, 2002). At the outset of this research I engaged in a presuppositions interview, which helped alert me to the expectations and assumptions that I was carrying into the study. Then throughout the study I met regularly with my supervisors, who again helped me to monitor how I was

gathering and analysing the data. I also kept a journal of my research experiences, which included reflections on issues such as my interactions with participants. The insights that I learned through these reflective processes have been shared in the first three chapters of this thesis. The intent of sharing these reflections and insights has been to assist readers to review the methods that I used and my findings, with an understanding of the perspective that I brought to the question under investigation (Savin-Baden & Fisher, 2002).

Summary

In the first three chapters of this thesis I have introduced the research question under investigation and provided background to its development. As part of the background to this study I have also included a literature review, which clearly identifies that this research is exploring an area of limited existing knowledge. In this third chapter I have outlined my research design, associated ethical considerations and the strategies I used to preserve rigour. In the following chapters I will present and discuss my findings.

Chapter 4 – Findings

Introduction

In this chapter I will present the findings that emerged from my research. For clarity I have chosen to divide the chapter into four sections. In the first section, ‘My observations — setting the context’, I discuss my observations from the three Family Days that I attended and also from conducting the initial and follow up interviews. In the second section, ‘Participant profiles’, I describe the participants in the study. In the third section, ‘Analysis of the transcripts’, I present the themes that emerged through the interviews. Finally, the chapter concludes with an overall summary of my findings. I chose to structure the chapter in this way for two reasons, firstly as a means of providing readers with a context from which to understand the information shared by the participants during their interviews and secondly, to ensure that my observations from the Family Days and subsequent interviews were transparent, due to the influence they had on data collection and analysis.

My observations — setting the context

I attended three Family Days between October 2010 and March 2011. All three Days were structured around the same format (Appendix 2), and with the exception of the gym component of the second programme, the staff member(s) involved in each aspect of the Day remained consistent. A different staff member took the gym component of the second Family Day, as another member was on leave. The content presented at each of the Family Days and the style of delivery also remained consistent throughout the three programmes, with only natural variation occurring in the way that a facilitator delivered their material e.g. to respond to a question. Despite this consistency, each of the Family Days had a different ‘feel’ about it e.g. each group interacted differently and was of a different size. Each of the programmes also included one or two people who had been sitting in on the group as part of their own learning; one group had been joined for the 3 weeks by a Clinical Psychology student and another group had been joined by a staff member from a newly established pain service in South Auckland, as part of her training.

The first Family Day consisted of twelve people, six of whom had pain and had attended the 3 week programme. Four of those with pain were joined on the Day by a marital spouse, one was joined by a partner and also by a friend, and one had no

significant others present. The group had the feeling of being relaxed, supportive and welcoming. The second group had commenced with six participants but for a variety of reasons had decreased to four by the Family Day. All four individuals with pain were present on the Family Day – one was accompanied by his wife and preschool aged son, another by her teenage daughter and a friend. Two others were joined by a significant other for part of the day. While a small group, the atmosphere was again welcoming, however distractions were created by the presence of a young child and people coming and going through the course of the Day. In contrast to the first two groups, the third Family Day that I attended was much larger – with many of the programme participants being accompanied by several significant others (including young children, partners and extended family members). Due to the numbers attending, it was not clear from just observing, who was accompanying who and overall the atmosphere on the Day was that of a ‘closed’ and less welcoming group i.e. the group took themselves away at morning tea time, whereas those from the two earlier Family Days had tended to remain in the education room or bring their morning tea back to the education room to talk.

During the interviews many of the participants commented on aspects of the Day that they had attended, such as parts that they had particularly enjoyed or the way in which material had been presented and they referred to these examples when discussing their views on the involvement of significant others in the programme. For example, several of the participants felt that one of the facilitators had not encouraged questions and referred to this when talking about the importance of the right facilitators running sessions involving significant others. Two out of three participants with pain, who had been recruited from the first programme, also talked about the bond that had developed amongst those with whom they had shared the 3 weeks. By contrast, the only participant with pain who had been recruited from the second programme, talked about the benefit that he had gained from talking to others with whom he had shared the 3 weeks but not of a bond forming between the group members. Rather this participant talked about the value that he placed on the relationship that he had with his wife. During the interviews the differing experience of the group was observed to influence the degree to which those with pain felt significant others should be included within the programme.

Participant profiles

Of the eight people interviewed, four were individuals with chronic pain and four were significant others. Six of the participants in this study were related to another participant via marriage. Tables 4.1 and 4.2 provide an overview of the individuals who participated in this study.

Table 4.1 - Demographic description of the individuals with pain who participated in this study

Participant	Programme	Accommodation during the programme	Gender	Age*	Pain – location and duration	Ethnicity ⁺
R1	1	Home	Male	60	Stomach, 1 year	Celtic
R4	1	Lived in	Male	36	Left leg, back, right arm, shoulders, neck, head, 10 years	NZ European
R7	1	Home	Female	56	Back, 5 years	Filipino
R14	2	Home	Male	31	Back, 1.5 years	NZ European

*Age - in years

⁺ As identified by participants

Table 4.2 - Demographic description of the significant others who participated in this study

Participant	Prog- ramme	Loved one's accommodation during the programme	Gender	Age*	Relationship to & duration of support	Ethnicity ⁺
R2	1	Home	Female	54	Wife, 1 year	NZ European
R3	1	Lived in	Female	36	Wife, 13 years	NZ European
R13	2	Home	Female	32	Wife, 1.5 years	NZ European
R16	3	Lived in	Female	55	Wife, 4 years	NZ European

*Age - in years

⁺ As identified by participants

Analysis of the transcripts

Analysis of the interview transcripts revealed that participants considered it essential for significant others to be involved in the programme for two reasons. Firstly, participants felt it was important so that everyone was on the same page about pain and its management and secondly, so that significant others could have an opportunity to access support. These two themes and the sub-themes contained within them are presented below under the headings: 'The involvement of significant others in the programme is essential because managing pain necessitates being on the same page' and 'Creating opportunities for significant others to share how it has been for them, have their experience acknowledged and gain support'. It was chosen to present the themes in this order as not all participants considered the second theme to be as important as the first. This variation in opinion was influenced by the degree of support that participants desired from the programme i.e. those that expressed low support needs did not prioritise the second theme to be as important as being on the same page, whereas those with a wish for greater support described both themes as being of equal importance.

The involvement of significant others in the programme is essential because managing pain necessitates being on the same page

All of the participants were united in the view that it was essential for significant others to be directly involved in the programme because the ramifications of chronic pain are not limited to an individual. As one of the significant others stated:

***R16:** “I think it’s important [that significant others are involved] because it’s not just about the person; it involves the entire network of family and friends.”*

The impossibility of addressing pain without the involvement of significant others was further highlighted in the comments made by another participant, who described recognising his pain to have had ripple effects on his immediate family and his community as well. Equally however, he described being aware that he was affected by the behaviours of those around him and that the presence of pain had catalysed an overall change in interpersonal dynamics.

***R4:** “I think...anything like this affects them [family] so much and they affect you so much....the family is so involved with this sort of thing...It [has] changed the overall dynamics of our family...It is a huge thing and it affects, in my case, not just the 5 members of my family, but you know the extended family, as well and the community I’m part of.”*

Many of the participants (both those with pain and significant others) described recognising a relationship between how they thought, felt and behaved in response to the presence of pain and the effect this had on the behaviours of those around them. Similarly, participants described how the responses of others affected their own behaviour. For example, one participant with pain described how his family supported him on days that his pain was “just horrible...and...I’m at my wits end” (**R14**) by doing things outside the home and leaving him in peace. Another participant who had been supporting her husband for several years described how important she felt it had been for her to come to her own acceptance of her husband’s pain, so that he could fully accept it and they could work together on adjusting their lives.

***R3:** “I realised [through the experience of the programme]...that this condition is not going away - that this is part of our lives... [and] not just an aspect of his life that I have to step around...To really accept that and...to learn to be okay with that...was a really powerful transition for us and...”*

probably me making the transition then allowed him to make the transition on a much...deeper level and...that...had implications for the way we arrange our lives."

For this participant, the new level of acceptance that she had gained about her husband's pain had come about from both the time to reflect while he had been living at the programme and also her experiences at the Family Day. Not all the significant others described undergoing the same level of transition as a result of their involvement in the Family Day but all participants (those with pain and their significant others) agreed that because of the social dimensions of pain, significant others had to have direct involvement in the programme, in order for the individual with pain to achieve maximum benefit from their 3 week attendance.

R1: *"While I was on the course it was good to be speaking to these people but at the end of the day that can only ever be a relatively short period. I mean, most of your life is spent with your family, so I think it's very important that the family see what you've been going through and what's happened there. So I'd certainly say it's important the family does go, some representative is there."*

Having significant others involved in the programme was considered by the participants to serve the important purpose of ensuring that everyone was on the same page. All those with pain described the programme to have resulted in changes in the way that they perceived and managed their pain. They described having embraced a range of changes relating to both themselves, such as practicing relaxation or regularly watching funny videos to lift their mood, and also their relationships with significant others. For example one participant described having become more aware of his behaviour and had been working on asking himself questions such as *"Do I need to talk about my pain at this point?...Is it going to be helpful for me and her and the kids or is it not?"* (**R4**). Significant others also described recognising their loved one with pain to have gained benefit from the programme and made comments such as *"he's carried on all the different coping mechanisms...Yeah, it's definitely made huge changes for him"* (**R16**). Consequently, knowing how to, or the most useful way to continue supporting a loved one with pain following the programme, was a commonly expressed wish amongst significant others.

Changing habits (which for some had been habits of a lifetime) and adopting self management strategies, such as pacing, was not always described as feeling easy or natural by those with pain. As one participant with pain stated:

R14: *“It’s [pacing is] something I’ve been trying my hardest to do...but it’s really a change in habit thing, because all my life I’ve boom and busted and because I’ve had quite an able body that’s been okay. But that doesn’t work with my situation now, so it’s just trying to change...I mean that...is another tough thing because it’s everything you do. You’ve got to sort of re-monitor and refocus you know. It can get extremely, extremely monotonous...that’s why you need your family to be understanding.”*

Support and understanding from significant others was described to be crucial by those with pain; both helping them to maintain the energy required to persist with change and to apply pain management strategies within their daily lives. The challenges that can be faced by those with pain, when trying to implement change if they do not feel supported by significant others, was demonstrated in the comments made by one participant. This participant (who had pain) had been living with her sister at the time of the programme. Her sister had not been able to attend the Family Day and because of this the participant felt that her sister had not had an opportunity to gain an understanding about pacing. As a consequence, the participant described how she had felt “*guilty*” about needing to take breaks when they had moved home not long after the programme and so “*I try to push myself so that I can show her...I can pack a lot but I end up...in pain for 3 days.*” (**R7**).

Those with pain described being aware that while their behavioural responses to the pain were observable to significant others, they were not necessarily understood by them. For this reason those with pain considered that the inclusion of significant others in the programme was important, as it provided significant others with an opportunity to learn about pain and thus reduce the risk of tension developing within a relationship, through misunderstandings.

R7: *“To me...[the family] understanding what chronic pain is about, you know...it may be there for quite a while and also understanding...some of the signs...you know how sometimes you are grumpy or withdrawing...If family would know those signs...at least in the relationship there would be no...tension points, because otherwise...the family may not understand...and...in a way feel marginalised...you know the kind of tension.”*

Relationship tension was recognised by those with pain, as being closely linked to their experience of pain. A “*cyclical effect*” (**R4**) was described, whereby tension would escalate pain, and greater pain would in turn fuel relationship tensions. Eliminating or minimising sources of stress within a relationship was therefore highlighted by those with pain as an essential part of managing their pain by breaking the tension – pain cycle.

Social support was experienced by those with pain, when they felt that significant others “*really have an understanding of what is going on*” (**R7**). Those with pain felt it was valuable for significant others to understand three things about pain: firstly, to have awareness about the things that are common to many people with pain, secondly, the individual signs that identify a person to be in pain, and thirdly, the strategies available to manage pain and the rationale for their use. Involving significant others in the programme and providing them with an opportunity to develop knowledge in these three areas, was felt by those with pain be a value means of enhancing communication and reducing relationship tension.

R1: “*You need someone to talk to away from there [the programme]...So [my wife] needed to see a wee bit of what was involved so that...she could appreciate what... you’re going through and that makes it easy to talk to her later on you know.*”

Significant others described attending the Family Day with a diverse background of knowledge about pain and its management. For example, one participant was a nurse, another described being “*into...self-meditation and breathing*” (**R2**) and some had been supporting a loved one with pain for many years. Greater experience or knowledge about pain however, did not automatically equate to a greater sense of being able to provide support. One significant other who had been supporting her husband for many years stated “*this thing has...absolutely floored me*” (**R3**) and another stated “*he would definitely not have done that [meditation] if I said...try this or I think that might be [helpful]*” (**R2**). Significant others described being motivated to attend the Family Day by a variety of reasons including: “*to see what it was all about*” (**R16**); a wish to develop knowledge or because they had been asked to attend by a loved one with pain. Despite these varying motives, it was commonly felt that involvement in the programme positively facilitated communication around a common reference point i.e. the ability to talk about understanding acquired together, through a shared experience. One of the

significant others expressed concern that if the programme was not intimately shared and a shared understanding developed, well meaning efforts to support could create tension e.g. through the loved one feeling like “*I’m stepping on his territory*” (**R3**).

R3: “*If it [the programme] has been a journey you’ve gone on together, that is part of your relationship...It is part of your relational vocabulary, it is part of your joint experience, it is part of your wealth of knowledge together as a couple.*”

The value of having had a shared experience was supported in the comments made by one of the participants with pain, who felt that having his wife attend the Family Day had enabled a depth of communication that would not have been possible otherwise.

R1: “*If I’m in pain...I always sort of deal with it by thinking back to other people on the course, and that’s something I can then discuss with my wife ‘cos she’s seen the other people who were on the course...she’d be able to relate to some of the other people who were on the course you know, so that helped.*”

The comments made by this participant were echoed by others with pain. These participants described the value they placed on having someone who really understood about their pain, and who they could talk to and “defrag” (**R14**) with at the end of a day. Having access to such support was identified as a positive strategy for managing pain.

R7: “*I think for me and...the support person to understand that...sometimes we need to talk... So having...somebody...to talk to and share ...you know, so that you don’t get overwhelmed by a lot of things, or sometimes they remind you about...what to do next...My family doesn’t have communication...there’s no communication so....it is contributing to my stress and I think that’s why I went through more pain symptoms and other health issues after my TARPS programme.*”

Where those with pain felt unable to talk with significant others, such as in the case that they were a source of stress or it was felt that they did not understand, knowledge that TARPS could be contacted was described as a valuable “safety net” (**R14**).

Seeing makes the difference

Significant others described having had varying levels of involvement in the programme prior to the Family Day. The reasons for this varied involvement included factors such as whether their loved one had lived at the programme or returned home in the

evenings. All described their loved ones to have talked regularly with them about what had been going on in the programme and some reported having read the programme workbook. One of the significant others also described having had quite a significant level of involvement because she had needed to assist her husband with homework tasks due to his literacy difficulties. While these means of involvement had given significant others some additional knowledge about pain and the programme, especially for the latter participant who had been supporting her husband with homework tasks, direct involvement in the programme was considered essential. One of the significant others commented “*it’s understated what you do there*” (**R3**) and direct involvement in the programme was felt to provide significant others with an opportunity to develop their own knowledge of pain and learn how to support their loved one, with a fluency and confidence that could not be achieved by just hearing about the programme or reading the workbook.

***R16:** “I’m a nurse so I know a lot of the stuff anyway, but the specific TARPS way of dealing with things was new to me, and it was great to get that knowledge...you know, through the lectures and everything- how it worked and how it was a feedback thing...There was a definite area that... was sketchy before that programme and...it gave me greater insight... whether it helped me to help him more I don’t know...probably...yip, probably...more supportive in what he was trying to do to retrain his brain.”*

Beyond the opportunity that direct involvement created to attend presentations about pain, it was the opportunity to “*meet other like-minded people with the same or similar issues*” (**R14**) and to see what had happened in the programme, which participants repeatedly identified as having been of significant benefit. For this reason, involving significant others in the programme via a group forum was considered superior to individualised input, which was not felt to have “*the same impact*” (**R1**).

All the participants acknowledged the logistical challenges of running a group programme and the additional demands it placed on significant others to take time off work or to rearrange other commitments. The use of technology e.g. the internet, to involve significant others was touched on by several of the participants, however all agreed that while it was a “*convenient thing...interaction on a personal level was better*” (**R16**). Several participants did however suggest that technology could be used to supplement presented material, perhaps through an online discussion forum accessible to both those with pain and significant others.

R13: *“I mean you can use technology and the reality is now that most people Skype and that sort of thing, but...face-to-face... sometimes you may not even be seeing it but you can feel it, you can feel the emotion and you can feel the pain, or you can feel the excitement that you have gotten through something without people having to say something. I’m thinking you miss that level of engagement when you’re on a phone call or audio conference room or anything like that.”*

Collectively, participants identified the opportunity to see others as offering three key benefits. Firstly, it provided significant others with an opportunity *“to observe...who else is in the same position” (R16)* and experience a sense of camaraderie, which one of the significant others described to have helped her *“enormously... [Just]...being able to understand that oh yeah right, yes of course, everyone gets mad about that or whatever...really, really helped” (R3)*. Secondly, seeing others at the Family Day was described by participants to provide them with a sense of perspective on their personal situation e.g. observing that there were other people *“going through a lot worse” (R2)* in terms of the pain that they were experiencing or the level of social support that they had. Thirdly, those with pain felt that the opportunity for significant others to see others with pain was a useful way of validating their own experience and ensuring that *“she knew I wasn’t taking her for a ride” (R14)*.

R1: *“I thought it was good for [my wife] to see other people that were in a similar boat to me...She’d been obviously looking after me when I was ill and had been putting up with my pain, so it was probably good for her to realise that there were other people...who’ve had similar problems... [and] what I was going through was not something that was just unique to me.”*

Due to the degree of disruption that pain had imposed in their lives, those with pain described the completion of the programme to be associated with a sense of pride and achievement. Having significant others involved in the Family Day, the last day of the programme, and seeing what had been happening was therefore identified as being an important part of sharing in the celebration of their accomplishments.

R14: *“I think it’s important for people to see what you’ve been doing during the weeks, how much commitment and time you’ve put into it, because there is quite a lot... I mean, a lot of us weren’t doing anything of what we’d done when we were at the course and we’d muddled our way through, so accomplishing that was a great thing.”*

For those with pain, having significant others attend the Family Day was not only about showing them what had been happening in the programme but also provided the opportunity to be seen as part of a family context.

R1: *“The...thing I thought... important, was that...they [the staff members at TARPS] knew I had support at home...that they could see that I had a wife who was quite keen to help...so I wasn’t on my own as it were.”*

While participants repeatedly expressed the view that the involvement of significant others in the programme was important, one of the participants shared her concern about the possible emotional impact on those people with pain, whose significant others were not able to attend the Family Day. This participant described having been in a position where she had not been confident that she would have a significant other present for the Day and anticipated that had this been the case, it would have had an adverse effect on her. For this reason she described having empathy for a male participant with pain in her group, who was the only one not to have been joined by a significant other on the Family Day.

R7: *“It was really great seeing those people being present and showing their support but...I know there was one without a family member or a friend...I didn’t...want to ask [and] put him on the spot, but...I could feel--- because...it almost happened...that I...didn’t have anyone with me... [and]...I think that would have affected me.”*

The comments made by this participant reinforce the value those with pain place on social support, its influential role in shaping their experience of pain, and their wish for significant others to be involved in the programme.

A look in on the programme

Time and opportunities to address topics in depth were considered essential when involving significant others in the programme. With the exception of one participant who thought the Family Day “was great” (**R2**) and had no suggestions for change, all the other participants considered that half a day was only long enough to give significant others a feel for what had happened in the programme. The overall feeling from participants was that ideally there would be more involvement of significant others woven into the programme. The benefit of this additional involvement being to enable “time to discuss...some of the things in depth” (**R1**) and an “opportunity for families to work through the process a little bit more” (**R4**). Having significant others involved in

the Family Day was identified to have generated discussion within families about what had been seen and experienced “*because now hopefully your family is sort of in on the recovery plan*” (**R14**). For this reason the opportunity for more than one contact point was felt to be valuable, so “*you’re not just walking away from it*” (**R1**) and so that both those with pain and significant others had an opportunity to ask questions, debrief and work through any issues that had arisen.

R3: “*I could imagine for example, if the families...were part of the process from day one and got...you know a big picture kind of idea about...what was going to happen, how to support our partners, how to work with what was about to happen and were given some reading material about how these...conditions affect your long-term relation dynamics. Then...have a session say...midweek of the middle...week...and then a final thing...you know, that would be a reasonably doable and potentially really, really powerful...and the potential for follow up if you could swing it somehow.*”

Participants varied in their thoughts on how much more significant others should be involved but all agreed that involvement required striking a balance between what might be beneficial for all and feasible for significant others amongst their various commitments. Just as it was recognised that each person’s situation would be different, it was also acknowledged that the most beneficial balance would also vary from one person to the next. As one participant stated “*it really depends on the couple*” (**R14**). While greater involvement of significant others was felt to be important, many of those with pain expressed the view that the involvement of significant others should not come at the expense of the benefits that they had gained from the opportunity to participate in the programme independently. The two key benefits that those with pain described were the opportunity to develop a bond with others on the 3 week programme and the opportunity to focus on the programme without the distractions of home life. For example, one participant with pain described having valued the time and opportunities she had had during the programme to gain knowledge about herself and the areas that she needed to work on. This knowledge had then given her the words to communicate more effectively with significant others, in a way that she did not feel that she could have done prior to counselling through the programme.

R7: “*From my experience, you wouldn’t know what you don’t know...I remember [my partner] asking me, ‘What’s wrong with you?’ - you know that kind of thing. I didn’t even understand what was going on with me you know, a lot was going on. I couldn’t even say one thing you know because*

it's all complex. So I only learn about what I don't know...much later when I go to the counselling and I was able to see, oh, my issue actually is...

Although those with pain had reservations about significant others being directly involved in the whole programme, inclusive of the follow up sessions, they felt that the opportunity for significant others to have access to other resources throughout the course would be beneficial.

R4: *"I wouldn't want them involved...daily or anything like that. I think it was really nice to have...it sort of, you know, you can just be, you don't have any other expectations around you...I think...there was great value in being able to concentrate and just be away from the family for the course as well...which just say might mean...resources being available...which aren't part of the pain course as such...I think a little bit of encouragement... for the family can go a long way."*

In addition to the programme workbook, participants suggested that resources such as educational YouTube clips, books and informative CDs would be useful sources of information for significant others.

Being pointed in the right direction for more support and resources outside of the programme

Having significant others directly involved in the programme was considered by the participants to be a necessity, so that all parties in a relationship were on the same page about where *"you can actually tap into resources in the future"* (**R16**). Joint knowledge about where information and support could be accessed after the programme was described by the participants to be an essential part of moving forward and managing the presence of pain.

R1: *"I think... [it's]...important both you and your partner...know where to go...[for more support]...because sometimes... the person them self gets so wrapped up in their pain they think there is nothing they can do and it's the other person who's been on the course... they would then know... that there is something more that we can do... So I think it's important both the person and their family support person know where and how they can re-contact... people to get help."*

All those with pain spoke highly of the follow up support that they had received from TARPS, however most of the participants described lacking in knowledge about follow up resources for families. Beyond knowing where to go to access general information about pain, knowledge about where to go for more support if necessary after the

programme was identified to be important for three reasons: Successful and timely re-entry into the workforce, consolidation of skills learned during the programme and support during times of crisis. GPs were identified as one source of information however cost was described to be a significant barrier to access and how much knowledge individual GPs had on pain was reported to vary.

R4: *“I think...being...pointed in the direction...whether it’s counselling, couples counselling or...something for children...being pointed in the direction where you can get those resources would be valuable...so possibly that might...mean on that last day...having...[organisation] representatives, or somebody who is available [to say]... this is what it costs or there is funding available...and...things like that, having some of those resources made available for later use could be something worthwhile...I mean, I’m sure there are resources...online already and those which you can receive and so forth, which...can be utilised...to sort of point people in the direction...[but] just...making that easier for people to do that and also to access those things.”*

The need for resources to be easily obtainable through a straightforward process was echoed by other participants. Several explained that due to the exhaustion and frustration of living with pain, things needed to be simple. As one participant stated “*wishy washy doesn’t work*” (R13).

The need for the general public to also be on the same page

While the involvement of significant others in the programme was considered essential so that all parties were on the same page, many participants stressed the need for this shared knowledge to extend beyond friends and family, to the wider community. The need for community awareness about pain was particularly discussed in relation to employment — both the challenges faced when trying to explain to an employer why it was necessary to take regular breaks and conversely the stigma of unemployment. Amongst those with pain who were unemployed, queries regarding the legitimacy of their limitations were described to be particularly distressing. One participant provided an example of the stress she experienced because she was unemployed and how this was compounded by frustrations regarding the limited understanding that her WINZ Case Officer had about pain.

R7: *“The thing is having this pain and also being on...a government benefit, it’s...causing me a lot of stress. Because...when you are on an unemployment benefit...there is an underlying pressure that you have to find work and...the reality is...we cannot simply find work...My God, if only [Work and Income] knew, because the case officer told me ‘why don’t you*

go on the Sickness Benefit?’ Because I said, it won’t help me because I’m already losing my confidence and...you are not really like a disabled person...And dealing with that, you know, the chronic pain situation in relation to the issue of being an unemployed and being under the government benefit and being under pressure to find work. You want to find work, but, yeah... it’s causing me further...distress and panic.”

Several of the significant others also described being affected by queries around the legitimacy of their loved one’s pain and the extent to which it caused them disability.

Creating opportunities for significant others to share how it has been for them, have their experience acknowledged and gain support

Throughout the interviews participants repeatedly acknowledged the impact that pain had on family and friends. *“It affects everything” (R16)* stated one of the significant others. For example all the participants talked about the need to adjust roles and responsibilities within the home, the effects of loss of income and the absence of fun — *“We haven’t had fun for so long” (R3)* stated the wife of a gentleman who had pain. Thus, the second theme that emerged regarding why participants felt that it was important for significant others to be involved in the programme, was so that they also had a chance to access support. Support was defined in terms of opportunities for significant others to talk about their experiences and to develop practical skills to help them to live with someone who has pain. It was recognised that each person’s support needs would vary depending on their situation and accordingly not all significant others would need or wish for support during the programme. However, having the option to access support and knowing where to go for support after the programme was considered to be valuable, so that significant others could maintain their own wellbeing and be in a position to effectively support their loved one with pain.

R3: *“I was very nervous coming home [from the Family Day]...because I felt as though, well what am I going to do when I crash? What am I going to do when he crashes?...Having a package of skills is good, but I think you actually also need to have a phone number as well...You know, you need to have humans...Even if you never ever used the phone numbers that you’ve been given...just knowing that it’s there gives you so much security...because otherwise you...have that feeling of...being cornered and not knowing where to go, that is just a terrible feeling.”*

Significant others described varying levels of distress, from one who described things to have been hard but did not consider that she was *“suffering” (R2)*, to another who

described things to have been *“dark and hard...Basically...it feels as though there is no way to succeed... then it has health effects ... I can see that I get a lot sicker...because of my mental health” (R3)*. Amongst the key issues raised by significant others were those relating to stigma, a sense of helplessness, fatigue, guilt and frustration. All participants felt that it was very important for significant others to be involved in the programme and to have *“an opportunity...to be able to speak out and...say...it is bloody hard” (R13)* and for their experiences to be validated.

R4: *“You know, just... somebody who has dealt with hundreds of thousands of people with pain saying...yes...this is hard and it is going to affect you...and, it’s...ok that that’s the case, you know. Because I’m guessing a lot of people probably fall into that trap...of well here’s the person with the pain, they are the one suffering but I feel angry or...frustrated...or whatever...Just letting them know that actually this is something...which effects go well beyond just the person with the pain.”*

The opportunity for significant others to access support so they could develop *“some ways of processing the complex emotions that come along with the whole thing” (R3)*, was considered to be beneficial for their own mental wellbeing but also for those with pain, by reducing underlying sources of tension within the relationship. It was recognised that significant others were often placed in a position where they had to take on additional responsibilities, giving rise to the potential for *“unsaid things in a relationship” (R7)*. For this reason it was felt important that the programme provided significant others with a safe outlet in which to express their feelings and also an opportunity to discuss these feelings with their loved one. As one participant with pain stated, *“they [significant others] may be able to raise some issues that the person having the pain may not be aware of...or...might over look” (R7)*.

R16: *“I think in the situation of the person with the pain, it’s very difficult for the family members to continue to be tolerant of it...you’re carrying an extra load physically sometimes. And I’d say with people with more problems, like back problems, I think the family members do need a little bit more support for sure, because it’s all about the person with the pain and they do on occasions...become a little bit self-orientated around it. You know, constantly saying lifting the kettle hurts or whatever. You know, it can become aggravating around other people long-term...But just an understanding and support for the family is important and I think would help the person with the pain as well, they wouldn’t get that sort of agitation.”*

As well as the opportunity to express and address feelings, involvement in the programme was seen as an opportunity for significant others to gain “*little tips*” (**R4**) and strategies to assist them to manage in the long term. Strategies to manage stressed interactions e.g. during times of crisis or when a loved one was experiencing high levels of pain, were identified to be of particular interest — “*like, the person with the chronic pain is all tetchy and aggro and just what to expect on the emotional side of it and how to react to it, how to help*” (**R16**). The opportunity to go through scenarios, develop individualised self management flow charts and the provision of tip sheets were all suggested by the participants as useful ways for significant others gaining skills which they could then apply at home.

Making it comfortable for people to talk

It was recognised by the participants that each person would have varying comfort levels around participating in the Family Day and not all would feel comfortable raising personal matters of concern. Time, formal and informal opportunities to talk to both staff and other attendees, skilled facilitators and a comfortable physical environment e.g. seating arrangements, were all identified as necessary elements when creating an environment where it felt safe to share information and ask questions. One participant also suggested feedback forms or expressive art activities as an alternative means of addressing issues that anyone attending the Family Day may have had, but which they felt unable, or did not have an opportunity to talk about with staff.

R7: “*I think after the programme some stayed...[and]...talked to some of the staff. But...maybe an evaluation form or a feedback form from the family...somehow for them...to give...feedback...or write something about...their issues and concerns.....so the team may be able to...address those issues within the programme you know...because sometimes it's not that easy to discuss your family or personal [situation].*”

All the significant others described having attended the Family Day with a degree of uncertainty about what to expect, or what was going to be expected of them. Knowing information such as the length of the Day was felt to be crucial, especially for those considering whether to bring young children or taking time off work. All the significant others described their loved one with pain to have talked about the programme in the lead up to the Family Day, however those with pain indicated that how much information they had been able to share with significant others about what was going to happen on the Day, had been limited by how much “*we picked up*” (**R14**). For this

reason several of the participants suggested the provision of written information prior to the Day, such as a timetable.

Involving children in the programme

The involvement of children, particularly young children in the programme generated a number of thoughts from participants. Some felt their presence on the Family Day had been distracting and those that had attended with preschool aged children acknowledged that much of the Day had gone over their child's head. All participants agreed that children could be affected by a parent with pain and that even though it might create logistical challenges around attendance, they would gain the most benefit from carefully structured, age appropriate sessions *"where they begin to get it, you know, they begin to understand. They are part of the process, they are part of the healing, they are part of the coping"* (R3). Amongst those who were parents, it was felt necessary for children to have an understanding about pain and also for any sessions provided for them, to include a psychological component aimed at helping them cope with situations such as *"why does daddy snap all the time?"* (R3)

R13: *"I think it's really important [for children to be involved] because with a toddler he mimics everything his father does, so come a good period of time after the accident, the little ones going... 'my back's sore' you know, and that sort of thing. And also that kind of thing is pretty huge, because it is how the child interprets their parent...so...to see...perhaps other people in that situation or having their eyes opened to it, so it is a bit more normal, it does create a better balance for the kid I think...Perhaps just a smaller period of time for the child, 'cos a lot of that relaxation stuff...it depends on the age of the child, but that went over [my son's] head...His attention span is reasonably short...Cos then you've got logistical problems of parents having to bring the children at different times."*

Several participants who were parents expressed reservations about children attending the programme, in the event that it opened up *"a can of worms"* (R4) that could not be closed. One participant suggested family therapy sessions as a way around this and another participant with pain suggested that the programme could focus on providing parents with the skills to educate their children and knowledge about where to go if their child needed more support.

R4: *"They [children] are affected...a lot...but...my thoughts have sort of been around enabling the parents to make changes...So maybe...a little bit more time spent maybe without the family...you know some more specific time on – 'how does this effect children?'...and so forth...I think it would be quite difficult to involve children because it is a completely different...field"*

of expertise and...because you never know...what is happening in families and...I think there is just the possibly of opening a can of worms that couldn't be shut...so I'd probably....steer away from involving children but possibly, if there was some sort of...resource available...a pamphlet...or something and then...direction to places people can go if they need help in that area."

This participant also suggested the provision of Family Packs at the outset of the programme, containing appropriate information for parents and children. For the parents, this participant suggested information on parenting with pain and for children, educational resources about pain, which they could work through with their parents.

Summary

In this chapter I have explored the views of those who have participated in a TARPS Family Day, which occurs on the final day of every 3 week multidisciplinary chronic pain management programme. Specifically, participants were asked to share their views on the involvement of significant others in the programme. All participants were in agreement that the involvement of significant others in the programme was essential, however children had to be included in a way that was age appropriate. The participants provided two reasons as to why they felt it was important for significant others to be involved. Firstly, so that all parties were on the same page about pain and its management and secondly, so that significant others have the opportunity to access information and support. Meeting the needs encapsulated within these two areas was felt to require time and opportunities to talk, ask questions and begin developing positive strategies to manage the presence of pain after the programme. It was acknowledged that everyone's support needs would be different and for this reason knowledge about where to go for further support after the programme was considered essential.

Chapter 5 – Discussion

Introduction

This qualitative descriptive study sought to investigate the question: “What are the views of individuals who have participated in a Family Day, delivered as part of the 3 week multidisciplinary chronic pain management programme at TARPS, on the involvement of significant others within the programme?”

This study had three purposes. The first was to address a gap in the current body of knowledge about pain management programmes, by investigating whether the theoretical rationale for involving significant others within a programme is supported in the views shared by those with pain and significant others. Secondly, to provide TARPS with feedback on their service, and thirdly, to contribute to the body of knowledge that informs the delivery of pain management services in general.

The findings that have emerged from this research demonstrate that participants view the involvement of significant others in the TARPS programme to be important. The participants provided a number of reasons as to why they considered involvement to be important, however all fell within one of two themes: ‘The involvement of significant others in the programme is essential because managing pain necessitates being on the same page’ and ‘Creating opportunities for significant others to share how it has been for them, have their experience acknowledged and gain support’. These findings and the focus of the study itself i.e. to seek the views of people who have attended a Family Day at TARPS, are of particular relevance in the current New Zealand healthcare climate, where the focus is on involving families in the design and delivery of services, to ensure that services are providing the most appropriate care (Ministry of Health, 2011; Ministry of Social Development, 2010).

In the remainder of this chapter I will discuss the findings that have emerged from this research in relation to the literature, their implications for practice and my own learning. I conclude by discussing the strengths and limitations of this study, and identify areas where further research is greatly needed.

Theme 1: The involvement of significant others in the programme is essential because managing pain necessitates being on the same page

In the first and largest of the two themes, participants stressed the importance of significant others being involved in the programme, as pain does not just affect an individual. The participants described the ways in which pain had become enmeshed in their relationships and altered the way that they lived their lives. For this reason it was felt essential that significant others were involved in the programme, so that all parties were on the same page about pain and were able to work together to manage its presence effectively.

Being on the same page was considered to require three areas of shared understanding: a general understanding about pain; the individual signs that identified a person to be in pain, and the strategies available to manage pain. Developing a shared understanding in these areas was felt to be an important means of enhancing communication, and in turn reducing the risk of relationship tension developing through misunderstandings about the pain and its management. Those with pain identified a direct relationship between the intensity of their pain and relationship tension. Thus, due to this relationship, strategies to minimise or eliminate sources of tension were described as an essential part of pain management.

This theme contained four sub-themes: 'Seeing makes the difference', 'A look in on the programme', 'Being pointed in the right direction for more support and resources outside the programme', and 'The need for the general public to also be on the same page'. In the first sub-theme, 'Seeing makes the difference', participants shared the view that significant others had to be directly involved in the programme and that it wasn't enough for them to just hear or read about what had been happening. For those with pain, having significant others present on the Family Day was also an important part of sharing in their sense of accomplishment about what they had achieved during the programme. Equally however, those with pain described having valued the presence of significant others at the Family Day, as it had provided them with an opportunity to show others who they were outside the programme.

Time and opportunities to discuss topics in depth were considered to be essential to the development of a shared understanding. For these reasons it was felt that the Family Day only enabled significant others to have 'A look in on the programme' and

participants talked about ideally having a “*wee bit more*” involvement of significant others, to enable opportunities for greater discussion. However, participants also described the importance of finding a balance between what was beneficial for all parties and feasible for significant others. While there was no consensus amongst the participants regarding how much more involvement there should be, all agreed that everyone’s support needs would be different and for this reason they discussed the importance of ‘Being pointed in the right direction for more support and resources outside the programme’. Additionally, many participants described experiencing stress due to the limited understanding they encountered within the community, about pain, and highlighted ‘The need for the general public to also be on the same page’ about pain and its management.

Theme 2: Creating opportunities for significant others to share how it has been for them, have their experience acknowledged and gain support

In the second theme participants expressed the view that significant others needed to be involved in the programme, as they also required opportunities to access support. All participants acknowledged the impact that pain had on significant others and the variety of changes it imposed on the way that they lived their lives. Not all significant others described being affected in the same way or wanting the same degree of support through the programme. For example, one participant expressed her contentment with the Family Day as it was delivered, however several others shared a wish for more support. Amongst those wishing for more support, the opportunity to share the struggles that they faced, to know they weren’t the only one and to have their experiences validated were felt to be of benefit for both their own wellbeing and, in turn, the support that they could provide to their loved one. The participants acknowledged that just as significant others would have different support needs, they would also have different levels of comfort around sharing their experiences and asking for help. Accordingly, ‘Making it comfortable for people to talk’ was one of two sub-themes identified within this theme. In the second sub-theme, ‘Involving children in the programme,’ participants talked about the need and feasibility of involving of children in the Family Day. Some queried the safety of including children, with their concerns centring on the possibility that it might open up a “*can of worms*”. However all agreed that any resources made available for children and their parents needed to be child friendly and age appropriate.

Placing the findings in context

The findings of this study support what is already known about the impact of pain on individuals, their significant others and interpersonal relationships (Fisher et al., 2007; Kerns & Otis, 2003; Lewandowski et al., 2007; Snelling, 1994). For the participants with pain in this study, one of the reasons that they considered it to be important for significant others to be directly involved in the programme was so that they could see others with pain and receive reassurance that they weren't being "*taken... for a ride*". Pain is a subjective experience and as such it is a hidden condition. Outwardly an individual may appear fine and the only evidence that they are in pain may be changes in their behaviour e.g. the presence of a limp or a person may decline to sit in favour of standing at an appointment. The absence of objective measures to determine the severity of an individual's pain means that many of those affected face constant questions around their legitimacy (National Pain Summit Initiative, 2010).

The experience of validation from others and also one's self that the pain is real and the individual is not to blame for the absence of a cure, has been shown to play a central role in determining a person's ability to manage their pain and to achieve a sense of wellbeing i.e. the ability to describe living a fulfilling life in spite of pain (Howell, 1994). This is not the first study to find that those with pain carry concerns that others (including members of the medical community and significant others) do not fully understand the pain and may perceive it as 'fake' or a source of attention seeking (e.g. Fisher et al., 2007; Slade, Molloy, & Keating, 2009). On the other hand however, the results from a recent study involving 2,511 Australians found that while those with pain perceive others to have limited understanding, the majority of Australians without pain describe having an understanding attitude towards those who do (Stollznaw Research, 2010). For example, over half of those without pain in that study expressed the view that pain could be physical and psychological and could occur in the absence of a medical diagnosis. Similarly, Subramamiam, Stewart and Smith (1999) found that those with pain rated family members as less supportive than family rated themselves. For those working with families affected by pain, the findings from these two studies reinforce the importance of being aware that the experiences and perceptions of the person with pain may well vary from those around them — an issue that has previously been raised by Lewandowski et al. (2007). The contrasting perceptions reported by

those with and without pain do also raise queries about the possible influence of internalised stigma (Corrigan & Watson, 2002), however any form of stigma is of concern as it may act as a barrier to accessing support and attending a programme (Slade et al., 2009).

While the involvement of significant others in the programme was considered to be a valuable means of *enhancing* social support by those with pain, for significant others involvement was described as a valuable means of *accessing* social support. During times of crisis where an individual feels powerless to change their situation, social support is recognised to play a vital role in the promotion of self esteem, personal strength and stress reduction (Dennis, 2003; Wright, 2011). For significant others in this study, involvement in the programme was viewed as a means of meeting others in the same position, learning that they were not alone and having their experience validated. The need for support to be available to significant others as well as those with pain has previously been stressed in the literature (e.g. Ahern & Follick, 1985; Lewandowski et al., 2007; Sharp & Nicholas, 2000). One of the reasons for this is that several studies (Flor et al., 1987; Schwartz et al., 1991) have reported the prevalence of depression amongst the spouses of those with chronic pain to be in the vicinity of 26-28%. None of the significant others in this current study reported having been given a diagnosis of depression but one did describe things to have been “*dark and hard*” and being aware that she experienced a lot more sickness due to her mental health.

The significant others in this study described facing two common challenges, firstly, managing the effects of pain on the way in which their household functioned and secondly, knowing how to support their loved one. These challenges are well reported in the literature (e.g. Snelling, 1994; Subramamiam et al., 1999), however I was not able to find any literature examining the support needs desired or required by significant others, to assist them to meet these daily challenges. Such research has been undertaken with significant others who support people with other chronic conditions (e.g. Munn-Giddings & McVicar, 2007) and those studies concur with the finding of this research regarding the benefits of meeting others who are in the same position and who are felt to really understand. Further, the participants in this current study identified time and opportunities to talk in a physically comfortable environment as being prerequisites to feeling at ease and able to share information. This view is consistent with literature on

the factors that need to be considered when setting up and running a therapeutic group (Hagedorn, 2000).

Although the literature review for this study highlighted the absence of conclusive evidence regarding the benefits of involvement of significant others in chronic pain management programmes, the findings from this study do lend support to the theoretical rationale that is commonly used to advocate for their inclusion. Family Systems Theory conceptualises the family “as a complex unit of interacting personalities and forces” (Hudgens, 1979, p. 68). This theory recognises the way in which pain can change interpersonal dynamics, communication and overall family functioning. In theme one, participants described the way that pain had impacted on their lives and the need for everyone to be on the same page to ensure maximum benefit was achieved from programme attendance. This speaks to the assertions made in Family Systems Theory that change in an individual alone will not be effective, as it will typically be resisted by other family members in an attempt to maintain homeostasis (Hudgens, 1979; Lewandowski et al., 2007).

The wish expressed by the participants for the programme to be shared can also be explained by theories on dyadic coping, which are concerned with the variety of ways in which couples can interact as they attempt to deal with the presence of a stressor (Berg & Upchurch, 2007). According to theories on dyadic coping, the success with which each partner in a relationship adjusts to a stressor is dependent on a number of factors, including whether they perceive the stress to be shared (Berg & Upchurch, 2007). Where a stress is perceived to be shared, adjustment is facilitated through the adoption of supportive and collaborative coping strategies (Berg & Upchurch, 2007). By contrast, when a stressor is perceived to belong to one partner, adjustment is facilitated through non-involvement by the spouse (Berg & Upchurch, 2007). The findings from this study are in keeping with the former explanation.

Cognitive Behavioural Theory is another framework that has played an influential role in explaining how families respond to pain and directing lines of intervention (Kerns & Otis, 2003; Lewandowski et al., 2007). Central to this theory is the assertion that a person’s response to stress and their perceived ability to cope, is dependent on flexible, adaptive problem solving, which is fostered through the experience of success, development of internal resources and knowledge of external resources (Lewandowski

et al., 2007). The participants in this study expressed a wish for families to have more time together in the programme so that they could work through issues of concern and develop some practical solutions for the everyday challenges that they faced. Equally, the participants talked about the importance of learning where they could go to access more resources after the programme.

Chronic pain requires adjustment by both those with pain and their significant others (Berg & Upchurch, 2007). Developmental and temporal factors have been shown to influence how people appraise and respond to stressors, for example, the way in which people appraise a health related stress varies with age and time since diagnosis (Berg & Upchurch, 2007; Linton, 2000). Thus, the information and support that an individual with pain and their significant others require during a pain management programme maybe quite different to that required after it. Self efficacy, which is the ability to appraise stress as a challenge rather than a threat and the confident use of problem focused coping strategies to define the stress and select from alternative solutions, has repeatedly been recognised as an important determinant of psychological and physical wellbeing for those affected by pain (Dysvik et al., 2005; Keefe et al., 2004; Riemsma et al., 2003; Turner, Holtzman, & Mancl, 2007). Accordingly, the promotion of self efficacy is a central focus of chronic pain management programmes (Bender, Radhkrishnan, Diorio, Englesakis, & Jadad, 2011; Dopson, 2010; Dysvik et al., 2005). The findings from this study reinforce the importance of those with pain and their significant others being supported to develop internal and external resources, which equip them to confidently respond to the challenges that they encounter following a programme – a finding that aligns with the assertions made by Cognitive Behavioural Theory.

The general support needs of those affected by pain were touched on in a recent survey by Stollznow Research (2010). The findings from that survey were that income and area of residence (i.e. rural or metropolitan) had an influence on the nature of the support that people desired. Their results confirm that a variety of resources need to be available to those affected by pain and that health professionals working in the field of pain need to be aware of these so that they can direct people accordingly (Fisher et al., 2007).

Areas of new knowledge

To my knowledge this is the first study that has sought to ascertain the views of those with pain and significant others, regarding the involvement of significant others within a chronic pain management programme. As a new area of research the findings that have emerged contribute several new areas of knowledge. Firstly, the findings identify a wish for significant others to be directly involved in the TARPS programme rather than via media such as the internet. Secondly, the importance of involvement reflecting a balance between what is feasible and beneficial, and thirdly, the findings raise issues regarding the involvement of children in the programme.

The wish for significant others to be directly involved in the programme rather than via media such as the internet

All the participants in this study were of the view that the inclusion of significant others in the programme was important and had to occur through direct involvement. This was considered important so that all parties were on the same page about pain and its management. All those with pain described having talked about the programme with at least one significant other prior to the Family Day and some of the significant others also reported having read the workbook or assisting with written homework tasks. However, the participants did not feel that significant others could develop a true understanding about pain, its management and what had been achieved in the programme through family conversations and reading the programme workbook alone. For those with pain, having someone to talk to, who was felt to really understand their situation was identified as playing an important role in pain management. Conversely, the perceived implication of those with pain and significant others not being on the same page was the risk of relationship tension and, in turn, the aggravation of pain for those with pain. The significance of relationship stress for people with pain has previously been discussed in the literature (e.g. Dysvik et al., 2005), as has the importance of a person with pain having access to someone with whom they can confide (Fisher et al., 2007; Howell, 1994; Subramamiam et al., 1999). Neither area has however been discussed in relation to the benefit of having significant others involved in a pain management programme.

For the participants with pain in this study, having significant others directly involved in final day of the programme was also considered important, as it was part of celebrating all that they had achieved during the 3 weeks. The importance of accomplishment for

those with pain has previously been discussed by Fisher et al. (2007), but not in this context. Nor has the opportunity that the involvement of significant others creates for those with pain to be seen as part of a family. One of the commonly cited aims of a pain management programme is to help people to see themselves as more than just their pain and to not allow it to rule their lives (Dopson, 2010). Throughout the interviews those with pain frequently described the programme to have prompted changes in the way that they viewed and managed their pain. This outcome and the value that those with pain placed on being seen as part of a social context may reflect that they had begun to internalise the message and had begun to see themselves as more than just someone with pain, but rather as a husband or father.

The wish expressed by participants for significant others to have direct involvement in the programme is in conflict with the current interest in E-health, which refers to the use of technology, such as the internet, to provide distance based health information, support and intervention (Bender et al., 2011; Keogh, Rosser, & Eccleston, 2010). The increasing popularity of technology has resulted in the suggestion that E-health might be a means of encouraging people to seek help and overcoming many of the commonly identified barriers to accessing traditional clinical services e.g. inconvenience of attending at a particular time, mobility limitations due to pain and the stigma potentially associated with accessing face to face health services (Bender et al., 2011; Keogh et al., 2010; Marks & Cavanagh, 2009; Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009; Wright, 2011).

While the primary focus of this research was not to explore the use of E-health vs. traditional forms of intervention, the use of technology was raised by participants. The view shared by all the participants in this study, including those with young children and significant others who had chosen to travel from outside Auckland city to attend the Family Day, was that while convenient, technology could only ever be used as an adjunct to the direct involvement of significant others in the programme. All the participants identified having attended the Family Day with differing levels of need and acknowledged that their needs may not have been shared by others. However, despite these differing needs it was the opportunity to see others in the same position, realise that they weren't the only ones affected and gain perspective on their situation which was described as having been of immense value. This finding suggests the need for E-health to be used cautiously and supports the recommendations made in a recent

systematic review of internet based Cognitive Behavioural Therapy interventions, for more research into use of internet based therapies for people with pain (Bender et al., 2011). The view expressed by participants in this study regarding the superiority of group programmes over individualised input also challenges the suggestion made by several authors that, given the idiosyncratic nature of pain and cultural diversity, individualised input is better as it allows for intervention to be tailored (Martire et al., 2010; Okifuji, 2003).

It is not possible to know whether the wish of participants to have significant others directly involved in the programme was the result of their own experience of the programme and would have been different if their experience of involvement had been different. For example, an internet delivered Cognitive Behavioural Therapy intervention for young people and their families reported that the vast majority of participants had been satisfied with the internet intervention (Palermo et al., 2009). However, participants in that study again only had one experience of the programme and the authors did not report on those who were not satisfied. While the place of distance based interventions i.e. E-health, in the management of chronic pain continues to be explored and debated in the literature, the findings from this study raise important questions regarding the delivery of pain management services in New Zealand.

Chronic pain has been identified as a major health concern in New Zealand and one that cannot be ignored (Dominick et al., 2011). The participants in this study were clear in their wish for the direct involvement of significant others in the programme. TARPS is one of only three services in New Zealand, which creates issues around access to these services if the wish is for face to face pain management programmes. One solution could be outreach clinics for those with pain who do not qualify for support from a community team funded through ACC, however this would require innovative service design to account for the travel time involved for the health professionals. A second solution could be for specialist pain services to utilise a consultation model, such as the approach described by Arora et al. (2011), to support less experienced community services to provide face to face pain management interventions. The introduction of a consultation model would also provide a means of raising awareness about pain in the wider community and addressing issues relating to stigma which were raised by participants in this, and other studies (e.g. Fisher et al., 2007).

The importance of involvement reflecting a balance between what is feasible and beneficial

Amongst the participants in this study, there was a strong wish for significant others to have greater involvement in the programme. All the participants were clear however, that the involvement of significant others needed to be carefully balanced. On one hand participants felt that greater involvement would facilitate opportunities for discussion and for families to begin working through issues of concern. On the other hand, many of those with pain described having experienced benefit from time to engage in the programme on their own and all were conscious that the involvement of significant others placed additional demands on their time.

Within the existing literature there is wide variation in the degree to which significant others are involved in pain management programmes. For example, some programmes include a half day session for significant others, similar to that provided by TARPS (e.g. Dopson, 2010), whereas in other programmes significant others are involved throughout the whole programme (e.g. Saarijärvi, 1991). The two most commonly described methods of involving significant others within a pain management programme are partner assisted and disorder specific interventions. These approaches relate to the intentions of, rather than the balance of involvement i.e. whether the intention of involvement is to teach the significant other how to support their loved one to adopt new behaviours or to address any interpersonal dynamics which may be maintaining and/or exacerbating an individual's pain (Baucom et al., 1998; Martire, 2005). While various authors have acknowledged that different families and couples will benefit from, and require different levels of input (e.g. Martire, 2005; Martire et al., 2010), to my knowledge no research has yet investigated whether an optimum balance exists between the involvement of significant others in a chronic pain management programme and time for an individual with pain to engage in the programme independently.

Gaining clarity around the integration of significant others in pain management programmes is much needed, as recent work by authors such as Martire et al. (2007) and Riemsma et al. (2003) have suggested that the involvement of significant others may carry risks for those with pain and their significant others. For example, Martire et al. (2007) found that male spouses experienced an increase in stress as a result of their involvement in a programme, whereas female spouses experienced distress if they were

not involved. None of the significant others in this current study reported their involvement in the Family Day to have resulted in distress, however all of the significant others interviewed were female, so this outcome needs to be considered in relation to the findings by Martire et al. (2007). Equally, none of those with pain reported experiencing distress as a result of their significant others having been involved in the programme. Clearly, involvement does not place everyone at risk of distress however given the dearth of literature investigating the potential risks associated with the involvement of significant others in a pain management programme, routine follow up of significant others may be warranted. After completing the 3 week programme at TARPS, those with pain but not their significant others are followed up by the team for 1 year. Many of the participants described interest in some form of follow up being offered to significant others and while not all those with pain felt it was appropriate for significant others to attend the scheduled group follow up sessions, some suggested that follow up could occur via phone, internet or feedback forms.

The involvement of children in the programme

The findings that have emerged from this study highlight important issues regarding the involvement of children within a chronic pain management programme — an area, which to my knowledge has not previously been investigated. Within the literature it is acknowledged that children are affected by the experience of having a parent with pain (Bigatti & Cronan, 2002; Bustin & Hughes, 2009). Although none of the significant others in this study identified themselves as the child of a parent with pain, many of the participants reported being parents and shared their thoughts on the impact that pain had indirectly had on their children. It has been suggested by Bigatti and Cronan (2002) that working with a child's parents and helping them to develop the skills required to manage the presence of pain will, in turn, enable them to share those skills with their children. I did not find any research investigating this suggestion in practice but similar sentiments were shared by one of the participants in this study, who expressed reservations about involving children in the group setting due to the potential risks it carried i.e. that it might open up "*a can of worms*". Amongst the other participants, the feeling was that there needed to be a child friendly session so that children could be supported to learn about pain and develop psychological tools to cope with its presence. Outside the programme, all participants agreed that there was a need for resources to be available, which could be used to supplement a child's understanding about their parent's pain and also provided parents with tips on parenting with pain.

One in six New Zealanders are reported to have chronic pain (Dominick et al., 2011) and many of these people will also be caring for children. Pain can significantly alter a parent's relationship with his or her children (Bustin & Hughes, 2009).

Given the rates of youth suicide in New Zealand (Ministry of Health, 2010), any factors that may place children and young people at risk of psychological distress cannot be ignored. Similarly, some of the participants in this present study described observing their children to have mimicked pain behaviours. This is not the first study to report this finding (e.g. Snelling, 1994) and is of concern as Social Learning Theory would suggest that observing a parent's pain behaviour may place a children at risk of developing a pain condition in the future (Atkinson, Atkinson, Smith, Bem, & Nolen – Hoeksema, 2000).

Strengths and limitations

This study has generated valuable knowledge about the involvement of significant others within a pain management programme. While this study has a number of design strengths, it is not without its limitations and both will now be discussed. In keeping with the exploratory nature and intent of qualitative descriptive research, every effort was made in this study to ensure that a range of views were captured through the use of purposeful sampling. Although all the participants were recruited through TARPS, the final sample consisted of individuals from three different cohorts. The programmes that they attended were also not run consecutively and each had distinct features, such as the size of the group and the interpersonal dynamics between those who had been involved. Participants also varied in terms of their characteristics, such as their ethnicity, age and the number of years that they had been living with pain or supporting a loved one with pain.

A second strength of this study was the recruitment of both those with pain and significant others who had been present on the Family Day. This dual recruitment enabled the perspectives of those with pain and significant others to be considered simultaneously during the analysis. Thus, the findings that have emerged from this study reflect a holistic perspective on the involvement of significant others in the programme. It must however be acknowledged that all the participants were self-selecting, in that they volunteered to be part of this research and it cannot be ignored that the views shared by the participants may only reflect the perspectives of a vocal

group. Similarly, it is acknowledged that the findings from this research only reflect the views of individuals who have experienced one method of involving significant others within a programme i.e. via a Family Day. Had the participants been recruited through a different pain management service that had a different approach to involving significant others or even if this study had been repeated with a different group of participants from the TARPS programme, the themes which emerged from this research may well have been different. Thus, the inability to generalise the findings from this research could be argued by some as a limitation.

A third strength of this study is the timing of both the initial and follow-up interviews. The first interview for all participants occurred between 2½-4 months after they had attended the Family Day, with a time lapse of between 2-8 months before the follow up interviews occurred. These timeframe variations occurred as a natural consequence of needing to negotiate the commitments of both the participants and myself, however they usefully enabled data to be collected (and analysed) for up to 1 year after a person's participation in the Family Day. This means that the themes which have emerged from this study do not just reflect a brief snapshot in time i.e. a period directly following the programme when energy may have still been high, but reflect the enduring views of the participants. As there was a time lapse of several months between the initial and follow up interviews, it was common at the follow up interview for a participant to apologise that they could not recall the content discussed in the first interview. Nonetheless, their views on the involvement of significant others in the programme were observed to remained consistent. This consistency adds weight to the findings that have emerged from this study, as it demonstrates that the views shared by participants during the follow up interviews were not influenced by memories of 'what they said last time'. Unfortunately only seven of the eight participants that I initially interviewed were available to participate in a follow up interview and given the small sample size, the feedback provided by this remaining participant may have been valuable.

A factor that cannot be ignored is the influence that I may have introduced, albeit unintentionally, to the collection and analysis of the data. All the interviews for this study were undertaken by myself, a 30 year old female of New Zealand European descent, with a background in occupational therapy. While some of the participants were also in their 30's and identified as New Zealand European, others were from an older generation and a different ethnic background. Qualitative interviewing requires

the interviewees to share their experiences with the researcher and my demographic profile may have hindered the development of rapport and in turn my ability to understand the interviewee's worldview (Cohn & Lyons, 2003; Finlay, 1998). This said, all attempts were made to minimise the effects of differing world views on the collection and analysis of data through the use of open ended questions, follow up interviews with the participants as a means of clarifying and checking my interpretations of the gathered data, regular supervision, a presupposition interview and journaling throughout the study.

The use of strategies to monitor the collection and analysis of data are an important part of demonstrating the trustworthiness of research findings. I embarked on this research motivated by a desire to learn how I could provide families with the most effective support during a programme. Because of this strong motivation, I found the use of strategies such as journaling to be a particularly important means of keeping myself 'on track' and monitoring that I was not just looking for the answers that I wanted to find in the data.

Had I not been an occupational therapist with a strong interest in pain management, the way that I framed my research question and collected and analysed my data may well have been different. At the outset of this research I undertook a presupposition interview with my primary research supervisor, the purpose of this being to raise my awareness about the assumptions that I was carrying into the study. This interview helped me to become aware that for significant others, speaking to me might be the first time that they had had the chance to talk about their experiences relating to their loved one's pain. Significant others did indeed disclose varying levels of distress during the interviews and at times during the collection of data I struggled not to fall into the role of a therapist, a challenge which has been highlighted by Carpenter and Suto (2008). The use of a reflective journal also helped me to become aware, and address the fact that at one point through the analysis, my own feelings about how I might have felt if I was a significant other attending the Family Day was hindering my ability to see what the participants were actually saying. The nature of qualitative research means that the findings will always be influenced to some degree by the person undertaking the analysis (Sandelowski, 2000). However, rather than attempting to hide this influence, I have made every effort in this thesis to make insights regarding my own worldview

public, as part of helping readers to establish the trustworthiness of the findings (Curtin & Fossey, 2007; Finlay, 1998; Savin-Baden & Fisher, 2002).

The findings that have emerged from this research do support my existing knowledge about the impact of pain on individuals and their significant others, and my belief regarding the importance of significant others being involved in a programme. A finding that I had not been expecting was the importance that participants placed on significant others being directly involved in the programme. Rather, I had been expecting that the participants would wish for internet based technology, due to its convenience. Similarly, the involvement of children in the programme was something that I had not given much thought to, nor had I fully appreciated the importance of involvement going beyond education about pain, to include practical strategies and direction to further resources.

Finally, an aspect of this study which may be considered a strength by some and a limitation by others, was the use of phone rather than face to face interviews. Concerns have previously been expressed that phone interviews restrict the quality of data that can be gathered in qualitative research due to the absence of visual information, such as might be gathered if an interview was undertaken in a participant's home (Holt, 2010; Sturges & Hanrahan, 2004). However, in more recent years this concern has been challenged and the absence of visual information highlighted as a useful means of keeping the researcher focused at the level of the data (Holt, 2010). For qualitative descriptive research where the intent is to go no further than to report the findings in everyday language (Artinian, 1988; Milne & Oberle, 2005; Sandelowski, 2000), this indicates that phone interviews offer a highly valuable strategy for collecting data and preserving rigour. Overall, the experiences of this study supports comments by Sturges and Hanrahan (2004) and Holt (2010) that participants value being able to choose the interview method and that quality data can be collected in a confidential manner over the phone.

Suggested areas for future research

The findings from this study suggest numerous areas for further research. Firstly, in this research participants were interviewed after they had attended the Family Day and it is possible that had they been interviewed before attendance, their views about the

involvement of significant others in the programme may have been different. One of the significant others in this study described having held reservations about attending the Family Day as she thought it would be “*a waste of time*”, especially as she had had to take time off work. After attending the Day however, this participant described her views to have changed. Many of those with chronic pain may have unsuccessfully trialled a number of treatments before attending a pain management programme (Dopson, 2010; Dysvik et al., 2005) and significant others may understandably have mixed feelings about ‘another thing’. Learning what those with pain and their significant others think about the involvement of significant others in the programme, before they have attended, may identify ways of targeting strategies to encourage more significant others to attend the Family Day.

Participants in this study also acknowledged that everyone’s situation and psychosocial support needs would vary. Ascertaining the views that people have about the involvement of significant others in the programme prior to the Family Day, especially what support they would like or require, may help to target which resources need to be available to which people before, during and after the programme. Equally, ascertaining these views could be undertaken for the purpose of clarifying if a common theme exists regarding what is considered by families to be the most beneficial balance between the involvement of significant others and time for an individual with pain to engage in the programme independently.

Due to the absence of existing literature about the views that those with pain and their significant others have about the involvement of significant others within multidisciplinary chronic pain management programmes, it is not possible to compare the findings that have emerged from this study. Repeating this study with participants recruited from other pain services or with a larger sample from the TARPS programme would however represent a useful method of developing the body of knowledge about the involvement of significant others in programmes.

Those with pain who were not accompanied by a significant other on the Family Day were excluded from this research. Thus, a valuable area of future research would be to repeat this study without that exclusion criterion, so that the views of those with pain who were not joined by a significant other on the Family Day could be obtained. The

inclusion of those with and without significant others present may reveal new insights regarding the involvement of significant others in the programme.

The inclusion of children in the programme was an area of debate amongst the participants in this study and represents an area of much needed research. There was no doubt amongst the participants that children are affected by a parent with pain and several suggestions were provided as to ways of addressing their needs within the programme. A useful next step would be a qualitative investigation with parents and children focused around the question of how children can be supported within a programme. The information gained during this process could then be explored quantitatively. Finally, concerns have been raised about the potential for the involvement of significant others within a chronic pain management programme to be associated with risks for those with pain and their significant others. Quantitatively, one means of exploring this concern through TARPS would be via the inclusion of measures assessing the psychological wellbeing of significant others before, during and for a period after the programme.

Although this research was focused on the involvement of significant others in the TARPS Family Day, the comments raised by the participants did highlight a need for research regarding support systems (such as support groups) for the significant others of those with pain. Significant others in this study and also several of the participants with pain expressed the importance of support being available for family and friends, however I was unable to locate any literature on support groups for significant others caring for a loved one with pain. Given the prevalence of depression that has been reported amongst significant others (Flor et al., 1987; Schwartz et al., 1991), research into support groups and other such support systems is greatly needed and would help to determine if such input would aid in their wellbeing.

Conclusion

The findings that have emerged from this qualitative descriptive study show that participants view the involvement of significant others in the TARPS programme to be important; this is so that everyone is on the same page about the pain and so significant others can access their own support. These views on involvement reinforce what is already known about the psychosocial dimension of pain and lend support for the

theoretical rationale which is commonly used to justify the involvement of significant others in a pain management programme.

The findings also extend existing knowledge about the involvement of significant others in a pain management programme in three ways. Firstly, they highlight a wish for significant others to be directly involved in the programme, rather than via media such as the internet. Secondly, the findings point to the importance of involvement finding a balance between what is feasible for significant others and beneficial for all, and thirdly the need for the involvement of children in the programme to be carefully considered.

To my knowledge this is the first study that has sought to ascertain views on the involvement of significant others in a chronic pain management programme, from the perspective of those with pain and significant others. For those involved in the delivery of pain management services, the findings from this research highlight the urgent need for research into *when* and *how* significant others, including children, are involved within programmes.

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Appendix 1 – TARPS Timetable

THE AUCKLAND REGIONAL PAIN SERVICE (TARPS)	
3-week Pain Management Programme	
12 th April – 30 th April 2010	

PROGRAMME TIMETABLE

(changes will be posted on the whiteboard)

Week 1

Time	Monday 12th	Tuesday 13th	Wednesday 14th	Thursday 15th	Friday 16th
8.15	Overview of PMP (RGL)		Review	Review	Weekend planning
8.30	Questionnaires	Exercise Circuit	Dr Butler.	Exercise Circuit	Exercise Circuit
9.30	Introductions What can you expect? Intro to the gym Video assessment House keeping	Intro to Relaxation (KM)	Free time & feedback with team/ medication review	Art Session (RC)	Mind /Body Connection (RGL)
10.30	Morning Tea	Morning Tea		Morning Tea	Morning Tea
11.00	Benefits of Exercise (CP)	Relaxation cont. (KM)	Exercise Circuit	Relaxation (KM)	Self Hypnosis (RGL)
12.00	Lunch	Lunch	Lunch	Lunch	Lunch
1.00	Adjustment to Pain (PW)	Communication (MH)	Ways of Thinking (AL/MH)	Hurt not Harm (CP)	Family Issues (PW)
2.00	Intro to Stress Management (KM)	Individual Activation Programme	Intro to activity planning (RC)	Individual Activation Programme	Individual Activation Programme

Coursework Checklist:

Goal set and achieved by 20th April

Activation during the weekend

Relaxation practice

Bring private X-rays, MRI, CT etc for Radiology Session - Tuesday 27th April

Host for the Programme - Peter Waddell

Week 2

Time	Monday 19th	Tuesday 20th	Wednesday 21st	Thursday 22nd	Friday 23rd
8.15	Weekend review		Review	Review	Weekend planning
8.30	Exercise circuit	Exercise Circuit	Overview of medication use (TA)	Exercise Circuit	Exercise Circuit
9.30	Activity Planning (RC)	Creating a Productive Life (RC)	Free time & feedback with team/ medication review	Anger management (MJ)	Setback management (KM)
10.30	Morning Tea	Morning Tea		Morning Tea	Morning Tea
11.00	Relaxation (KM)	Relaxation (KM)	Exercise Circuit	Pain Pathways (BG)	Family Issues (PW)
12.00	Lunch	Lunch	Lunch	Lunch	Lunch
1.00	Sleep Management (KM)	Pain Loss and Grief (AL)	Self Hypnosis (RGL)	Relaxation (KM)	Relaxation (KM)
2.00	Individual Activation Programme	Individual Activation Programme	More Ways of Thinking (and Doing) (AL/MH)		Individual Activation Programme

Coursework Checklist:

Goal set and achieved by 27th April

Planning for Inspiration and Challenge Friday 30th April

Activation during weekend

Relaxation practice

Week 3

Time	Monday 26th	Tuesday 27th	Wednesday 28th	Thursday 29th	Friday 30th
8.15	Weekend review		Review	Video re-assessment questionnaires	Family morning
8.30	Exercise Circuit	Exercise Circuit & Home Exercise Planning (CP)	Dr Butler	Exercise Circuit	Introductions
9.30	Communication Skills (MH)	Activity Planning (RC)	Free time & feedback with team/ medication review	Relaxation (KM)	Acute v Chronic pain (RGL)
10.30	Morning Tea	Morning Tea		Morning Tea	Speed walk
11.00	Relaxation (KM)	Relaxation (KM)	Exercise Circuit	Setback management (KM)	Gym session
12.00	Lunch	Lunch	Lunch	Lunch	Relaxation and Pacing
1.00	Planning for Productivity (RC)	Radiology session (bring your x-rays etc)	Pain Traps (PW)	Self Esteem (RC)	Morning tea
2.00	Individual Activation Programme	Individual Activation Programme	Relaxation (KM)	Individual Activation Programme	Pain and the Family (PW)
					Inspiration & Challenge

Coursework Checklist:

Setback plan & discharge summary for Thursday 29th April

Planning for Inspiration and Challenge Friday 30th April

Relaxation practice at home

1 month follow up: Friday 28th May, 2010 at 1.30pm

Appendix 2 – Example of the TARPS Family Day

8.30am –	Those with pain and their significant others arrive at TARPS Introductions and Health and Safety notices
9.00am-	1 Presentation (Psychiatrist, supported by the whole team) Overview of chronic pain and impact that it has on peoples' lives + an overview of the TARPS programme and the approach that is taken by team to help people manage their pain
9.30am-	Gym session (Physiotherapist) Includes speed walk, gym circuit (those with pain show significant others what they have been doing in the gym) and overview by the physiotherapist of the rationale behind the approaches used in the gym e.g. individualised and graded programmes
10.00am-	Relaxation session (Nurse) Practical relaxation session + an overview of the rationale for its use in pain management
10.30am-	Morning tea
11.00am-	Presentation 2 (Clinical Psychologist) Relationship issues – overview of how pain can affect those with pain e.g. mood and interpersonal relationships
12noon-	Group lead session Each programme participant gives a short presentation about a personal challenge that they have set themselves or achieved and describe one thing that gives them inspiration
1.00pm-	Graduation ceremony (Psychiatrist, supported by the whole team) Certificate of programme completion + final farewell
1.30pm-	Day ends

Appendix 3 – Letter of Approval from ADHB



14 September 2010

Ms Catherine Swift
2 Wingate St
Meville
Hamilton 3206

Dear Ms Swift

RE: Research project A+ 4786 (Ethics # NTY/10/06/053) - The Involvement of Significant Others Within a Chronic pain management Programme: The Views of Programme participants and Their Significant Others

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the ADHB Research Review Committee
Dr Mary-Anne Woodnorth
Manager, Research
ADHB

c.c. Wendy Hoskin

Fionnagh Dougan

Kierien Davis

....../continued next page

Research Office
Level 14, Support Bldg
Auckland City Hospital
PB 92024, Grafton, Auckland
Phone: 64 9 307 4949 Extn. 23854
Fax: 64 9 307 8913
Email: mwoodnorth@adhb.govt.nz
Website: www.adhb.govt.nz/ResearchOffice

Institutional Approval

MAINTAINING YOUR RESEARCH APPROVAL

Your Ethical and Institutional approval is dependant on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. While the RO endeavours to send reminders for annual approvals and missing documents, it is **your responsibility** to ensure you have kept Ethics and the Research office up to date and have the appropriate approvals.

Please note, when missing or updated document reminders are sent, if the RO receives no response from you after 3 reminders it will be assumed that your research has been completed and we will notify the relevant Department CD, the RRC and Ethics Committee that your **Locality Assessment Approval has been withdrawn**. This will not be reinstated until all issues have been resolved.

All documents / communications must be referenced with the **ADHB project number**. For simplicity when sending information to the Ethics Committees, please cc the RO. When receiving letters from Ethics, please copy and send to RO for our records.

TOPIC	REQUIREMENT	ACTION
ETHICS		
All Ethics Correspondence	All formal Ethics Committee communications to you	<ul style="list-style-type: none"> o send a copy to RO immediately
Annual Ethics Renewal	Use Ethics form, complete and submit BEFORE anniversary date of original research approval	<ul style="list-style-type: none"> o copy to Ethics o copy to RO (e-copy) o send copy of Ethics approval letter to RO when received
Changes to Research (design, PI, protocol etc)	Write letter detailing changes, Mark up changes in relevant documents. Ethics approval must be received BEFORE implementing	<ul style="list-style-type: none"> o copy of changes to Ethics o copy changes to RO o send copy of Ethics approval letter to RO when received
Stopping Study or Study Complete	If the study is stopped for any reason or study is complete	<ul style="list-style-type: none"> o notify Ethics and attach relevant documents (final report etc) o notify RO and attach relevant documents
Final Report	Complete Ethics template for final report	<ul style="list-style-type: none"> o Send to Ethics and RO o Inform RO if all finance elements also complete
LEGAL		
Contracts, Indemnities, Agreements, insurance certificates	All legal must be reviewed and approved before signing	<ul style="list-style-type: none"> o Send all legal documents to RO
Amendments – Non-financial	As above	<ul style="list-style-type: none"> o Send all legal documents to RO
Amendments - financial	As above and revise Budget	<ul style="list-style-type: none"> o Send all legal documents to RO o Send revised budget using template to RO
FINANCIAL		
Budget Changes i.e. change in visits or tests or proposed income	Liaise with accountant and adjust budget accordingly	<ul style="list-style-type: none"> o Send revised budget using template to RO
Budget maintenance	it is recommended that you review and update budgets at least quarterly	<ul style="list-style-type: none"> o Liaise with accountant and forward update to RO

All documents must be referenced with the ADHB project number and can be sent via email to: RDOAdmin@adhb.govt.nz. All paper copies can be faxed to: 09 307 8913 or by post to: Research Office, Level 14, Support Building, Auckland City Hospital, Private Bag 92024, Auckland, New Zealand.

For further information go to www.adhb.govt.nz/researchoffice/

Appendix 4 – Letter of Approval from the ADHB MRRC



17 August 2010

Ms Catherine Swift
2 Wingate Street
Meville
Hamilton, NZ

Maori Research Review Committee
c/o Research Office
PB 92024, Grafton, Auckland
Email: jennym@adhb.govt.nz

*This support letter is issued by the Maori Research Review Committee and **does not** represent the Ethics approval or the ADHB management approval. Investigators are advised to seek other approvals separately.*

Tena koe Catherine

RE: Research project A+4786 - The Involvement of Significant Others Within a Chronic pain management Programme: The Views of Programme participants and Their Significant Others

The Maori Research Review Committee (MRRC) would like to thank you for excellent response in your email dated 16 August 2010 and revised documents that include changes suggested by the MRRC.

The MRRC is happy to support your research study.

Please send a copy of the final report that includes ethnicity data to the Maori Research Review Committee (c/o Jenny Ma, Research Office, Level 14, Support Bldg, Auckland City Hospital, PB 92024 Grafton, Auckland) at the conclusion of the study.

We wish you the very best in your research.

If you are forwarding a copy of this letter to the Ethics Committee please ensure you add the EC number to the document (if not already listed). This will ensure there are no delays in processing your application at the Ethics Committee.

Noho ora mai,

On behalf of ADHB Maori Research Review Committee
Mata Forbes
Maori Health Advisor, Maori Health Services
Auckland DHB

Appendix 5 – Letter of Approval from Northern Y Regional Ethics Committee



Northern Y Regional Ethics Committee

Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton 3204
Phone (07) 858 7021
Fax (07) 858 7070

Email: northern_y_ethicscommittee@moh.govt.nz

8 September 2010

Catherine Swift
2 Wingate Street
Melville
Hamilton

Dear Catherine

Ethics ref: NTY/10/06/053 (please quote in all correspondence)
Study title: The involvement of significant others within a chronic pain management programme: The views of programme participants and their significant others.
Investigators: Dr Clare Hocking, Ms Catherine Swift

This study was given ethical approval by the Northern Y Regional Ethics Committee on 8 September 2010.

Approved Documents

- Information Sheet and Consent form version 3 dated 14/07/2010
- Interview Questions
- Expressions of interest
- Transcriber confidentiality statement

This approval is valid until 17 May 2012, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by 8 September 2011. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

For the purposes of the individual reporting of SAEs occurring in this study, the Committee is satisfied that the study's monitoring arrangements are appropriate.

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

- are *unexpected* because they are not outlined in the investigator's brochure, and
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, if your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely



Amrita Kuruvilla
Administrator
Northern Y Regional Ethics Committee
Email: amrita_kuruvilla@moh.govt.nz

Appendix 6 – Letter of Approval from the Faculty of Health and Environmental Sciences Postgraduate and Research Committee AUT



8 March 2010

Catherine Swift
2 Wingate Street
Meville
Hamilton 3206

Dear Catherine

Private Bag 92006
Auckland 1020, NZ

T: +64 9 921 9999
www.aut.ac.nz

ST1091763 MHSc Thesis topic and supervisor

Thank you for submitting your MHSc thesis *Research Proposal PG1* application. Your proposal has been reviewed and approved by the Faculty of Health and Environmental Sciences Postgraduate and Research Committee 26 February 2010 meeting. Details are:

Your topic: The involvement of significant others within a chronic pain management program:
The views of program participants and their significant others.

Primary supervisor: Associate Professor Clare Hocking
Secondary supervisor: Dr. Kirk Reed

Start date: 1 March 2010
Expected completion date: 1 March 2012
Enrolment: Part-time

Please note that you cannot be enrolled into the MHSc thesis paper until you have applied for 120 points RPL formal credit for a postgraduate diploma through the Postgraduate Examination Board.

You will see processes for your progress within the thesis paper are laid out in the *Postgraduate Handbook*. If you do not have a copy of this booklet please contact the Executive Administrator on (09) 921 9999 extension 7020. The AUT website for forms and handbooks is:
<http://www.aut.ac.nz/study-at-aut/current-students/postgraduate-support>

Please contact your supervisors to complete your *Postgraduate Supervisors Agreement* and development of your ethics proposal, if you have not already done so.

Please feel free to contact the Executive Administrator Jennifer Warrington on (09) 921 9999 ext. 7020 with any questions or clarification you may require.

Yours sincerely

A handwritten signature in black ink, appearing to read 'M. Jones'.

Associate Professor Marion Jones
Associate Dean Postgraduate
Postgraduate and Research Office
Faculty of Health and Environmental Sciences

CC: **Clare Hocking**
Kirk Reed

Appendix 7 – Information Sheet 14.07.2010



INFORMATION FORM

The involvement of significant others within a chronic pain management programme: The views of programme participants and their significant others

Background information

My name is Catherine Swift. I am an Occupational Therapist and also enrolled in a Masters of Health Science at AUT. I have a particular interest in the management of chronic pain and I am interested in learning about your thoughts on the involvement of significant others in the TARPS, 3 week pain management programme. For the purpose of this study, significant others refer to those people who you consider to be your key sources of support.

An invitation

You are invited to take part in this study if you are a participant in the TARPS pain management programme and one of your family/whanau or a significant other(s) attended the family session, OR, if you are a member of the family/whanau or a significant other of someone on the programme.

Participation in this study is entirely voluntary (your choice). You do not have to take part in this study and if you choose not to take part, this will not affect any future care or treatment.

What are the aims of the study?

The aim of this study is to learn what people who attended the family forum, as part of the TARPS 3 week pain management programme, think about the involvement of significant others in the programme.

It is expected that the information gathered during this study will lead to an increased knowledge about the involvement of significant others within pain management programmes and thus assist with programme development.

What will happen if I decide to take part?

Participation in this study will involve an interview with the researcher, and possibly a brief follow-up interview. These interviews will be at a mutually agreed venue and time. Interviews may be conducted over the phone or Skype, if preferred by the participant. The first interview will be approximately 1-1 1/2 hrs in duration and will provide participants with the opportunity to discuss their views on the involvement of significant others in the TARPS programme. The second interview will be used to clarify information collectively gathered during the first round of interviews and will be approximately 45mins-1 hour long.

Can I have a support person present?

Participants may choose to have a support person present at each interview and may request for male to be present if appropriate to a participant's cultural practices.

INFORMATION FORM

How will the study affect me?

No risks and/or adverse effects are expected to be experienced by participants as a result of involvement in this study. However if any participants do experience distress as a result of their involvement, they will be supported by Catherine to access appropriate support services.

Participants are not expected to incur any costs as a result of their participation. Participants, who chose to be interviewed at a venue more than 5 kilometres from their home, will be offered a koha to cover transport costs.

What is the length of the study?

The anticipated duration of the study is 1 1/2 years, including the write up of results.

How many people will be involved?

It is estimated that 12 participants will be involved in this study.

Confidentiality

All interviews will be recorded and transcribed immediately after the interview. All data will be kept confidential. Files will be created for each participant and include a record of all communication, as well as interview data. Each file will be coded to maintain participant confidentiality and will be stored with all other material associated with the research in a locked filing cabinet, only accessible to the researcher and her Post Graduate supervisors. Any information stored on the computer will be password secured.

All participants are reassured that the information that they provide will not be disclosed to members of the TARPS team.

Data gathered during the study will be written up so that no material can be used to personally identify you. The final report will be marked for Post Graduate Study and may also be submitted for publication by relevant journals and/or relevant conferences. All participants will be offered a summary of the final report, as will TARPS.

All data collected during this study, with the exception of audio tapes used to record interviews, which will be erased after transcripts are made, will be retained for at least 10 years. Electronic data will be stored on a CD and remain password secure. The CD will be stored with all hard copy material, in a locked filing cabinet at AUT. At the end of 10 years the CD will be destroyed and hard copy material shredded.

Ethical approval

This study has received ethical approval from the Northern Y Regional Ethics Committee, ethics reference number NTY/10/06/053

INFORMATION FORM

What if I have any questions?

Should you have any further queries about this research, please call Catherine Swift (Researcher), 0800 9064 64 or fgc4766@aut.ac.nz

Your rights

Participants will have an opportunity to consult family or their significant others before agreeing to participate in this study.

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact an independent health and disability advocate: Free phone 0800 555 050

Free Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

Study investigator

The Principal Researcher for this study is:

Catherine Swift

Occupational Therapist

Student: Masters of Health Science

AUT

Private Bag 92006

Auckland 1142

The principal researcher (Catherine Swift) is not employed by the Auckland District Health Board and is undertaking this study as part of Post Graduate Studies, through the Auckland University of Technology (AUT).



Catherine Swift
Principal Researcher



Clare Hocking
Principal Supervisor

Appendix 8 – Expression of Interest Form



Expressions of interest

The involvement of significant others within a chronic pain management programme: The views of programme participants and their significant others

Thank you for expressing your interest in participating in this study. Please find attached an information sheet about the study and what participation would involve. Please feel free to discuss the content of the information sheet with your significant others/family members/support people. I will contact you in approximately 2 months to answer any questions that you may have about the study and confirm your ongoing interest in participating.

The aim of this study is to learn what individuals, who have participated in the TARPS, 3 week pain management programme, and their significant others, feel about the involvement of significant others in the programme. To achieve this aim I am keen to speak with individuals from a wide range of backgrounds to ensure that the information collected reflects a diverse perspective.

To assist me to ensure that I speak with individuals from a diverse range of backgrounds, can you please provide information on the areas below. All information will be treated in the strictest confidence.

Your name: _____

Address: _____

Phone number: _____

Email: _____

Age: _____

Ethnicity: _____

Religion: _____

Occupation: _____

Relationship status: _____

Number of children: _____

Who you live with: _____

Where you experience your pain: _____

Length of time that you have experienced chronic pain: _____

I consent to the researcher (Catherine Swift) contacting me in one month to answer any questions about the study and confirm whether I would like to participate in the study.

Your signature: _____

Date: _____

Thank you for your time and expression of interest in this study.



Catherine Swift

Post Graduate Student (Masters of Health Science)

Auckland University of Technology

Appendix 9 – Consent Form 14.7.2010



CONSENT FORM

The involvement of significant others within a chronic pain management program: The views of program participants and their significant others

- | | |
|--|----------|
| 1. I have read/had explained to me, and understand the Information Sheet (Version 3, 14.07.2010) for the above study. | Yes / No |
| 2. I have had the opportunity to discuss this study. I am satisfied with the answers that I have been given. | Yes / No |
| 3. I understand that participation in this study is voluntary (my choice) and if I choose not to take part, this will not affect my future health care or treatment. | Yes / No |
| 4. I understand that participation in this study may involve two interviews with the researcher, at a mutually agreed venue and time. I understand that the first interview is anticipated to be approximately 1-1 1/2 hrs in duration and that during this time I will be asked to discuss my views on the involvement of significant others in the TARPS, 3 week pain management programme. The second interview will be used to clarify information collectively gathered during the first round of interviews and will be approximately 30mins long. | Yes / No |
| 5. I understand that while no risks and/or adverse effects are expected to be experienced as a result of involvement in this study, in the event that I do experience distress, I will be supported to access appropriate support services. | Yes / No |
| 6. I understand that this research is part of the researcher's postgraduate studies and that the findings will be published in a de-identified form. | Yes / No |
| 7. I understand that no material that could identify me will be used in any reports on this study. | Yes / No |
| 8. I have had time to consider whether to take part. | Yes / No |
| 9. I know whom to contact if I have any questions about the study. | Yes / No |
| 10. I have been given the opportunity to have a member of my family or a friend present while the study was explained to me. | Yes / No |

CONSENT FORM

- | | |
|--|----------|
| 11. I understand that my involvement in the study will not affect my relationship with the TARPS, pain management team, and their management of my health. | Yes / No |
| 12. I understand that the information that I provide will not be disclosed to members of the TARPS team. | Yes / No |
| 13. I have been told that this study has been approved by the Northern Y Regional Ethics Committee. | Yes / No |
| 14. I understand that should I have any concerns or queries about this research I can call Catherine Swift (researcher), 0800 906464 or fgc4766@aut.ac.nz | Yes / No |

I am indicating my approval (or otherwise) to the following:

I wish to receive a report of the results. I understand that there may be a significant delay between the data collection and the publication of the study results YES/NO

I hereby consent to take part in this research.

Signed Date

Study explained to me by :

Study role.....

Signature.....

Date.....

Appendix 10 – Follow up Letter



The involvement of significant others within a chronic pain management programme: The views of programme participants and their significant others.

Dear

Thank you for expressing your interest to share your experiences of participating in the pain programme at TARPS. I will be in contact in the next couple of days to determine if you remain available to participate in the study and if so, discuss an interview time.

In the interim please find enclosed another copy of the information sheet which you received during the programme. For your information I have also enclosed a copy of the consent form that I will need you to sign on the day of our interview.

Once again, thank you for your expression of interest.

Regards

A handwritten signature in black ink, appearing to read 'C. Swift', is positioned above the printed name of the Principal Researcher.

Catherine Swift
Principal Researcher

Appendix 11 – Interview Questions



Interview questions

Sample questions

1. Did you attend the family forum as a programme participant or as a significant other?
2. Please tell me about the Family forum from your perspective
3. What do you think about the level of family/significant other involvement in the 3 week programme
4. How important do you feel it is for family members/significant others to be involved in pain management programmes?
 - a. Please explain your answer.
5. Was it helpful to attend the forum?
6. Was the forum harmful in any way?
7. What are the key things, that you think are important for family/significant others to know about chronic pain in the programme?
8. Are there things it's not useful to know?
9. What do you feel would be the most beneficial way of involving family/significant others in the programme?
10. Can you please describe any things that have changed as a result of family/significant other involvement in the programme?
11. Are there things that haven't changed?
12. Would you recommend to other programme participants, that they encourage their family/significant others to attend the family forum?
 - a. Why, why not?

Appendix 12 – Transcriber Confidentiality Statement



Confidentially statement: Transcriber

I understand that I will be transcribing for the study titled:

The involvement of significant others within a chronic pain management programme: The views of programme participants and their significant others

This study is being conducted by Catherine Swift, for a Masters of Health Science, AUT. The study is being supervised by Associate Professor Clare Hocking, Dr Kirk Reed and Professor Jennifer Strong.

As a transcriber I am privy to confidential information.

I agree to keep all information heard or seen during this study, confidential and not reveal it to anyone outside the research team.

I will delete all files on my computer at the completion of the study and will not keep any electronic or hard copies of the documents I have been working on.

Name: Irene Bodman
Signature: *Irene Bodman*
Date: 20/12/2010

Witness name: Catherine Swift
Witness signature: *Catherine Swift*
Date: 20/12/2010

Appendix 13 – Transcriber Confidentiality Statement



Confidentially statement: Transcriber

I understand that I will be transcribing for the study titled:

The involvement of significant others within a chronic pain management programme: The views of programme participants and their significant others

This study is being conducted by Catherine Swift, for a Masters of Health Science, AUT. The study is being supervised by Associate Professor Clare Hocking, Dr Kirk Reed and Professor Jennifer Strong.

As a transcriber I am privy to confidential information.

I agree to keep all information heard or seen during this study, confidential and not reveal it to anyone outside the research team.

I will delete all files on my computer at the completion of the study and will not keep any electronic or hard copies of the documents I have been working on.

Name: Loryn Anne SINTON



Signature:

Date: 06 January 2011

Witness name: Catherine Swift.

Witness signature: 

Date: 06.1.2011

Appendix 14 – Overview of the Analysis

Stage one of the analysis – Immersion and analysis of each transcript

The process of analysing the data began as I listened to each interview several times, either while typing up the transcript or proofing an interview typed by my transcriber. This process enabled me to gain an overall sense of the information shared in each interview and begin reflecting on the way that it might relate to the data gathered in other interviews. I then read each transcript line by line and made a summary note or word in the margin as a way of coding the content of the corresponding data. At the same time I also highlighted any recurring words, phrases and/or themes appearing in the transcript. Once completed, I listed all the summary notes and words that I had made on a piece of paper, along with the words that I had highlighted for each transcript. At the same time I also made notes about my initial impressions of the key themes contained within each transcript. Below are examples of the summary lists that I made for two of the participants, including my summary notes, initial impressions of the data contained within the transcript, and **highlighting** to demark reoccurring words or themes. At the end of each summary list, I developed a second shorter summary (identified in **bold**) of key words and phrases.

Example 1 - Participant R4

- Would recommend family involvement and would like more.
 - o More family involvement needs to be balanced with the benefits of being able to focus on the programme as an individual
 - o Being away from the family during the week reduces distractions from the programme
 - o Acknowledges the challenges and logistics for family of having to travel to the programme
- The last day gives family a “look in” on the programme and allows people to see each other in context of their social support. A little bit of information/teaching is provided. Would have liked more opportunity to work through the process so that family feels involved
 - o Other media could be explored to incorporate families more and provide more info

- Children are affected but numerous challenges to involving children – rather enable the parents to make the changes.
 - o Perhaps more time could be spent with participants, increasing their awareness of how pain affects the wider social network – was covered to some degree in the programme
 - o Perhaps family could be present on the first day to get an overview of the programme and put people in the context of family. Then direct them to other resources so that they feel included and are able to grow in their knowledge too.
- Important to be able to direct families to appropriate resources for additional support. This could possibly be achieved by having other organisations present at the final day so families could book follow up appointments. Or providing other resources outside of the programme
- Key knowledge for families – an understanding of the generalities of pain and that it is not always controllable; strategies that help family members to manage living with someone in pain to reduce the impact on them. Give families knowledge of the tools that the individual has to manage their pain and how the family can support them.
- There can be challenges putting things into play at home e.g. incorporating exercise into a family routine, however the 3 weeks of the programme helps to establish a habit. TARPS then provide good ongoing support.
 - o Talks with family about changes but also does some individually
- Demeanour has changed through the programme and this has benefits for the whole family.
- Humour good in the family day but also concerns that it discouraged feedback from family.
- Acknowledge the impact on the wider family/social unit and their need for support
 - o Need to support and encourage the wider family e.g. it's ok to feel this way... it is not all in your head.
 - o Stigma also an issue for the family
 - o Need for information that you can share with the wider social network

Key words/phrases: Help family to feel included from the beginning; point families in the direction of where to go for more information/support and make it easy

Example 2 - Participant R2

- “I expecting it to be a waste of time but actually I absolutely loved it. I didn’t expect it to be so good...”
 - o Had to take the day off work
 - o I went because my husband asked me to go and I didn’t know what to expect... It was a good surprise
- They made it **fun** for everybody even though they were dealing with crap
 - o Important because people are dealing with hard things in their life... you know pain is not a happy thing
 - o Helps people to relax in a situation where they don’t know each other
- Well grafted
 - o Appreciated the effort that was put into the day and the programme over all
- Trying to do meditation and exercise etc now – things that he would never have done if I had tried to get him into. “ **I was delighted to see** they did that... cos there really isn’t much else you can do”
 - o **Understated what they do there**
 - o **We’re doing the self hypnosis thing cos I’m kinda into that sort of thing**
- Haven’t really read those {F/U bits sent to husband}
- “I’m not suffering so you know... it’s hard but...”
 - o **Seeing** others going through a lot worse
 - o Some of those people are really dealing with real.. my husband was not the worst by far, but I know we’ve been through a hard enough time....
- *Good on the final day...it’s the finale... quite a good bonding session*
- Husband talked about the programme at nights
- *Needs to be 1:1 presentation, to important to be via DVD etc ?*
- Did not feel that she left with unmet needs.

- General acknowledgement pain can’t be taken away but good to see that they gave tools to help manage the pain.
- General sense that the education etc did not apply to her but maybe to others... just pleased to see them encouraging her husband to do things to help himself.

Questions to ask at the follow up interview

- So is family involvement important in the programme
- What sort of things did your husband share in the evenings of the programme
- Presented as very realistic about the pain not being able to be fixed – did this come from the programme?

Key words: Seeing others and what's done in the programme, fun, loved it, great, didn't want to go and didn't know what to expect, it was a surprise

Stage two of the analysis – organising the collected data into emerging categories

The next stage involved a cross participant analysis by reviewed the lists that I had made for each transcript and organising the information contained within each list, into meaningful clusters under emerging themes and sub themes. This process was repeated, and the categorises revised many times throughout the analysis, as themes emerged. Below is an example of one of the early stages of analysis, containing eleven themes, some with sub-themes

- 1. Support from significant others is important**
- 2. Being able to talk with someone is important and if family are not able to provide the level of support required all participants valued knowing that TARPS was there.**
- 3. Family and the individual need to learn and share the same skills**
- 4. The importance of internal change (hope).**
- 5. Family involvement in the programme is important**
 - **Share achievements**
 - **Family involvement allows others to see you in the context of family**
 - **An opportunity to increase understanding**
- 6. Value of the group delivery**
 - **Gain support**
 - **Validation of experiences**
- 7. Level of involvement**
- 8. Beyond and outside the 3 week programme what do families want and need?**
 - **Point families in the right direction for more support**
 - **Family follow up**
- 9. Help families to feel included**
 - **Provide opportunities and encourage feedback from family**
- 10. Timing of the family day**
- 11. Acknowledgement of logistics**

Stage three – collating data in relation to emerging themes

The next step involved collating the data in relation to emerging the themes. The following example reflects the process of refinement that occurred for the theme ‘Level of involvement’.

Extract from - Version 3

Theme heading: Level of involvement

CS: When you say more, would you want like a longer session on the Friday or do you want the people involved from, from day one or, what, what do you mean?

R4: I, I think there is definite value in, in keeping that hmm, I think that umm you know the idea of it, it focusing in on the person with pain and setting up systems to help that person’s marriage and, and you know, possibly alleviate some of that pain. I think that’s good, but I think ummm possibly rather than just giving the family a look in on that ummm, on, on that last day there was, there was a little bit of family systems stuff, you know a touch on that ummm... But it was largely a look in I felt on what we had been doing and, and a little bit of information on the sort of cycles that people go through and, and stuff like that, but I think there could be more about, umm, sort of, some sort of opportunity for families to work through the process a little bit more umm so that the family feels that they are part of it as well....So, Maybe, maybe upping it from... what it is ummm... 3 weeks.... 15 days... 1/15 to 2/15 or you know, so it maybe one whole day, you know one half day like they did, and another 2 half days or something. Or 2 two hour sessions or something like that

R4: Well... and yeah... I mean... I think basically what, umm you know, from the course, the family got what was on that day and there was some teach which was good and it was interesting and so forth but then that was it you know and, and it was probably not, probably not quite half a day umm and I just think that it is too important a thing to limit to that ummm, it doesn’t mean that it has to be, has to overrun the course either because I think, like I said earlier, you know, there was great value in ummm being able to concentrate and just be away from the family for the course as well so...(?) which just say might mean just those resources being available ummm ... which aren’t part of the pain course as such. And just that....ummm I think, just... like what you were saying with the depression advertisement. Umm, I think a little bit of encouragement like that for the family can go a long way

CS: The family forum was half a day; do you think that was long enough?

R7: Actually that’s fine you know ah, but also on the practical side... like... ah. I would understand, like, my sister was working and she had to really take some time off from work.... just working example (?) too, so half a day is really -

- you know really is good enough to have a feel of it in a way, but also there's reasonably for those who are also taking some time off from work just to, you know, show support to a family member. Yeah, so much as one day would've been great you know, but ah at least half a day would be definitely. - - because I mean....well going to the exercise - - also the break, you know, where they can also talk to some other people.

R7: Yes, yes, so basically that's? There's not enough time within the programme to assess. I would ... you know, when I look at the programme, I said, "Oh, there is family issue there". There is also" like a - - I don't know what - - and we thought we would be able - - not just discuss, because sometimes it's not that easy to discuss your family or personal but... you know how it was... let's say through an art activity you sometimes can express it, sometimes some people cannot be that creative but ah. There's something about - - yeah, you know, but only maybe a counsellor or maybe they'll be able to read through your - - what you're saying... in between what you're saying or what your art is saying, you know.

R14: She came to my first interview, but she sat outside... I think it really depends on the couple. With [*Wife*] and I, I think it would've been good for her to be present through most of it, but I know that that's probably not completely possible either. You know, if you've got both of you's working and stuff... Yeah it is, it's really hard, I mean it's the same even with your Uni, trying to get time to do stuff and then, you know, anything else that crops up. Let alone if you had an injury that you're trying to cope with.

Stage four – ongoing refinement

As the process of analysis and collation continued, theme headings were refined. The theme ‘Level of involvement’ developed to become ‘A look in’, with three associated sub-themes ‘Needs & Expectations’, ‘Half a day gave significant others a feel for the programme’ and ‘The Involvement of Significant others is a balance’

Extract from Version 11

Theme heading: ‘A look in’

Subheading - Needs & Expectations

R3: ...Umm, and was the forum what I expected – Umm, umm. I, yes it was pretty similar, the, the format and the delivery and the umm the situate all that sort of stuff was what I had expected, or pretty close to what I had expected...Umm but I really did expect more of an in depth umm engagement with how these issues affect family life which they didn't...I.... also... felt...that... it... wasn't ...really... addressing the true needs of the family...and I'm not really sure what the intention. I had, I... Perhaps this is getting back to your question about what I expected because I think maybe on some level I did expect that they would be looking at the issues surrounding how these types of things affect family dynamics and how they affect an intimate relationship and how they affect the marria.. you know... a long-term umm, partnership and, and those sorts of things and those issues, weren't... didn't really come up at all and I was really surprised at that because I have come to the conclusion that the support of the family or not is one of the fundamental breaking points of a person whose in chronic pain, and that's like one of the major, yeah, pivotal issues and it was not even addressed. And I just thought “Oh well”, I was amazed actually.

CS: Yep. So when you went did you have a clear idea about what was going to happen on that day?

R13: No, not really. I sort of assumed that they would be doing an overview of what they'd taught them, so that other people were aware of it, and that was exactly what happened.

CS: Yeah. So were there any things that you thought were harmful or umm maybe detrimental that, that happened at the forum?

R3: Umm no, well I mean the only harmful thing personally, was simply that I felt so needy and didn't feel my needs were meant but it's, that's (*Laugh*), that's not anyone else's fault (*laugh*)

R7: Yes, yes, so basically that's? There's not enough time within the programme to assess. I would ... you know, when I look at the programme, I said,

“Oh, there is family issue there”. There is also” like a - - I don’t know what - - and we thought we would be able - - not just discuss, because sometimes it’s not that easy to discuss your family or personal but... you know how it was... let’s say through an art activity you sometimes can express it, sometimes some people cannot be that creative but ah. There’s something about - - yeah, you know, but only maybe a counsellor or maybe they’ll be able to read through your - - what you’re saying... in between what you’re saying or what your art is saying, you know.

CS: Excellent. And what are the key things that you wanted to know when you went to the forum? What were the key things you hoped to get out of it?

R2: I don’t know about key things, I went along ‘cos Husband asked me to go and I didn’t know what to expect so there’s no key things really. Really, I guess in a sense, you know, I suppose they’re not going to be able to treat Husband, he’s just got to be able to live his life. So in a way it was good because it gave him - - you know, it’s never going to take all the pain away because you can’t, you’re not God, but you gave him tools to be able to help him to manage it.

C: Yep, and what was your perspective? How did you find that last day?

R2: Oh, actually I was expecting it to be a waste of time if I’m honest, but actually I loved it. I absolutely loved it! I didn’t expect it to be so good. Yeah, I thought it was great.

CS: Would there have been anything they could’ve done before the forum to prime you for what was coming?

R2: No. In a way I thought it was quite a good surprise, ‘cos I didn’t know what to expect, and I just went along, oh it’s the last day. And I had to take a day off work you know, so I thought, oh, you know auuuuh, but umm actually I was delighted I went.

R2: ... God, it sounds a bit gooey, and you can write it down like that, but I loved it. Put it like that because then I’m telling the truth. It sounds gooey but I really loved that day. I thought it was great and I SO wasn’t expecting that at all!

CS: So what do you think are the most important things that family should know if they’re coming to the programme?

R14: The time that they’re supposed to be there.

CS: Like on the final family day or just ...?

R14: Yeah. So how long they need to be there or if coming for a short period is going to be possible, you know, sort of what frame is best. Ummm I think that’s pretty crucial. And see, I had a little boy and I brought him and I was the only one that brought a child. That was, that just felt full on.

CS: Yep. Did they give you any guidelines about bringing children in at all?

R14: They said that they loved them to come, they think it’s important.

CS: I imagine it would’ve been a long morning for him.

R14: Yeah, it really was.

R1: Yeah, they’d given a rough outline of what would happen, so I kind of knew... I certainly gave my wife a bit of an idea of what would happen, so, you know, it wasn’t too much of a surprise you know.

CS: Are there any things that they could've done - - like you mentioned giving people timeframes and those sorts of things, are there any things they could've done to have enhanced the way that they communicated with family prior to the family day or involved family prior to the family day?

R14: I mean...I think they did quite well, I think it's just about how much we picked up. Because I remember hearing them talking to us saying that you need to sort of let them flick through your red folder and know what's going on. But then, right at the end, they told us forget one bit, 'cos that one above bit they're going to tell them on family day, so I got a little confused and didn't know what I was supposed to tell her.

Subheading - Half a day gave significant others a feel for the programme

R3: Well, my ideal would be to be involved from day dot. I mean, I think that would be absolutely ideal umm because I don't think it can be done in a one, it's not a sole deal unless you are truly solo, which none of us are, but you know, if there was some way of having it more integrated..Umm ... I would have gladly move heaven and earth to find to find a way to be at 3 weeks of that stuff with husband because that would have ummm...you know for our relationship, that's, that's life changing and potentially umm, but I don't know how helpful that, I mean some of the content wouldn't have been relevant for me perhaps ...Umm, but certainly, a, a, much more hand 'n' hand approach. I think, you know, umm, a one off session with a psychologist would be very helpful umm, but in isolation would be limited because I think that if you... I could imagine for example, if the families... they were, were part of the process from day one and got some umm, you know a big picture kind of idea about how to work with what was going to happen, how to support our partners, how to work with what was about to happen and were given some reading material about how these dynamics effect... how, how, these umm, umm, yeah these condition affects your long-term relation dynamics, then umm, have a session say you know mid, mid week of the middle of the week or something, sometime during the process and then a final thing...you know that would be a reasonably doable and potentially really, really powerful process and the potential for follow up if you could swing it somehow

CS: So, they had it for half a day, do you reckon that was too long or too short?

R13: I thought it was too short - - I mean sorry, too long in the sense of it just being a one-day session, although I could've done a couple of narrowed down versions of that over a course of days or over a course of a month or whatever the story might have been. So maybe once at the beginning, once in the middle, once at the end. Potentially I know that is a lot more extra time, but if it was a shorter period of time, it is considered more of a meeting, than a half a day out.

CS: Yip. And it's easier to negotiate with work and those sorts of things.

R13: Absolutely, you can say the amount of time, "I need four hours over the course of the next three weeks" In one hour slots... yeah I think that's a lot more... I mean I've got a pretty flexible ummm position so I'm alright like that, but not everyone is

CS: When you say more, would you want like and longer session on the Friday or do you want the people involved from, from day one or, what, what do you mean?

R4: I, I think there is definite value in, in keeping that hmm, I think that umm you know the idea of it, it focusing in on the person with pain and setting up systems to help that person's marriage and, and you know, possibly alleviate some of that pain. I think that's good, but I think ummm possibly rather than just giving the family a look in on that ummm, on, on that last day there was, there was a little bit of family systems stuff, you know a touch on that umm... But it was largely a look in I felt on what we had been doing and, and a little bit of information on the sort of cycles that people go through and, and stuff like that, but I think there could be more about, umm, sort of, some sort of opportunity for families to work through the process a little bit more umm so that the family feels that they are part of it as well....So, Maybe, maybe upping it from... what it is ummm... 3 weeks.... 15 days... 1/15 to 2/15 or you know, so it maybe one whole day, you know one half day like they did, and another 2 half days or something. Or 2 two hour sessions or something like that

CS: The family forum was half a day; do you think that was long enough?

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R14: She came to my first interview, but she sat outside...I think it really depends on the couple. With Wife and I, I think it would've been good for her to be present through most of it, but I know that that's probably not completely possible either. You know, if you've got both of you's working and stuff... Yeah it is, it's really hard, I mean it's the same even with your Uni, trying to get time to do stuff and then, you know, anything else that crops up. Let alone if you had an injury that you're trying to cope with.

R1: "Yeah, I mean it's hard because people have got to get time off work and there's a commitment, but probably it could've done with being a wee bit longer I felt, just to have more time to discuss - - you know because we'd discussed a lot of things in the 3 previous weeks. We only really touched on the outside of a couple of them on the family day I think. You know more time could have been spent - - even though owing to the fact that people have got other things to do. Yeah, probably, I think they could've - - if they'd had a chance they could maybe have a bit more in-depth, rather than just touching over the top of it, you know."

CS: Mmmm. Are you thinking a chance for the family to share information or share their experiences, or were there particular parts of those three weeks that you wanted the team to talk about again on that family day do you think?

R1: Yeah, I think, I mean, we covered a lot of topics and, as I say, you can only just touch on briefly the background of some of them. I just felt maybe, you know, there could've been a wee bit more detail on some of the other stuff we had covered, you know. Because I think the likes... we discussed the meditation and relaxation, and maybe we didn't really get much chance to get into that individually too deeply on the family day that might've been helpful if we'd had more time on it.

R1: Ummm, within the constraints you'd have on people's ability to get time to go and do it, I think. It was done quite well, I don't think there's much... you know... I like to think... maybe a wee bit more time going into some of the things in depth would be helpful, but again other than that I wouldn't think - - I think it wouldn't need changing too much.

R4: but ummm... yes, I think something like that umm, aimed at ummm... incorporating the families a bit more and making them feel a bit more... or giving them a bit more information is definitely worthwhile.....

R13: (1100) Oh yeah, I definitely would, I think if a few of those things are taken into account, and geared it more towards the family a little bit, just for people and narrowed down the kids time. But yeah, absolutely.

R7: ... so I have that kind of ummm, family issue with... actually we're not able to tackle more in the programme.

CS: And were there any things at the end of the day that you thought I wish they had covered or wished they'd covered in a little bit more detail?

R2: No, actually 'cos, as I said, I thought it was great! And I wouldn't have said that usually... I thought it was... I thought it was great.

Subheading - The Involvement of Significant others is a balance

R4: I wouldn't want them involved you know daily or anything like that. I think it was really nice to have, just to have it sort of, you know, you can just be, you don't have any other expectations around you etc. ummm, and I think that was good, umm, yeah maybe on the first day you know, ummm the families are there, they are introduced and so on and so forth and then umm so that people know people in the context of families... maybe giving them a brief introduction right at the beginning to the course and what is happening and everything so that they feel umm some self inclusion and then send them off to a You Tube site umm which has a small mono blog or something which gives a small update ummm, everyday or, or you know once a week or something I don't know... Ummm, yeah so I'm talking about that sort of thing, not, ummm not hugely more, just enough one to make them feel included and two... just too... perhaps feed them sort of helpful information if you like hmmm...well maybe not updates, maybe just ummm, for them so there is a bit of a learning thing alongside... You know whether it be umm, sort of podcast or, or I don't know, some people would be limited in the technology but ummm, or whether it be through a You Tube site or have umm, or have a CD that they could, you know to ummm listen or watch during the, during the week or something like that. Something where they can

sort of grow in their knowledge and so forth at the same time as their person with pain is.”

R4: Well... and yeah... I mean... I think basically what, umm you know, from the course, the family got what was on that day and there was some teach which was good and it was interesting and so forth but then that was it you know and, and it was probably not, probably not quite half a day umm and I just think that it is too important a thing to limit to that ummm, it doesn't mean that it has to be, has to overrun the course either because I think, like I said earlier, you know, there was great value in ummm being able to concentrate and just be away from the family for the course as well so...(?) which just say might mean just those resources being available ummm ... which aren't part of the pain course as such. And just that....ummm I think, just... like what you were saying with the depression advertisement. Umm, I think a little bit of encouragement like that for the family can go a long way.”

CS: Ummhmmm. So do you think if they had counselling available for families through the programme that would be okay, or should it happen after the programme?

R7: I think after. After, because then umm, you know like sometimes, from my experience, you wouldn't know what you don't know, you know what's going on, until you've been through that. Like, umm, I remember Partner asking me, “What's wrong with you?” You know that kind of thing. I don't even understand what's going on with me; you know a lot is going on. I couldn't even say one thing you know because it's all complex. So I only learn about what I don't know - - is much later when I go to the counselling and I was able to see, oh, my issue actually is.... is something about my childhood actually, you know, the pain is affecting their relationship and actually at the time I'm having my peri menopause you know, I didn't know that I was having peri menopause... I mean. That, I think that would be really good afterwards, as well, because more or less you have the mental knowledge, then you will have the situation after the TARPS like what happened to me. Something really unexpected happened and to me also because I think it is a problem that I don't have resources to access counselling. I know that I needed counselling, but umm I said I do need that, and talk about it. Somebody other than, let's say, the person other than my sister or Partner because they are actually involved with my issues, and without wanting them to feel, wanting to... you're not moaning and complaining about them, but actually you want a grasp of what's going on and how to relieve... how do I do my.... how do I really start with assertive communication. You know how can I make the other person feel like I'm not really blaming but I just need to talk.”

Stage 5 – development of descriptions

As the central meaning of each of the themes became clearer, I developed description for each and selected supporting extracts from the coded data so that only those that I felt best conveyed the theme remained. The example below shows an early description that was developed for the theme heading ‘A look in’.

Extract - version 22

Theme heading: A look in

With the exception of one significant other who thought the Family Day “... *was great!*...” (R2) and had no suggestions for change; all the other participants considered that half a day was only long enough to give significant others a feel for what had happened in the programme. The overall feeling from participants was there ideally would be a “bit more” involvement of loved ones or the opportunity for more involvement e.g. in order to ask and obtain answers to questions and or work through issues of concern

R4: “...I, I think there is definite value in...you know the idea of it, it focusing in on the person with pain and setting up systems to help that person’s marriage and, and you know, possibly alleviate some of that pain. I think that’s good, but I think...possibly rather than just giving the family a look in on that... last day there was, there was a little bit of family systems stuff, you know a touch on that... But it was largely a look in I felt on what we had been doing and, and a little bit of information on the sort of cycles that people go through and, and stuff like that, but I think there could be more about...sort of, some sort of opportunity for families to work through the process a little bit more... so that the family feels that they are part of it as well....”

Participant varied in their thoughts on how much more significant others would ideally be involved, with their thoughts shaped around considerations regarding what might be feasible for significant others and beneficial for all. Some participants shared a wish to have significant others involved throughout the entire programme, however they also acknowledging that that might not be completely possible or helpful.

R3: “...Well, my ideal would be to be involved from day dot. I mean, I think that would be absolutely ideal...because I don’t think it can be done in a one, it’s not a sole deal unless you are truly solo, which none of us are, but you know, if there was some way of having it more integrated ... I would have gladly move heaven and earth to find to find a way to be at 3 weeks of that stuff with [my husband] because ...you know for our relationship, that’s, that’s life changing and

potentially... but I don't know how helpful that, I mean some of the content wouldn't have been relevant for me perhaps ... but certainly, a, a, much more hand 'n' hand approach. I think..."

Many of those with pain were also very clear that they would not want to have significant others directly involved in the whole programme, inclusive of the 1, 6 and 12 month follow up sessions, however they indicated that they would happy for other resources to be made available to loved ones throughout the course. Participants provided several reasons as to why they considered it useful to limit when and where significant others were involved. For one participant who had lived away from this family during the programme, it was about the benefit he had gained from the chance to be away from the distractions of family life and thus fully focus on the programme.

R4: *"... I wouldn't want them involved you know daily or anything like that. I think it was really nice to have...it sort of, you know, you can just be, you don't have any other expectations around you... I think...there was great value in being able to concentrate and just be away from the family for the course as well ... which just say might mean just...resources being available ... which aren't part of the pain course as such... I think a little bit of encouragement... for the family can go a long way..."*

Another participant described valuing the time and opportunities she had had during the programme to independently gain knowledge about herself and the areas that she needed to work on. This knowledge then gave her the words to communicate more effectively with significant others in a way that she did not feel that she could have done prior to counselling through the programme

R7: *"... from my experience, you wouldn't know what you don't know... what's going on until you've been through that. Like...I remember [my partner] asking me, "What's wrong with you?" You know that kind of thing. I don't even understand what's going on with me; you know a lot is going on. I couldn't even say one thing you know because it's all complex. So I only learn about what I don't know...much later when I go to the counselling and I was able to see, oh, my issue actually is.... is something about my childhood actually, you know... I think that [counselling] would be really good afterwards...because more or less you have the mental knowledge, then you will have the situation after the TARPS like what happened to me..."*

The third reason given was described in relation to the bond that forms amongst those who had shared the experience of the 3 week programme together. Because of the intimate knowledge that the group shared about each other, it was felt by one participant that the follow up sessions were a special time that was best done without significant others

R1: *“...I would think the follow-up and the group thing would be more just for the people. That’s something a wee bit special, you know, because you’re sharing that with people who really understand the situation you are in. So it wouldn’t have occurred to me you know, as a social occasion I wouldn’t say no, but in general terms I would view subsequent stuff as something I would do without the family just because of the... nature of it, the intimate knowledge you have about your pain and the other people, and I think for that you’re really looking, when you do that follow up... just to do amongst yourselves really...”*

When talking about what more involvement of significant others might look like, participants suggested having more sessions interspersed through the course of the programme and or the option of follow up to the Family Day. One participant also suggested that if the sessions were shorter it would make it easier to attend, as they would be *“...considered more of a meeting, than a half a day out...”* (R13). The option for more involvement from the outset of the programme was described by several of the significant others as a way to gain knowledge about what was going to happen in the programme and chronic pain, plus how they could support their loved one. A significant other living outside Auckland city also suggested that the provision of a prospectus at the outset of the programme would help to inform those with pain and their loved ones know what was going to happen in the programme

R3: *“ ...I could imagine for example, if the families... were part of the process from day one and got... you know a big picture kind of idea about how to work with what was going to happen, how to support our partners, how to work with what was about to happen and were given some reading material about how these... conditions affect your long-term relation dynamics, then... have a session say you know mid...week of the middle of the week or something, sometime during the process and then a final thing...you know that would be a reasonably doable and potentially really, really powerful process and the potential for follow up if you could swing it somehow...”*

Many participants felt that the option of either a group based or individualised follow up session after the Family Day i.e. for those with pain and their loved ones, would provide a useful opportunity to ask questions, debrief from the Family Day and work through any issues that had arisen.

R1: *“...Maybe on reflection, maybe you know it was a three-week programme so maybe... maybe after the second week it might’ve been an idea so that people would then still have another week to work on and the family could’ve seen what you do, and you’re not just walking away from it. It’s hard really to say but maybe on reflection, if you’d had it after two weeks so that people knew what was happening and the detail. Then when you’d finish your third week or whether you’re during that third week you’d get more questions because your family*

would understand you know... 'Cos I'd come home and just explain what had happened, but maybe... if you'd had the Family Day after a couple of weeks and people are well enough into the course to know what it is about, you'd still have time to do things to help if, you know, you'd get some benefit from the Family Day you hadn't thought before..."

or

R14: "...I reckon the only thing that they could probably get away with is maybe having it a couple of days before the end, and that gives you a couple of days to sort of talk it over with them and explain to them...Just how your family took it, where you go from here again. You know, like a reiteration, because now hopefully your family is sort of in on the recovery plan.... I think for me having my wife come along to the follow-up session would be a good thing...I'd like it to be very similar to what it would've been if it was just us...like, there'd be things that she'd like to ask, just sort of clarify from them. Yeah, maybe there might be a couple of trouble shootings or things that she might want to ask nurse herself that she wouldn't like me to relay....who knows, you know, but that's just sort of what I think..."

or

R16: "I think ummm, well they have what ummm, one-month, three-months, 6 months or something. I think on the last review day it would be nice to have the family again so you can see the progress and, you know, sort of round it up in that way...You know what's happened in the last year that's different and how you've improved and how you know - - that would be quite good."

Stage 6 – Refinement of themes and descriptions

Through the course of analysis each description was refined and supporting extracts replaced as appropriate i.e. as themes and sub-themes were refined. The example below shows the description for the theme heading ‘A look in’, after it had been refined. The process of refinement concluded in consultation with my supervisors and once a comprehensive description of the participants views on the involvement of significant others in the programme had been achieved.

Extract - version 27

Theme heading: A look in

Time and opportunities to address topics in depth were considered essential aspects to the involvement of significant others in the programme. With the exception of one participant who thought the Family Day “*was great*” (R2) and had no suggestions for change, all the other participants considered that half a day was only long enough to give significant others a feel for what had happened in the programme. The overall feeling from participants was that ideally there would be a “bit more” involvement of significant others woven into the programme to enable “*time to discuss... some of the things in depth*” (R1) and “*opportunity for families to work through the process a little bit more*” (R4). Sharing in the involvement of the programme was identified to generate discussion about what had been seen and experienced “*because now hopefully your family is sort of in on the recovery plan*” (R14). For this reason the opportunity for more than one contact point was felt to be valuable so “*you’re not just walking away from it*” (R1) and both those with pain and significant others had an opportunity to ask questions, debrief and work through any issues that had arisen.

R3: “ *...I could imagine for example, if the families... were part of the process from day one and got... you know a big picture kind of idea about...what was going to happen, how to support our partners, how to work with what was about to happen and were given some reading material about how these... conditions affect your long-term relation dynamics, then... have a session say... midweek of the middle...week...and then a final thing...you know, that would be a reasonably doable and potentially really, really powerful process and the potential for follow up if you could swing it somehow...*”

Participant varied in their thoughts on how much more significant others should be involved but all agreed that involvement required striking a balance between what might be feasible

for significant others amongst their other commitments and also beneficial. Just as it was recognised that each person's situation would be different, it was also acknowledged that the most beneficial balance would also vary from one person to the next. As one participant stated "*it really depends on the couple...*" (R14). While greater involvement of significant others was felt to important, many of those with pain expressed the wish that the involvement of significant others should not come at the expense of the benefits that they had obtained from the bond that they had developed with those whom they had shared the 3 week programme or the benefit that they had gained from the opportunity to focus on the programme, independent of their significant others. For example one participant with pain described having valuing the time and opportunities she had had during the programme to independently gain knowledge about herself and the areas that she needed to work on. This knowledge had then given her the words to communicate more effectively with significant others in a way that she did not feel that she could have done prior to counselling through the programme.

R7: "*... from my experience, you wouldn't know what you don't know...I remember [my partner] asking me, "What's wrong with you?" - you know that kind of thing. I don't even understand what's going on with me you know, a lot is going on. I couldn't even say one thing you know because it's all complex. So I only learn about what I don't know...much later when I go to the counselling and I was able to see, oh, my issue actually is....*"

Although those with pain had reservations about significant others being directly involved in the whole programme, inclusive of the follow up sessions, they felt that the opportunity for significant others to access other resources throughout the course would be of benefit.

R4: "*... I wouldn't want them involved you know daily or anything like that. I think it was really nice to have...it sort of, you know, you can just be, you don't have any other expectations around you... I think... there was great value in being able to concentrate and just be away from the family for the course as well ... which just say might mean just...resources being available ... which aren't part of the pain course as such... I think a little bit of encouragement... for the family can go a long way...*"