

**Patients' experiences of a clinical trial physiotherapy
programme for hip or knee osteoarthritis**

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Abstract

Osteoarthritis (OA) is the most common form of joint disease and the leading cause of pain and physical disability in older adults. New Zealand's population is ageing and by the late 2040s, the proportion of the population aged 65 years and over will have doubled.

This study aimed to capture the experiences of patients with OA participating in a physiotherapy clinical trial programme designed to reduce disability and pain.

A qualitative interview study was conducted. Sixteen individuals were recruited from the four intervention arms of a randomised controlled trial (RCT) and interviewed twice: once in the early stages of the intervention and post-intervention. A further five individuals who chose not to participate in the RCT were also interviewed on one occasion. Data were collected from the face-to-face interviews using open-ended questions. The interviews were transcribed verbatim and analysed using interpretative analysis.

Interview data contained three main themes, each with two subordinate themes. Theme one, *The OA Story*, provided a broad narrative of participants' experience of their OA condition. The subordinate theme *No Way Back* reflected how they experienced living with a progressive, deteriorating, painful joint condition; *Life Goes On* embodied the stoicism and perseverance required to cope with normal daily activities in the face of worsening pain and increasing loss of function. Theme two, *The Research Story*, reflected on participants' experiences of being in the RCT; *Give it a Go* represented the uncertainty of what the trial intervention could offer; *Shown a Signpost* captured the positive impact from participating in the trial. Theme three, *The Surgery Story* described joint replacement surgery (JRS) and the health system. *Light at the end of the Tunnel*, symbolised surgery as the cure-all option; *Waiting 'n' Hoping* signified the frustration with the health system and their OA.

In summary, the experience of living with a deteriorating and disabling condition shaped participants' beliefs about the necessity of JRS. The physiotherapy intervention "made a difference" in that participants felt more confident in coping and managing their OA. Despite this, for most, surgery was still perceived as the "fix it" for their condition.

Studying participants' stories provided some understanding of the lived experiences of people with OA and their expectations of a clinical trial physiotherapy programme. Osteoarthritis is a complex condition that presents with frequent discordance between the pathology, symptoms and disability. Physiotherapy interventions for OA are also complex in that they are made up of various interconnecting parts. This research has demonstrated that both quantitative and qualitative evidence is required to evaluate the complexities of living with OA and receiving physiotherapy interventions.

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List of Abbreviations

ACR	American College of Rheumatology
ES	Effect Size
EULAR	European League Against Rheumatism
NICE	National Institute for Health and Clinical Excellence
ICF	International Classification of Functioning
IPA	Interpretative Phenomenological Analysis
JRS	Joint Replacement Surgery
NAP	National Action Plan
NSAID	Non-Steroidal Anti-inflammatory Drug
NZ	New Zealand
NZOA	New Zealand Orthopaedic Association
OA	Osteoarthritis
OARSI	Osteoarthritis Research Society International
RCT	Randomised Controlled Trial
SR	Systematic Review
UK	United Kingdom
WHO	World Health Organisation

Chapter One

Introduction

1 Introduction

This chapter begins with a brief description of the researcher's clinical background followed by an overview of the key concepts, a statement of the aims of the study and a description of the structure of the thesis.

1.1 Clinical Background

As a manual therapist working in private physiotherapy clinics for twenty-five years, the researcher has been involved with the ongoing treatment and management of OA hip and knee problems. Physiotherapy treatment regimes for OA commonly incorporate manual therapy techniques in combination with exercise, education and a home programme of exercises. As with any therapeutic intervention (particularly for complex conditions) it is difficult to ascertain which component of the management is most effective. From observations of patients in clinical settings, the researcher became interested in finding out more about different aspects of the therapeutic relationship such as patients' beliefs and expectations of treatment. How do we as physiotherapists influence the outcome of treatment? Previous studies looking at the outcomes of physical interventions for OA have noted that psychosocial issues could account for the variance in health outcomes. (Barron, Klaber Moffett, & Potter, 2007; Sharma et al., 2003). Psychosocial factors such as mental health, self-efficacy and social support have been demonstrated to optimize physical function (Sharma et al., 2003).

To fully understand the efficacy of physiotherapy interventions for OA and define what constitutes a good outcome, awareness of patients' personal characteristics and how they influence health behaviour may need to be addressed. The patients' perceptions, beliefs and interpretation of an intervention, the meaning they ascribe to their symptoms and treatment, and their views on what constitutes an important outcome, may not be congruent with the health professional's model. People experience their illness in the context of their lives. Hampson, Glasgow, & Zeiss (1994) suggest that "personal models of OA are shaped by

personal experience with a disease, which includes encounter with health-care providers” (p.155). To gain more understanding of lived experience, the researcher was interested to explore the above concepts in relation to patients participating in a physiotherapy programme within an RCT.

1.2 Osteoarthritis

Osteoarthritis is a major cause of disability, activity limitations and distress in the older population worldwide. In the United States OA is the most common form of arthritis affecting millions of people (Jordan et al., 2000); in Canada 10% of adults are affected (Hall et al., 2008); in the United Kingdom it is the most important cause of physical disability and limitation for elderly people and a major challenge to the health care system (Turner, Barlow, & Ilbery, 2002). Osteoarthritis accounts for half of all chronic conditions in people older than 65 years. In New Zealand (NZ) it is estimated that approximately one-quarter of the population will be over 65 years of age by the late 2040s (Cornwall & Davey, 2004). Since OA is a disease whose prevalence increases with age, it is likely to become even more prevalent in the future as the bulging cohort of baby boomers grows older.

Osteoarthritis can occur in any joint but appears most frequently in the knee and hip joints (National Arthritis & Musculoskeletal Group, 2004): it is the most common reason for total knee and hip replacements. Because of its prevalence and the frequent disability that accompanies OA in the knee and hip, it accounts for more trouble with climbing stairs and walking than any other disease (Jordan et al., 2000). Osteoarthritis causes pain and impairment in body functions such as muscle strength, range of joint motion, and joint stability: it has a major impact on physical functioning in daily life and frequently leads to severe limitations in participation and decreased quality of life (Pisters et al., 2007).

1.3 Physiotherapy

Exercise and physical activity are promoted as effective, non-invasive intervention strategies to enhance health and function among people with arthritis (Jette & Keysor, 2003). Systematic reviews and treatment guidelines recommend exercise for managing pain and disability particularly in knee OA (Altman, Hochberg, Moskowitz, & Schnitzer, 2000; Fransen et al, 2009; Jordan et al., 2003; National Collaboration Centre, 2008; Zhang W, 2008). In Fransen and McConnell’s Cochrane Review of exercises for OA knee (2008), the

authors concluded that there was strong evidence for short-term benefits from therapeutic exercises in reducing pain and improving physical function in OA knee. The Cochrane review of exercises for the hip by Fransen, McConnell, Hernandez-Molina and Reichenbach (2009) found there was only a small treatment effect for hip pain and no benefit in terms of self-reported physical function. A recent NZ systematic review suggested that there is limited information to make conclusions regarding the efficacy of exercise for hip OA (McNair, Simmonds, Boocock, & Larmer, 2009). Jette and Keysor (2003) in their discussion paper on disability models argue that although exercise interventions appear to have many different beneficial health effects there is no consistent evidence to support the theory that improvements in musculoskeletal impairment decreases disability.

Anecdotally physiotherapy is the predominant non-pharmacological, non-surgical intervention for the management of OA in NZ, with exercise being one of the mainstays of physiotherapy. Treatment takes place mainly in hospital outpatient settings and to some extent in private clinics. Due to the costs involved with private clinics, most people seek treatment in the public health system. The use of exercise is universal to all physiotherapists: basic manual therapy techniques are taught at undergraduate level and developed as a speciality area with post graduate courses. The development of the RCT in Dunedin, New Zealand, with Dr Haxby Abbott as principal investigator, was an extension of recent studies looking at efficacy of manual therapy compared to exercise therapy. As quoted from the trial protocol, “new developments in manual physiotherapy have demonstrated very promising improvements in pain and physical function, but effectiveness has not yet been definitely established” (Abbott et al., 2009, p.2). Details of the RCT, in which this qualitative study is embedded, are given below.

1.4 The Physiotherapy Trial Programme

Patients enrolled in the RCT were allocated to receive either (a) a supervised multi-modal exercise therapy programme; (b) an individualised manual therapy programme; (c) both exercise therapy and manual therapy; or, (d) no trial physiotherapy (usual medical care only). The exercise therapy group received a supervised programme of warm-up/aerobic, muscle strengthening, muscle stretching, and neuromuscular control exercises, in addition to an individualised home exercise programme of similar exercises. The manual therapy participants received hands-on techniques, where manual therapy was defined as “the application of therapist-applied manual forces in procedures intended to modify the quality

and range of motion of the target joint and soft tissue structures” (Abbott et al., 2009, p.6). Participants were also instructed in an individualised home exercise programme of joint range of motion exercises. The combination therapy of both exercise and manual therapy interventions was as described above. The usual care group received no trial physiotherapy but continued to receive the usual care offered by their General Practitioner. Those randomised to the intervention arms received nine treatment sessions: seven in the initial nine weeks of the trial and two ‘booster’ sessions at week sixteen.

1.5 Why qualitative research?

It has been suggested that outcome studies such as RCTs have limited value in explaining why and how change occurs. RCTS are designed to test a priori hypothesis by isolating, defining, and testing variables. Sometimes the relationships are unknown or poorly understood. Their main focus is to establish a link between intervention and outcome; they are less able to explain the process by which the intervention is translated into the outcome (Jette & Jette, 1996). It is these dynamic aspects of health that qualitative research is best able to illuminate. Greenhalgh and Hurwitz (1999) have suggested that “narrative provides meaning, context and perspective for the patient’s predicament” (p.48) and encourages a holistic approach within the therapeutic process.

The findings of qualitative research acknowledge the importance of the context in which data are generated, interpreted and presented (Barbour, 1999): they also provide an opportunity to inform the results of quantitative studies. Campbell et al. (2001) provided an example of qualitative informing quantitative in their study exploring exercise adherence in OA knee. A qualitative interview study was nested within a RCT, examining the effectiveness of physiotherapy in reducing pain and improving mobility for OA knee. They found that adherence was influenced by individual’s perception of their symptoms, the perceived effectiveness of the exercise programme and their willingness to incorporate the treatment into everyday life.

How and why do patients make choices to proceed with joint replacement surgery or not? How do they decide the intervention was successful or beneficial? What beliefs do they hold around expectations of the physiotherapy intervention? These questions are best suited to research that can uncover issues of meaning and context, complex relationships and processes of decision-making. Qualitative research can provide this richness of understanding.

Qualitative methodologies also permit the participant to introduce concepts of importance, as opposed to being restricted to areas deemed important by the researcher: they provide opportunities for serendipitous findings to emerge, particularly in exploratory research areas (Turner et al., 2002).

This qualitative interview study was nested in the larger RCT and employed an interpretative phenomenological analysis (IPA) approach (Smith, 2003). The RCT provided an opportunity to explore patients' experiences of the impact of physiotherapy intervention. The RCT was designed to investigate the effectiveness – and cost-effectiveness – of physiotherapy interventions for patients with OA of the hip and knee. The physiotherapy programme was intended to decrease pain and disability, maybe to the extent that participants chose to delay surgery. Interpretative phenomenological analysis allows the researcher to capture and explore the meanings that participants assign to their experiences. Within the context of the interview study, this related to how they experienced their OA, the trial intervention and the impact of the intervention. Living with the complexities of chronic OA contains psychological and social dimensions which require multiple understandings of how participants view their own particular situation. The focus of quantitative research is on 'knowing' whereas qualitative research is concerned with 'understanding' (Lempp & Kingsley, 2007). Interpretative phenomenological analysis allows the researcher to make interpretations that discuss meaning, cognition, affect and action, developed around a central account of the participants' experiences (Brocki & Wearden, 2006). Understanding the way in which the physiotherapy intervention was experienced provides a broader context for interpretation of the RCT results as well as some insight into the patients' social processes as they relate to health care interventions.

Expectations about treatment and outcome are an integral part of the psychosocial makeup of each individual patient; they have been shown to be directly linked to health outcomes and patient satisfaction (Barron et al., 2007). Hill and Kitchen, (2007) explored the theory of patient satisfaction with physiotherapy (focusing on musculoskeletal conditions in outpatient settings), and concluded that the two concepts of need and expectations are of particular importance in the physiotherapeutic context. They embody a range of factors such as previous experiences, the presenting condition, social background and personality. Exploring the patients' experience of a physiotherapy intervention (their perceptions, beliefs and expectations) may also provide a clearer understanding of how the intervention can achieve greater positive impacts on function and disability.

Few projects have focused entirely on exploring patients perspectives of a physiotherapy intervention. There is a lack of published research to inform and elucidate patient experiences of what impact physiotherapy interventions have in the context of a clinical trial.

1.6 Research Aims

The primary aim of this study was to learn about the experience of living with and receiving treatment for OA of the hip or knee, in the context of a clinical trial setting, by exploring: (1) peoples' beliefs about their OA condition and (2) their perceptions and expectations of the physiotherapy programme offered within the trial setting. The secondary aim was to explore the perceptions of people with OA who chose not to participate in the trial programme.

1.7 Structure of the thesis

The remainder of this thesis has been organised into four chapters. *Chapter two: Literature Review* provides a review of contemporary literature. *Chapter three: Methodology* presents the theoretical underpinnings of this project and describes the research design and method employed. *Chapter four: Results* describes the participants and presents the qualitative findings from interview data. *Chapter five: Discussion* discusses the findings in relation to existing literature followed by limitations of this project, personal reflections and clinical recommendations. Chapter five concludes with a summary of the main findings.

Chapter Two

Literature Review

2 Literature Review

The following literature review has focused initially on the wider management of OA with reference to international guidelines and the quantitative literature, followed by an exploration of the qualitative literature around peoples' experience of OA.

2.1 What is Osteoarthritis

Osteoarthritis is not a simple disease entity but refers to a clinical syndrome of joint pain accompanied by functional limitation and reduced quality of life: broadly, it can be defined as a *common complex disorder* with multiple risk factors (National Collaboration Centre, 2008). It is by far the most common form of arthritis and one of the leading causes of pain and disability worldwide (National Collaboration Centre, 2008). Any synovial joint can develop OA but the knee is the most commonly involved, followed by the hip (Jordan et al., 2000).

Osteoarthritis is a metabolically active process that involves all of the synovial joint tissues – articular cartilage, subchondral bone and synovium, capsule, ligaments and muscle. Pathologically, this condition is characterised by progressive hyaline articular cartilage loss with concomitant remodelling of adjacent bone, development of osteophyte formations at the joint margins and joint space narrowing (Hendry, Williams, Markland, Wilkinson & Maddison, 2006; Sharma et al. 2003). Soft-tissue changes can include synovial inflammation, ligament laxity, and weakened bridging muscles (Jordan et al., 2000; National Collaboration Centre, 2008). Clinically, this may present as joint pain and stiffness, loss of joint mobility and function, swelling and altered joint shape. The clinical presentation of OA usually evolves over an extended time period.

Historically, OA has been divided into primary and secondary forms. Secondary OA refers to degenerative disease of the synovial joints that results from some predisposing condition, usually trauma, that has adversely altered the articular cartilage and/or subchondral bone of the affected joints. Secondary OA often occurs in relatively young individuals. The definition

of primary OA is more nebulous. Although primary OA is associated with aging process and typically occurs in older individuals, it is essentially an idiopathic phenomenon, occurring in previously intact joints and having no apparent initiating factor. Some clinicians limit primary OA to the joints of the hands (specifically the DIP and PIP joints and joints at the base of the thumb), whereas others include the knees, hips, spine, and hands as potential sites of involvement. As underlying causes of OA are discovered, the term primary, or idiopathic, OA may become obsolete (Lozada, 2011).

The cause of OA is not completely understood, however, it is thought to be a complex, adaptive response of the joints to local biomechanical factors (such as muscle weakness, obesity and joint laxity), genetic and environmental stresses (including dietary intake, and bone density) (Jordan et al., 2000). The point of onset of OA is largely undetectable. Markers of the disease tend to be pathological changes within the synovial joints (with or without X-ray changes) and symptoms, in conjunction with self-report of the condition. However pathologic and radiographic evidence of OA does not necessarily predict the onset of symptoms or patient distress and disability. Currently there is no validated system for identifying stages of the condition based on the physical findings or symptoms of OA (WHO, 2003). Joint X-ray changes (evidence of structural and pathological change) do not correlate well with the levels of pain and disability experienced by an individual: not all people with X-ray changes have symptoms and not all people with symptoms have X-ray changes (Bedson & Croft, 2008; WHO, 2003). However, in individuals with a long history of persistent symptoms there is a more consistent association (particularly at the knee) between severity of pain, stiffness and physical function and radiographic OA changes (National Collaboration Centre, 2008): concordance between symptoms and radiographic OA seems greater with more advanced structural damage. Overall, radiological changes in knee and hip OA tend to occur late in the disease process; more than 50% of people aged over 65 years have radiological evidence of OA (Felson & Zhang, 1998).

Progression of OA is associated with a range of extrinsic and intrinsic risk factors which ultimately impact physical functioning and quality of life issues. These risk factors include family history, female sex, obesity, ageing, joint trauma, characteristics of prior occupational and recreational activities and muscle weakness (National Collaboration Centre, 2008). In addition the majority of people with OA have at least one co-morbid condition. Those commonly associated with OA include depression, peripheral vascular disease, renal disease,

hypertension, obesity and diabetes (National Collaboration Centre, 2008). Co-morbidity is associated with lower health-related quality of life and a higher level of disability in people with OA (National Arthritis & Musculoskeletal Group, 2004). Ayis and Dieppe (2009) explored determinants of change in functional status over time and found that deterioration in knee and hip disability were significantly associated with older age, lower socio-economic living, the presence of three or more co-morbidities, more problems with physical function at baseline and more severe pain. Obesity is an established risk factor for progression of knee OA and to a lesser extent hip OA, with the incidence higher in women than men (National Arthritis & Musculoskeletal Group, 2004). Age is one of the strongest predictors of OA development with the prevalence of OA rising with age (Felson et al., 1995). Many of these environmental and lifestyle risk factors can potentially be modified which has important implications for secondary and primary prevention of OA (National Collaboration Centre, 2008). Hampson (1997) suggested lifestyle factors (for example, diet, inadequate exercise and smoking) are ultimately involved in the management of chronic conditions like OA, but the varying ability of people to make recommended lifestyle changes has implications for effective interventions. She states the importance of “understanding these individual differences so that interventions can be developed to accommodate them...” (Hampson, 1997 p.402).

2.2 The Burden of OA

Osteoarthritis is a major cause of disability, activity limitations and distress in the older population worldwide. It has been estimated that around 10% of people 60 years of age and older report significant problems as a result of OA, with 40% of people older than 70 years suffering from OA of the knee (WHO and the Bone and Joint Decade, 2000, cited in Marcinkowski, Wong, & Dignam, 2005). In the United States OA is the most common form of arthritis affecting millions of people (Jordan et al., 2000); in Canada 10% of adults are affected (Hall et al., 2008); in the United Kingdom (UK) it is the most important cause of physical disability and limitation for older adults and a major challenge to the health care system (Turner, Barlow, & Ilbery, 2002). Increases in life expectancy and ageing populations are expected to make OA the fourth leading cause of disability by the year 2020 (National Arthritis & Musculoskeletal Group, 2004). Osteoarthritis will become a larger public health problem not only because it is a manifestation of ageing but because it usually takes several years to reach clinical relevance.

There are inherent difficulties in determining the exact incidence and prevalence of OA due to the problems in defining the condition and its point of onset (National Arthritis & Musculoskeletal Group, 2004; National Collaboration Centre, 2008; WHO, 2003). Despite these difficulties, some clear prevalence patterns have emerged from epidemiologic studies of OA. As noted above, OA is known to increase with age. The incidence of symptomatic hip and knee OA is reportedly twice as high among women compared to men. The wider literature suggests there is higher incidence of symptomatic OA among women in all age groups compared to men, particularly knee OA. Statistics from the UK suggest that half of adults aged 50 years have symptomatic radiographic OA of the knee with the larger proportion being women (National Collaboration Centre, 2008). Radiological evidence alone demonstrates that the prevalence of OA increases with age in all joints in men and women: more than 50% of people aged over 65 years have radiological evidence of OA (Felson et al., 1995; Felson & Zhang, 1998). The number of people with OA is also increasing as the prevalence of risk factors such as obesity and poor levels of physical fitness continues to rise. In western populations the estimated prevalence for hip-joint OA is between 1% and 11% (Felson & Zhang, 1998 cited in McNair et al., 2009). On the basis of symptoms alone (pain being the most common symptom), the prevalence of knee OA is approximately 3% to 11% (Felson & Zhang, 1998).

The number of people with OA disability is expected to double by the year 2020, thereby increasing the already significant economic burden of OA (Gupta, Hawker, Laporte, Croxford, & Coyte 2005). At an individual level people with OA incur higher health-related costs; they tend to use healthcare services at a higher rate than the general population and incur more costs associated with the care of co-morbid conditions. Gupta et al. (2005) looked at the cost of OA from the perspective of individuals with disabling hip and knee OA. Costs incurred were mainly for time lost from employment and leisure, and for unpaid informal caregivers. Costs increased with worsening health status and greater OA severity. The authors suggested that failure to value such indirect costs significantly underestimates the true burden of OA. In the UK two million adults visit their General Practitioner each year because of OA (National Arthritis & Musculoskeletal Group, 2004). In 2002-2003 OA was the second most commonly reported chronic condition in the primary care setting in Australia (National Arthritis & Musculoskeletal Group, 2004). Studies confirm the high personal economic burden to those who suffer from OA (Gabriel et al., 1997 & Lapsley et al., 2001, cited in Gupta et al., 2005) as well as the immense socioeconomic burden: OA is responsible for a large number of physician visits, hospitalizations, time lost from work and medical,

pharmaceutical and imaging costs (Juby, Skeith & Davis, 2005; National Arthritis & Musculoskeletal Group, 2004).

Australian researchers Busija, Buchbinder and Osborne (2009) argue that monitoring the population's prevalence of arthritis is an important part of developing strategies to reduce the impact of this condition. In Australia the estimated costs of arthritis due to health care and lost productivity is between 1-2% of the gross domestic product. Busija et al. (2009) suggest that obtaining information on the specific limitations that people experience with this condition highlights the extent and nature of the arthritis burden, and supports health initiatives and the design of future interventions.

The best method of measuring community prevalence is through well-designed clinical studies of populations, preferably longitudinal and prospective (Access Economics, 2005). In the absence of such clinical studies, the Ministry of Health's New Zealand Health Survey provides best estimate data. The age-gender distribution of self-reported prevalence rates in NZ are broadly similar to those reported in other community-based surveys (Access Economics, 2005): arthritis is more prevalent in older age groups, and is generally more prevalent in women than men (Access Economics, 2005 & 2010). Possible increases in future prevalence rates for NZ may be influenced by a marked increase in risk factors, in particular obesity. Between 1977 and 2003 the population classified as obese in NZ doubled (Ministry of Health, 2004b).

The term 'burden of disease' refers to the impact of pain, suffering, disability and premature death resulting from disease and injury. Based on prevalence growth estimates in arthritis between 2005 and 2010, it was estimated that in 2010 OA accounted for approximately 70% of the burden of disease in NZ (Access Economics, 2010). In financial terms, the estimated inpatient cost for 2010 was \$99.9million: 40% of this figure related to OA hip and 31% OA of knee (Access Economics, 2010). In 2003-4 OA of the hip and knee alone accounted for over 70% of total public inpatient costs.

The impact of OA is considerable both to individuals and society. A substantial body of literature documents the high personal burden of arthritis with adverse impacts on health and functioning for individuals and poor quality of life (Busija et al., 2009; National Arthritis & Musculoskeletal Group, 2004; National Collaboration Centre, 2008). Osteoarthritis of the hip and knee reduces people's mobility and accounts for more trouble with climbing stairs and

walking than any other disease: it is the most common reason for total hip and total knee replacement (Jordan et al., 2000). In older adults joint pain is more likely to result in participation restriction in areas of life such as social contact. Eighty percent of people with the condition have some degree of limitation of movement and 25% cannot perform their major activities of daily life (WHO, 2003). At a societal level there is lost productivity and significant costs associated with ongoing care and management. With increasing life expectancy and ageing populations, OA can be expected to have significant negative impacts on western economies (National Collaboration Centre, 2008).

2.3 Management of OA – overview

In a recent study by Thorstensson, Goberman-Hill, Adamson, Williams, and Dieppe (2009), disability appeared to be a more important determinant of help-seeking than pain severity or anxiety and depression, for adults with chronic pain in hip or knee. Pain severity was important but not as influential as mobility difficulties in determining help-seeking behaviour. The wider literature suggests that pain severity is the major symptom associated with OA and the most frequent reason for patients to present to their health practitioner, with over half of people saying pain is their worse problem (National Collaboration Centre, 2008). Persistent joint pain, particularly in the knee and hip joints, is a major contributor to disability in people with OA. Other factors and determinants contributing to disability include disease duration and severity, age, co-morbidities and psychosocial factors including depression, anxiety and helplessness (Botha-Scheepers et al., 2006; Sharma et al., 2003).

The broad aim of current treatment strategies for OA is to relieve symptoms (in particular pain), promote self-help strategies, improve physical and mental health, and quality of life. It has been suggested that optimal treatment requires a combination of pharmacological, non-pharmacological interventions and surgical management (Zhang, 2007; National Collaboration Centre, 2008; Jordan et al., 2003; Altman et al., 2000). The following section in the chapter will look at these optimal treatments within the context of international guidelines designed for the management of OA.

2.4 Guidelines

The American Institute of Medicine has defined clinical guidelines as "systematically developed statements to assist practitioner and patient decisions about appropriate health care

for specific clinical circumstances” (Steven, Grol, Hutchinson, Eccles, & Grimshaw, 1999, p.527). Clinical guidelines can potentially benefit healthcare professionals by improving the quality of clinical decisions: they offer explicit recommendations for clinicians about how to proceed. Guidelines based on a critical appraisal of scientific evidence (evidence based guidelines) help to clarify which interventions are of proved benefit and document the quality of the supporting data. Steven et al. (1999) suggested that patients also benefit from clinical guidelines, in that interventions of proved benefit are promoted which have the potential to improve quality of life and the consistency of care. Overall, clinical guidelines are a tool to promote best practice and optimal management of a condition.

For the purposes of this thesis, four recent guidelines were located, developed by the European League Against Rheumatism (EULAR) (Jordan et al., 2003); the American College of Rheumatology (ACR Update) (Altman et al., 2000); the Osteoarthritis Research Society International (OARSI) (Zhang et al., 2008); and the National Institute for Health and Clinical Excellence (NICE) (National Collaboration Centre, 2008). These guidelines were chosen because they are recognised international guidelines for OA used in the literature. They also represent countries with similar demographics to NZ, particularly with respect to ageing populations. The ACR Update recommendations (2000) were included in preference to the older 1995 ACR Guideline publication. The EULAR recommendations (2003) for the knee were included over the EULAR (2005) hip recommendations because of the predominance of published evidence relating to OA knee. Neither Australia nor NZ has developed their own guidelines, but Australia has incorporated recommendations for the prevention and management of OA in a National Action Plan (NAP) document. The NAP was developed to “guide” governmental agencies in determining and promoting a range of activities (at a national level) designed to deliver better health outcomes. New Zealand has a health strategy but musculoskeletal disease and arthritis in particular are not mentioned explicitly. Given the increasing burden of disease this may need reviewing.

Guidelines for the management of OA of the knee and/or hip have been developed to summarise evidence and facilitate the uptake by clinicians. Whilst there is general agreement among the recommendations contained in the above guidelines, it is worth noting how the guideline development methodologies differ. Increasingly guidelines are being scrutinised for issues such as stakeholder involvement and applicability. Lack of stakeholder involvement during the development processes has been shown to influence applicability of the guidelines and the uptake or not by end users (Poitras et al., 2007). Following a critical appraisal of

twenty-three guidelines Zhang et al. (2007) concluded hybrid guidelines, those that combine research evidence with expert opinion, are significantly better overall. Within the scope and limitations of such guidelines, attempts have been made to define core sets of treatment for OA, but to date there are no generally accepted sets (Zhang et al., 2008). OA is difficult to treat given the wide range of symptoms that present over an indeterminate time frame; inevitably a plethora of therapies have been advocated and published in the guidelines (Zhang et al., 2007).

The OARSI guideline was developed as recommendations for the management of hip and knee OA and the EULAR guideline for the knee. Although both guidelines had multinational committees with experts from Europe and North America, the committee members were predominantly rheumatologists. The ACR guideline (2000) was developed by an ad hoc committee of four North American physicians as an update of the ACR Guidelines for the Medical Management of Osteoarthritis published in 1995. Search strategies for all three guidelines focused on systematic reviews (SR) and experimental studies; the strongest weight was given to data from these sources and in the absence of research evidence, expert consensus was utilised. In contrast, the NICE guideline was developed by a stakeholder group that included physiotherapists, occupational therapists, individuals with OA and carer representatives, thereby including patient views and preferences: it was developed as a national clinical guideline for the care and management of OA in UK adults, advocating a holistic approach to OA assessment and management. This was reflected in the inclusion of seventeen observational studies to investigate patient experiences of OA and its treatments. The NICE guideline emphasizes that effective quality healthcare for OA requires a good knowledge of the context within which specific interventions are delivered.

The OARSI guideline generated twenty-five recommendations based on the critical appraisal of existing guidelines, SR of research evidence and expert consensus (Zhang et al., 2008). Recommendations covered the use of twelve non-pharmaceutical modalities which included education and self-management, referral to physiotherapy, aerobic, weight reduction, muscle strengthening and water-based exercises: eight pharmacological modalities were recommended including the use acetaminophen (paracetamol), topical NSAIDs and intra-articular injections; TJR was included as part of the five surgical modalities. The recommendations were presented in a table along with the level of evidence supporting them, the effect size (ES) for pain relief, the extent of consensus and the strength of recommendation for each proposition. The strength of recommendation for each proposition

was designed to reflect the “overall clinical effectiveness of the therapy in question” (Zhang et al., 2008, p. 153). The ES for pain relief was synthesized and overall there was no statistically significant difference between non-pharmacological therapies (ES=0.25) and pharmacological therapies (ES=0.39), although it was noted that ES for pain relief varied from treatment to treatment. Effect sizes are a useful way to interpret changes in health status in relation to a specific intervention; the accepted criterion for a large clinical effect is 0.80 (Zhang et al., 2007). The main, general recommendation of the OARSI guideline combines pharmacological and non-pharmacological treatments (usual clinical practice) which are largely based on expert opinion (Zhang et al., 2008). Zhang et al. (2007) acknowledges that evidence-based guidelines like the OARSI, tend to have lower applicability than hybrid guidelines.

The NICE guideline was developed using clinical evidence-based questions which guided and informed the systematic search for evidence in the literature. The guideline recommendations were presented in the form of evidence statements corroborated by tables. Individual treatment modalities (e.g. hydrotherapy) headed up the tables: each table provided headings for specified outcomes (e.g. pain), reference (e.g. RCT), the intervention, assessment time frame and outcome/effect size. The guideline provided an integrated approach using “key messages” and “key priorities for implementation” to inform the holistic assessment and treatment algorithms. Treatment options were presented in four groups namely pharmaceutical options, self-management techniques, surgery and other non-pharmaceutical treatments.

The following section will discuss OA management with reference to the guidelines and relevant literature, under the headings of non-pharmacological modalities, pharmacological management and surgical management.

2.4.1 Non-pharmacological modalities

Non-pharmacological interventions are recommended as the first line of treatment for hip and knee OA by the above international guidelines and are perceived as the cornerstone of OA management (Altman et al., 2000; Jordan et al., 2003; National Collaboration Centre, 2008; Zhang et al., 2008). The new recommendations in the ACR update (2000) re-emphasize non-pharmacologic measures as the foundation of OA management symptom. The guidelines make it clear that the initial focus should be on self-help and patient-driven treatments

including aerobic exercise, strengthening exercises, education, self-management. In addition, access to information and advice (education), and weight loss where appropriate, have also been recommended. However there is still insufficient evidence about many these interventions to make specific recommendations regarding management of OA (Abbott et al., 2009).

In their SR of randomized controlled trials Zhang et al. (2007) reported that in general non-pharmacological therapies have smaller ES than pharmacological therapies, meaning their effect on measured clinical outcomes was not as significant. For improvements in function and relief of pain with education and self-management the effect size was very small (ranging from 0.06 to 0.12). In spite of this, self-management was uniformly recommended as a core recommendation in the guidelines critiqued by Zhang et al. (2007). Self-management programmes remain one of the tenets for managing chronic conditions such as OA. Programmes include patient education that aim to impart knowledge and skills to individuals so that they may better manage their arthritis (Osborne, Buchbinder & Ackerman, 2006). There is also an increasing demand (from individuals with OA, families and carers) for education in developing problem-solving skills and confidence, and motivational activities needed to effectively undertake the ongoing day-to-day management of OA (National Arthritis & Musculoskeletal Group, 2004). The limited evidence for self-management in the literature may be more a reflection on the range and diversity of outcomes measured, in addition to the lack of studies (in particular qualitative research) exploring key concepts such as self-efficacy and wider psychosocial factors.

Exercise

Therapeutic exercise in various forms has been well established as one of the core treatment modalities particularly for OA knee, but there is still little knowledge about the specifics of an optimal exercise regime – that is, which forms of exercise are most effective (Abbott et al., 2009). The four guidelines referred to in this chapter identify muscle strengthening, aerobic fitness and range of motion exercises as being important. There are many SRs that have specifically addressed exercise therapies for OA knee but the optimum delivery mode, contents of programmes and doses of exercise are still unknown. The recommendation that patients with OA knee undertake regular aerobic walking exercises and home-based quadriceps muscle strengthening exercises is a core recommendation in a large number of published guidelines and SRs (Zhang et al., 2008). Pooled effect sizes for pain relief are in

the moderate range for both aerobic (ES 0.52) and muscle strengthening exercises (ES 0.32). These findings were confirmed by two recent meta-analysis of RCTs tabled in the NICE guideline (Roddy et al., 2005a & 2005b cited in National Collaboration Centre, 2008). Data for exercises for OA hip are very limited; there have been very few RCTs to date. Recommendations for patients with hip OA to undertake regular aerobic and muscle strengthening exercises is largely based on clinical expertise.

Systematic reviews are utilized to update clinical practice and commonly form the basis of treatment guidelines. The following section is a critical look at the quality of evidence from some SRs in relation to therapeutic exercise for OA knee and/or hip.

Jamtvedt et al. (2008) conducted an overview of SRs to look at physical therapy interventions for OA knee and concluded there was high-quality evidence that exercise (and weight reduction) reduce pain and improve physical function. The inclusion criteria were very broadly defined with pain and physical function as the primary outcomes. Physical function was defined as for the ICF and included body function, body structure, activities and participation (WHO, 2001). Reviews on patients with generalized OA were included if the results from knee OA could be extracted separately. Of the twenty-three SRs reviewed nine examined the effect of exercise on OA knee; four of these were rated as high quality evidence with minor limitations. Although the four were reported as SRs, three were meta-analyses and one SR. Two meta-analyses provided descriptive summaries: the first (21 RCTs, 18 knee) concluded that strengthening exercises reduce pain and improve strength, function, and quality of life; the second (12 RCTs, 11 knee) concluded that aerobic exercise (different forms) is better than no exercise for OA knee. The third meta-analysis (17 RCTs) examined exercise for hip or knee and compared land-based exercise with a control intervention; they demonstrated small ES's (0.31 to 0.39) for land-based exercise to reduce pain and function (Fransen, McConnell & Bell, 2001). The SR (13 RCTs) demonstrated a moderate pooled ES (0.52) for aerobic walking to reduce knee pain and a small pooled ES (0.32) for quadriceps muscle strengthening to reduce knee pain (Roddy, Zhang & Doherty, 2005). The variability and limited specific information in the reported results perhaps questions the usefulness of the findings. Although the authors' concluded that overall the evidence for exercise was high-quality, the results show small to moderate clinical effects over a range of unspecified exercises and a range of delivery modes.

Other methodological issues, such as the possible difference in definition of physical function in the SRs also question the strength of evidence. Providing an 'overview' limited the amount

of information available to make any specific clinical recommendations and as noted by the authors themselves, was possibly too broad to be useful for clinicians.

Pisters et al. (2007) conducted a SR to determine the long-term efficacy of exercise therapy for patients with OA hip or knee. Pain was used as an outcome measure in all eleven studies reviewed and self-reported physical function in ten. However the authors noted there was a wide range of different measures used to assess both outcomes in the primary studies, which to some extent, compromised the evidence synthesis. The authors concluded that the positive post-treatment effects of exercise therapy on pain and physical function in patients with OA of the hip and knee are not sustained long term. They also noted that most included studies investigated a standardised exercise programme (content, dose, and delivery mode), which did not reflect the reality of exercise programmes delivered by physiotherapists in daily practice, that is individualized exercise regimes based on patients' functional status. Results of the SR did not differentiate between the knee and hip for outcomes: of the eleven studies, three examined hip and/or knee OA, one hip only and the remaining seven, knee OA. Four of the RCTs had very small participation numbers.

A recent New Zealand SR by McNair et al. (2009) looked at exercise therapy for the management of hip OA. The authors found few well designed studies that specifically investigated exercise therapy for OA hip. Studies were restricted to patients with hip OA solely and exercise therapy had to be used as an intervention with a corresponding control or comparison group. The primary outcome measures used to evaluate the efficacy of each intervention were grouped into self-reported pain, hip function and quality of life; again the authors identified there was a range of outcome measures used by the primary studies. The range of exercise interventions included hydrotherapy, land-based mobility and stretching exercise, strengthening exercises and gait and balance exercises. It was concluded that there was insufficient evidence to support exercise as a treatment to decrease pain, improve function or improve quality of life.

2.4.2 Pharmacological management

Appropriate pharmacological analgesia forms one of the key platforms for pain management in OA when non-pharmacological therapy on its own is insufficient (Altman et al., 2000; Jordan et al., 2003; National Collaboration Centre, 2008; Zhang et al., 2008). The use of such analgesia may aim at different aspects of the patient's pain, including night pain or exercise-

associated pain. There is good evidence from RCTs on the efficacy of paracetamol (acetaminophen) for the relief of mild to moderate in knee OA, in addition to core treatment. The place of paracetamol in early pain management (particularly of OA knee) has been confirmed because of its overall cost and efficacy (Zhang et al., 2008; Jordan et al., 2003). However, the evidence for long-term use remains equivocal (Zhang et al., 2008). International guidelines also suggest early consideration of topical non-steroidal anti-inflammatory drugs (NSAIDs). Topical NSAIDs have been advocated ahead of oral NSAIDs, COX-2 inhibitors or opioids, if stronger pain relief is required (National Collaboration Centre, 2008). For knee or hip joint OA there is strong clinical trial evidence for short-term usage of both traditional NSAIDs and COX-2 selective agents in reducing the pain and stiffness (National Collaboration Centre, 2008; Zhang et al., 2008). In Zhang's critique article (2007), although the level of evidence from RCTs and the strength of agreement showed acetaminophen (paracetamol) had the highest recommendation, the effect size for pain relief with oral analgesics were small; for acetaminophen (ES 0.21) and NSAIDS (ES 0.32).

2.4.3 Surgical management

Demand for total hip and knee replacement surgery is increasing worldwide and this trend is projected to continue (National Arthritis & Musculoskeletal Group, 2004). Guideline recommendations for TJR, for both hip and knee, tend to be based on expert-guided consensus because of methodological and ethical problems of conducting randomised studies on surgical procedures; most of the evidence is either from observational studies or expert opinion. Although demand and frequency of joint replacement continues to rise there is very little evidence on which to base decisions about which patient to refer (National Collaboration Centre, 2008). The guidelines are in agreement that referral for joint replacement surgery should be considered for people with OA whose quality of life is severely compromised (Altman et al., 2000; Jordan et al., 2003; National Collaboration Centre, 2008; Zhang et al., 2008). Although there is widespread use of orthopaedic scores and question-based assessments, these measures have not been validated as appropriate tools for deciding who should be referred for surgery. Similarly, because of the poor correlation between X-ray appearances and symptoms, X-rays are also not reliable indicators for making referral decisions. There is also no evidence to support people being excluded from surgery because of age, gender, smoking, obesity or co-morbidities (National Collaboration Centre, 2008). The NICE guideline suggests that ultimately it is the patient who must decide on their own

risk-benefit based upon the severity of their symptoms, their general health, their expectations of lifestyle and activity and the effectiveness of any non-surgical treatments (National Collaboration Centre, 2008).

The Australian National Action Plan suggest that in order to maximise the benefits, JRS needs to be considered relatively early in the course of OA. Poorer pre-operative physical function and high baseline pain scores are predictive for worse function and pain outcomes following hip and knee replacement surgery. While the timing of JRS appears to be critical to its success, there are no validated criteria for the optimal timing of the procedure (National Arthritis & Musculoskeletal Group, 2004). Total joint replacement is seen to be an effective intervention for OA, improving mobility and relieving pain, and is cost-effective for patients with significant symptoms and reduced health-related quality of life (Altman et al., 2000; Jordan et al., 2003; National Collaboration Centre, 2008; Zhang et al., 2008).

In common with a number of health systems, NZ has waiting lists for elective surgery such as total hip and knee joint replacement. In December 2009, a press release by the NZ Orthopaedic Association (NZOA) strongly urged the government to ensure New Zealanders continued to access elective surgery, especially joint replacement (“NZers’ continued access to elective surgery”, 2009). In a 2008 press release, the president of the NZOA was quoted as saying...“joint replacements offer perhaps the greatest improvement in quality of life of any surgical procedure available today” (“11,500 extra joint replacements recognised, 2008). The same article goes on to describe a collaborative project between the Ministry of Health and the NZOA (the ‘National Joint Initiative’) reflecting the government’s commitment to JRS: extra funding was provided for hip or knee joint replacements over a four year period (“11,500 extra joint replacements recognised, 2008).

2.5 The Influence of Psychosocial Factors

It has been demonstrated that ...“the outcome of medical care for patients with chronic physical illness is determined to a considerable extent by nonmedical factors” (Kaptein et al., 2010, p.56). Kaptein et al. (2010) examined the association between changes in illness perceptions and changes in functional status over a 6-year follow-up period for patients with OA. They noted that over time with deterioration of functional abilities, patients perceived they had less control over their condition and experienced a higher emotional load regarding their OA: a more negative illness representation was associated with reduced functional

status. There is a growing body of research that suggests that global needs of the individual, for example psychosocial and personal factors such as feeling old, depression, anxiety and relationships, should be addressed if healthcare interventions are to be truly effective. The NICE guideline (2008) provided a wider context for evidence-based recommendations on treatments. They investigated patient experiences of OA and developed evidence statements from reviewing observational and qualitative studies. The guideline advocates the need for a 'holistic' approach to assessment and management of OA, in recognizing that every patient brings their thoughts, health beliefs, experiences, concerns and expectations to a consultation.

With regard to physiotherapy the assumption inherent in interventions such as therapeutic exercise (usual practice for physiotherapy treatments), is that improvement in musculoskeletal impairments will result in reduced disability; that is the ability to negotiate physical environments and participate in social role activities (Jette & Keysor, 2003). For example, an individual with knee OA and subsequent pain, poor aerobic capacity and muscle weakness may be instructed in an exercise programme to increase strength, flexibility and aerobic capacity; that is target impairment outcomes as a means of minimizing future disability. This approach does not necessarily take account of the influence a person's social and psychological context has on functional outcomes and disability nor factors such as patients' model of illness, health perceptions, experience of symptoms and their preconceived perceptions of the benefits or not, of exercise.

2.6 The Experience of OA

The qualitative study that is the focus of this thesis was nested within a larger RCT which investigated the long-term effectiveness and cost-effectiveness of a physiotherapy management programme designed to reduce pain and disability in adults with hip or knee OA. There is a growing body of knowledge exploring lived experience of OA, but to date there has been very little qualitative research conducted on the beliefs and experience of people with OA in relation to therapeutic interventions, particularly physiotherapy. An extensive literature search conducted in MEDLINE, CINAHL, EMBASE and PsycInfo and Google Scholar for studies published in the past 20 years revealed four studies that were close to the planned study (Campbell et al., 2001; Hendry et al., 2006; Maly & Krupa, 2007; Victor, Ross & Asford, 2004). One of these studies (Maly & Krupa, 2007) explored the experience of living with knee OA in older adults. Another study (Victor et al., 2004) explored the meaning and significance of arthritis for patients who participated in a trial of a health promotion

intervention. The remaining two qualitative studies examined the views of patients with OA knee towards exercise, in particular the issues of adherence to exercise regimes (Hendry et al., 2006; Campbell et al., 2001). The study by Campbell et al. (2001) has particular relevance to the work of this thesis, in that the authors nested their interview study (entitled “Why don’t patients do their exercises?”) in a RCT in order to gain some understanding of the reasons for compliance and non-compliance. The RCT physiotherapy intervention included a regime of home based exercises.

Maly and Krupa, (2007) conducted a descriptive phenomenological investigation aimed at understanding the experience of three older adults living with OA of the knee. Analysis of the data from interviews with these older adults complemented the quantitative literature that identifies pain and immobility as key features of knee OA. The authors provided a comprehensive description of the method which included issues of trustworthiness of the results. For their study three individuals were identified from a group of 54 participating in a quantitative study of knee mobility. The participants were interviewed on three occasions one week apart with each interview having a specific topic focus. The first interview topic was life history, the second concentrated on details of the present experience of knee OA and the third interview asked participants to reflect on the meaning between mobility and daily life. Despite the small number of participants, the depth of familiarity with each participant provided rich data that highlighted the emerging themes (Smith, 2008). The design of the study was robust, although there were also some minor methodological queries. For example, the nature of the interview questions; the third interview was stated to be “largely open-ended” but it was unclear how the first and second interviews were structured. English was a second language for two of the three participants; in the discussion there was no reflection on how this may have affected the results. In summary the findings highlighted the centrality of the pain experience and how it impacts physical and psychological issues in daily living for people with OA. In their discussion the authors suggest that it behoves health professionals to better understand patient priorities when making decisions in relation to management and treatment options.

Victor et al. (2004) chose to explore the meaning and significance of arthritis for those patients who took part in a trial of a health promotion intervention. The qualitative methodology for the study was loosely defined as...“exploratory qualitative work” (Victor et al., 2004, p 64). The quantitative and qualitative data collected during the trial were interrogated and analysed for converging themes. The actual trial involved 22 London

general practices being randomised to either a health promotion intervention or waiting-list control group. The three qualitative data sources used in the paper were: baseline interview, patient diaries and the transcribed group discourse from the health promotion intervention sessions. The results were reported as an integration of the quantitative and qualitative data in relation to: characteristics of participants; knowledge about OA and its management; outcomes desired from treatment; and quality of service. Results show the study population was predominantly female (reflected in the wider literature). Similar to the findings of this study, arthritis had a major impact on participants' daily lives with many experiencing significant limitations on a daily basis. Maintaining mobility and being functionally active were important themes that supported staying independent. Exercise (primarily "recreational exercise", although this was not defined) was seen as important in maintaining better health. The authors noted that participants had poor understanding of the causes of their OA, ways of managing it and poor knowledge of the trajectory of their condition. Unfortunately the reporting of the results of this study was a confusing mixture of qualitative and quantitative methods with no information about the methodology employed and no clear description of methods of data collection and analysis. This created ambiguities reading the paper. The conclusions regarding inefficacy of self-management and patient education programmes would also have to be viewed with caution. It is questionable whether the nurse-led "health promotion intervention" involving four, one-hour group information sessions constituted a self-management and education programme as seen in usual clinical practice (or other literature). Despite not being a scientifically robust paper, Victor et al.'s (2004) paper did provide some insights that relate to the current study, namely the impact that OA has upon activities of daily living, the desire to maintain functional mobility and the perception that exercise provides health benefits.

Campbell et al. (2001) set out to understand, from the patients' perspective, the reasons for compliance and non-compliance with a home based exercise regime for OA of the knee (specifically patellofemoral OA). The study was nested within a RCT, examining the effectiveness of physiotherapy in reducing pain and improving mobility in OA knee. Twenty participants from the intervention arm of the RCT were interviewed using topic checklists and open-ended questions. The method for analysing the transcripts was described in detail, but there was no over-arching qualitative methodology employed. This study has particular relevance to the current project from the point of view of design and aspects of the investigation, (i.e. understanding what it meant to take part in a physiotherapy trial programme). In the findings the authors noted that the patients appeared to associate their

initial compliance with the programme exercises with their perception of obligation towards the physiotherapist, particularly the desire not to let her/him down, or an altruistic desire to help in the research. The reasoning underlying continued compliance was more complex and revolved around the interplay between the individuals' perception of their symptoms, their assessment of the effectiveness of the exercises (intervention) and their willingness and ability to incorporate the treatment into everyday life. The findings have implications for both how good quality clinical intervention trials are conducted as well as interpretation of trial results. In a follow-up paper, Campbell, Quilty and Dieppe, (2003), provided a comparison of the two approaches to collecting outcome data: quantitatively by questionnaire and qualitatively by means of interviews. They noted that the level of concordance between the questionnaire and interview data, for pain and disability, was less than 50%. The authors suggested that the most likely explanation for the discrepancies was the context in which data were collected: the quantitative information was obtained in the trial clinic whereas the qualitative accounts were obtained by an interviewer in the patient's home.

A more recent qualitative interview study by Hendry et al. (2006) examined the views of patients with OA knee towards exercise, including exploring the factors that determined the acceptability and motivation to exercise, and barriers that limited its use. A sample of twenty-two primary care patients with diagnosed OA knee were recruited from five general practices across North Wales: participants were interviewed. The severity of their knee problem varied from mild (requiring occasional pain relief) to severe symptoms that had led to a referral for knee replacement surgery. To enhance the validity of the study, the emerging themes from the semi-structured interviews were presented in a focus group; six participants chose to take part.

Three main categories emerged that explained exercise behaviour. These were physical capacity, beliefs about exercise and motivating factors. Participants' ability to exercise was not only limited by pain and stiffness in their knees, but also by a perceived lack of physical fitness, sometimes attributed to old age as well as co-morbidity. Their beliefs about exercise were influenced by personal experience, exercise advice and ideas about the aetiology of OA. Motivational factors encompassed a wide-range of issues such as enjoyment, social support, taking control of disability, priority setting and context. The authors constructed an "exercise behaviour typology" and identified four groups: long-term sedentary, long-term active, retired from exercise and converted to exercise. In summary the findings from this study supported those of Campbell et al. (2001) on adherence to exercise, but also provide some insights into

patients' reasons for giving up or starting exercise – the typology of exercise behaviour. The importance of exercise beliefs as determinants of exercise behaviour is becoming well established in the literature.

2.7 Summary

Osteoarthritis is one of the most prevalent musculoskeletal disorders and is often associated with some degree of functional impairment and disability. In New Zealand, OA is the leading cause of disability in older people, creating direct and indirect social and economic costs to the whole community. Quantitative studies, such as RCTs have been established as the method of choice for measuring effectiveness of interventions. Although there is a growing qualitative literature base examining individuals' experiences of OA in different settings, few have focused on OA patients' beliefs and expectations of an intervention (such as a physiotherapy programme) and their subsequent engagement in and experience of the intervention. Two of the four qualitative studies mentioned above focused on the experiences of individuals with OA in relation to exercise; a third focused on understanding the daily experience of living with OA; and the fourth explored OA patients' perspective of a health promotion intervention. Aspects of the above four studies have some relevance to the current study in that they are all concerned with the constructed nature of peoples' illness experience and how that influences their health behaviour, whether making choices about exercising or treatment options, or simply how they function daily. It was hoped that this study would reveal some understanding of the reasoning processes that patients undergo when making decisions about their OA condition, particularly as it relates to a physiotherapy intervention. A qualitative method provides the means of obtaining rich data of the lived experience of participating in a clinical trial physiotherapy intervention.

Chapter Three

Methodology

3 Methodology

This chapter details the methodology adopted to address the aims of this research project and briefly discusses the theoretical foundations of the approach. The project set out to explore the expectations, beliefs, and perceptions of participants taking part in a clinical trial physiotherapy programme and to gain some insight into how it affected the management of their chronic OA hip or knee. A qualitative approach was chosen as it allows questions to be asked about how participants experienced their OA condition and the physiotherapy programme in the context of their everyday lives; it aims to elicit meaning and explore understanding of participants' lived experience of their health constructs (Lyons, 2003). This chapter will begin by discussing the rationale for nesting a qualitative project inside a RCT, the theoretical foundations of the research process used in this study, followed by a description of the research design and method.

3.1 Context for the Study

The overarching rationale when combining quantitative and qualitative methods is to seek “elaboration, enhancement, illustration and clarification of the results from one method with the results from another” (Murphy et al., 1998, p.79). Quantitative outcome studies such as RCTs have limited value in explaining why and how change occurs (Jette & Jette, 1996). Their main focus is to establish a link between intervention and outcome; they are less able to explain the process by which the intervention was translated into that outcome. By contrast qualitative research emphasises how social processes are created and what meaning they have for people especially within specific contexts. In general, the primary aim of qualitative research is to elicit meaning and to gain understanding rather than predict and control (quantitative research). In the realm of health research it can help to understand the way in which interventions are experienced. Lincoln (1992) argues that many aspects of health are socially and behaviourally orientated by nature and that individuals attach multiple meanings to their own care, behaviours, attitudes and practices. Qualitative methods allow complex behaviours and social patterns to be considered; they may be used to interpret, qualify or

illuminate the findings of quantitative research (Murphy et al., 1998). This qualitative study aimed to generate insights into the world of the participants and the meanings linked to their individual experiences of their OA and the physiotherapy intervention.

3.2 Foundations of the Research Process

Qualitative research methods provide a way of incorporating the social and cultural world of people into health research (Lyons, 2003). Denzin and Lincoln (2000) describe the qualitative research process as the interconnection of three broad activities, ontology, epistemology and methodology (also known as philosophical assumptions). The researcher approaches the world with a set of ideas, a framework (ontology) that specifies a set of questions (epistemology) that he or she then examines in specific ways (methodology). Denzin and Lincoln (2000) expanded these three activities or assumptions into five interrelated phases that define the research process. The first phase is acknowledging the researcher as a multicultural subject, realising that they will be shaping the research by their gender, ethnicity, social class and personal experiences. The researcher role will be considered later when reflecting on the study (see chapter five, section 5.7, Limitations and Strengths). Phase two is determining theoretical paradigms and perspective, incorporating the ontological, epistemological and methodological stance of the research project. The third phase is describing the research strategies to be employed to address the research question(s). Phase four of the research process is determining the methods of collection and analysis of the data. Phase two to four will be used as the basis for discussing the research process of this study in this chapter. The final phase of the qualitative research process relates to the interpretation and presentation of the research findings, and is covered in the discussion (see chapter five, Discussion and Conclusion).

3.2.1 Theoretical paradigms and perspectives

Qualitative research refers to a diverse range of approaches all with a common aim: to begin from experience and provide a trustworthy interpretation of that experience (Chamberlain, Stephens & Lyons, 1997). Each approach adopts a set of philosophical assumptions that reflect a particular stance and informs the research process. The research is further shaped by bringing paradigms to the research project. A paradigm can be described as the 'net' that contains the researcher's epistemological, ontological and methodological premises that relate to specifics of the research process (Denzin & Lincoln, 2000).

The structure of qualitative research in the area of health research is largely governed by four interpretive paradigms, namely positivism, post-positivism, critical theory and constructivist-interpretivism (Denzin & Lincoln, 2000; Lyons, 2003). The fundamental nature of this research project is underpinned by a constructivist-interpretive paradigm. The constructivist paradigm assumes a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalistic (in the natural world) set of methodological procedures (Denzin & Lincoln, 2000). Constructivism contends that different people may construct different meanings or realities for the same phenomenon through interaction with others and within the framework of their cultural/historical worlds. Any examination of individual beliefs, attitudes and behaviours must take the wider social and cultural context into consideration. This stance fits with the research question for this project which chose to explore participants' individual realities and the meanings they constructed in relation to their chronic OA and the physiotherapy intervention.

By contrast, the positivist paradigm assumes that there is a reality out there to be studied, captured and understood - objectively and free of individual bias. The notion of an "unequivocal real world" takes precedence over accounts of people formulating their reality (Ashworth, 2008, p.10). Positivist researchers are concerned with predicting and controlling events, using deductive logic and empirical tests to produce data that can be analysed with statistics. Simply, the emphasis is on measurement and causal relationships rather than meanings and processes. This approach is not well-suited to studying the dynamic and subjective aspects of peoples' health constructs and experiences nor to providing insights about these phenomena.

The two remaining interpretive paradigms, namely post-positivism and critical theory, were not considered so appropriate for the research question. Post-positivism advocates that reality can never be fully apprehended only approximated through the use of multiple methods as a way of capturing as much of this reality as possible (Guba, 1990). At the same time, emphasis is placed on the discovery and verification of theories; this fits with qualitative methodologies such as the traditional approach to grounded theory. Both positivism and post-positivism perspectives are shaped by the positivist and post-positivist traditions in the physical and social sciences. In contrast to constructionism, they work with realist ontologies, objective epistemologies and rely upon experimental, quasi-experimental, survey and

rigorously defined qualitative methodologies (Denzin & Lincoln, 2000). Critical theorists hold a view of reality as something that, over time, has been shaped by social, political, cultural, economic, ethnic and gender forces into a set of structure, and are now taken as 'real' and 'natural' (Guba & Lincoln, 1994). This paradigm is commonly encountered in feminism.

The different assumptions and perspectives brought to the research process by qualitative methods explicitly influence theory and evaluation in health research, therefore they need to be carefully considered and stated. Evaluation criteria depend on the epistemological assumptions of the particular research paradigm (Lyons, 2003). In qualitative research the ontology/epistemology distinction effectively disappears in the research process as the findings that result from the inquiry are created by the interaction between the researcher and the researched. In the next section of this chapter the key epistemological and methodological perspectives as they relate to this research project will be discussed.

3.2.2 The epistemological perspective

Epistemology is concerned with the nature and form of reality and asks what there is that can be known. Constructionism is described as having a subjective epistemology where the researcher and participant are merged into a single, interactive entity and the findings that result from the research are the creation of this interactive process (Lincoln, 1992). This epistemological stance is well suited to aims of this research project because it acknowledges that people create their individual realities through the processes of interaction with other people and the social world. In addition the researcher recognises that he or she brings her own experiences and background to the interpretation of the participants' data. This two-stage interpretative process creates a combined understanding of the phenomenon or experience under investigation. There is a recognition in this process that there is no single constructed 'truth' or reality but many individual participant accounts.

3.2.3 Methodological perspective

The different qualitative approaches have different, but overlapping epistemological underpinnings and theoretical and methodological emphases (Smith, 2004). Epistemology with its concerns about the nature of knowledge interacts strongly with methodology or the process of how we choose to gain knowledge and this ultimately informs the method used. Constructivism is described as having two methodological elements, namely hermeneutics

and dialectics (Guba, 1990). This research project is strongly informed by the hermeneutical element which contends that we live in an interpreted world and we ourselves are interpreters; in addition individual constructions are elicited through iterative interactions between the researcher and the participants (Lincoln, 1992). The hermeneutic approach is reflected in the interview research process whereby the researcher interprets the research participants' constructions of their world (Ashworth, 2003). This is in keeping with an interpretative phenomenological analysis methodology and this is the chosen methodology for this research. The methodology (phase three of the research process) links the theoretical paradigm to the methods of data collection and the analysis of the data. Research strategies anchor theoretical paradigms in specific methodological practices (Denzin & Lincoln, 2000).

Interpretative phenomenological analysis (IPA) as a methodology has roots in phenomenology, hermeneutics and symbolic interactionism (Smith, 2003). Phenomenologists believe that individuals need to be understood in their entirety within a situational context; they see the world in terms of complex human behaviours and multiple realities. Phenomenological research aims to capture as closely as possible the way in which a phenomenon is experienced within the context in which the experience takes place; it aims to clarify situations lived through by persons in everyday life (Giorgi & Giorgi, 2008). IPA is phenomenological in that it is concerned with individuals' subjective reports rather than the formulation of objective accounts and it recognises that research is a dynamic process (Smith, 1996). How events and objects are experienced and given meaning requires interpretative activity on the part of the participant and the researcher (Smith, 2008). This strongly connects IPA to an interpretative or hermeneutic stance which Smith (2004) suggests is centred in empathy and meaning recollection. Empathic hermeneutics is concerned with trying to understand what it is like from the point of view of the participant. IPA also employs a hermeneutics of questioning which allows the researcher to ask critical questions of the participant's account. Both stances can be seen to contribute to a more complete understanding of the participant's lived experience. This 'double hermeneutic' is a two-stage interpretative process in which the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant's interpretation. Thus IPA strongly recognises the dynamic role of the researcher and the research exercise as a dynamic process. The development of IPA has also been influenced by the tenets of symbolic-interactionism; how meanings are constructed by individuals within both a social and a personal world through social interactions (Smith & Osborn, 2008). The way an individual

describes and behaves in relation to an event or experience is a direct reflection of their perception of that experience.

As an inductive methodology, IPA aims to capture and explore the meanings that participants assign to their experiences. An IPA approach is commensurate with this research project which aimed to gain some insights into what OA participants' expected and believed the impact of a physiotherapy intervention programme would be for them and how this affected their perceptions of their condition. Smith (1996) suggests IPA is especially useful where 'complex' issues are being addressed, such as chronic OA. Whilst it is not possible to make broader claims to a general population, IPA allows the researcher to make inferences and raise awareness of the contextual, social and cultural issues that may influence outcomes for participants in the RCT. By exploring the participants' experiences of a physiotherapy intervention the researcher may be able to present a more in-depth understanding of how the intervention can achieve more positive impacts on function and disability.

Interpretative phenomenological analysis attempts to guide the researcher in the planning, implementation and analysis of a project intending to explore the specific experiences of individuals, by providing a detailed procedure (Smith & Osborn, 2008). There are three key characteristics of IPA, namely idiographic, inductive and interrogative (Smith, 2004). The idiographic characteristic refers to a detailed analysis of single cases, while the inductive process allows new or unexpected meanings to emerge. Finally the interrogative characteristic may help to explain or identify problems with existing research.

Grounded theory and IPA have been frequently contrasted. Brocki and Wearden (2004) suggest that IPA differs from grounded theory in its suitability for understanding personal experiences as opposed to social processes. The intent or process of grounded theory is the development of conceptual frameworks or theories from the data; the results are thus 'grounded' in the data. This emphasis on theory development is the methodology's most crucial distinguishing feature. In contrast, IPA allows the researcher to explore subjective experiences, and helps describe and understand the participant's account of the processes by which they make sense of their experiences (Brocki & Wearden, 2004).

3.2.4 Methods

Interpretative phenomenological analysis is a pragmatic rather than prescriptive methodology suited to a flexible data collection method. While it is possible to obtain suitable data in a number of different ways (e.g. personal accounts, diaries), Smith and Osborn (2008) describe semi-structured interviews as the ideal method for IPA. A semi-structured interview schedule offers a map of possible ways in which the interview may proceed, and allows for flexibility and modification of initial questions in the light of participants' responses (Smith, 2008). In practice, the interview may diverge considerably from what was originally envisaged; the interview schedule 'guides' rather than directs the interview. The researcher starts a semi-structured interview with a schedule of topics of interest and open-ended questions to pursue, but the participant shares closely in the direction the interview takes, thereby producing richer data (Smith & Osborn, 2008). The nature of one-to-one interviews supports the development of researcher/participant rapport, providing an opportunity for the researcher to "get close to the participant's personal world" (Smith & Osborn, 2008, p.53); it allows participants to think, speak and be heard; and it is well suited to probing interesting topic areas or following the participant's interests (Smith, 2008; Reid et al., 2005). It is assumed in the interviews that what a respondent says has some ongoing significance for them and that there is some relationship between what the person says and believes (Smith, 2008), since illuminating participants' beliefs and expectations in relation to their condition was important in finding out what governed their actions.

3.3 Research Design and Method

3.3.1 Overview of the project and study design

This qualitative evaluation study was exploratory and hoped to capture the experiences of people with chronic OA of the hip or knee, participating in a clinical trial physiotherapy programme. It also hoped to explore the experiences of a small group that did not wish to participate in the clinical trial. For this interview study, four participants were selected from each of the four treatment groups of the clinical trial. They were interviewed twice, in the initial stage of the programme and on completion. Their experiences of the clinical trial physiotherapy programme and being a participant were recorded. A group of five people who chose not to participate in the clinical trial were interviewed on one occasion about their experiences of OA and why they chose not to participate. The data were transcribed and then

analysed case by case. Notes were grouped to create themes and ultimately a narrative account.

3.3.2 Pre-Recruitment

Development of the Interview Schedules

Two semi-structured interview schedules were developed using questions and prompts framed around the research question and the different groups of participants recruited for this study.

The questions and prompts were developed in consultation with two supervisors. Extensive reading of the literature, the researcher's clinical knowledge and the nature of the physiotherapy interventions (namely manual therapy and exercise) provided the background for development of the interview schedules.

The first schedule was designed primarily for the Phase I interviews conducted during the early stages of participation in the RCT. The second schedule was designed for the Phase II interviews when participants had completed the RCT. Questions were structured in an open-ended manner (for example "will you tell me about... what do you hope...how do you see...") with prompts to further encourage disclosure of underlying beliefs and attitudes. Prompts (or cues) were used only if the conversation stopped or required guidance back to the topic, but the schedule was essentially a 'flexible tool' to provide participants with maximum opportunity to tell their story. Smith (2008) emphasizes that the flexibility of the interview schedule allows for questions to be asked in a different order, nor does every question have to be asked, or asked in exactly the same way. Participants' responses play a role in determining how the interview proceeds. The interview schedule is a guide to indicate the general area of interest (Smith, 2008).

The first schedule (see Appendix One) was designed to cater for three different but overlapping groups of participants: RCT participants (those people allocated to the three intervention arms of the RCT); RCT participants allocated to the 'usual care group' (they received no treatment); and the people who chose not to take part in the RCT. Consequently the schedule consisted of, general questions relating to OA that all three groups could answer, specific questions for the RCT participants regarding the physiotherapy intervention programme (e.g. perceptions of exercise, expectations of the physiotherapy programme), and questions for the people who chose not to participate in the RCT. The second schedule

questions were an attempt to evaluate the impact of the intervention and draw on participant's first accounts to develop individually tailored questions. These questions were sourced from initial analysis of each participant's Phase I transcripts and related to issues that stood out as being important for the participant. Consequently the question was formatted.... "in the first interview you said that you hoped that...how do things compare now?" The overall focus of the second interview schedule (see Appendix Two) was on what participants thought about the physiotherapy programme, how the programme impacted on them, how they found the exercises, their experience of being in a clinical trial, their perceptions of surgery now, and any relevant individual questions. For the 'usual care group' the follow-up interview (approximately three months after the first), focused on any changes that may have occurred in the management of their OA.

Ethical Considerations

An 'Expedited Review of Observational Studies Application Form' was completed and submitted for ethics approval. This study was appropriate for expedited review given the purpose was to evaluate and describe participant's perceptions of a process and intervention; this fits with criteria for observational research. The larger RCT had full ethics approval. Ethics approval was received from the Lower South Regional Ethics Committee prior to recruitment of participants (Appendix Three). A 'Research Consultation with Maori' form was also completed and submitted for approval under the umbrella of the RCT which had secured Ngai Tahu approval to undertake research.

All participants in the study gave written consent to take part. For the group of participants interviewed twice, verbal consent was obtained and recorded on the audio equipment prior to the second interview. It was possible that some people may have become distressed while talking about their chronic OA condition. Therefore participants were advised they could request to have the audiotape switched off at any stage and/or stop the interview or request the help of a disability advocate.

The interviews took place at the participant's choice of venue. During Phase I interviews, this was predominantly at the same location as the RCT physiotherapy intervention programme. The Phase II and remaining interviews took place at either participants' homes or their place of work. Consequently the researcher took measures to ensure her own safety; these included

providing a trustworthy person with the researcher's mobile phone number and key information regarding interview locations and times (txt contact was maintained).

3.3.3 Participant recruitment

Participants for this qualitative study were recruited from the population of the larger RCT, which looked at the management of OA; hence the acronym 'MOA trial'. The trial was based in the South Island and began recruitment in March 2008. Briefly, participants for the MOA trial were recruited from primary and secondary care sources: patients of community General Practices and patients referred to the Department of Orthopaedic Surgery, Outpatient Clinic Dunedin Hospital (Abbott et al., 2009). To be eligible for inclusion participants were required to meet the clinical criteria for diagnosis of OA of the hip or knee according to American College of Rheumatology criteria. Exclusion criteria included previous knee or hip joint replacement surgery; any other surgical procedure of the lower limbs in the previous six months, rheumatoid arthritis; initiation of opioid analgesia or cortico-steroid or analgesic injection intervention for hip or knee pain within the previous 30 days; uncontrolled hypertension or moderate to high risk for cardiac complications during exercise (Abbott et al., 2009). The expected rate of recruitment was four participants per week (over a one year period). At baseline assessment, participants were randomly allocated to one of the three physiotherapy intervention groups or the usual care group. The physiotherapy programmes comprised manual therapy, exercise or a combination of both.

Interpretative phenomenological analysis sample size is variable and has been shown to range from one to thirty (Brocki & Wearden, 2004). Recently Smith (2004) has argued the advantages of smaller samples and case studies to retain a strong idiographic focus. However, IPA sample size partly depends on several factors such as the constraints of the project, the depth of interpretation the researcher chooses, the richness of the individual accounts (Smith, 2008), and in the case of this study, the phenomenon being explored: that meant there were five potential sets of experiences or natural groups of participants, to draw from. Ethics approval was sought to recruit up to twenty participants; four from each of the four arms of the RCT and four non-RCT participants. The potential sixteen participants from the RCT would be interviewed twice. The homogeneity of the larger OA sample population was already defined by participants' inclusion in the RCT or, having been invited to participate and choosing not to. The intention of the sampling strategy for this study was to purposively select a sample for whom the research question would be significant. For the primary

research aim, the four groups of the RCT provided such a population. In addition a sample of participants for whom the secondary aim was significant, were purposively sampled from the larger OA sample population.

Participant recruitment was framed around the aims of the study and therefore required two strategies: (1) for participants in the RCT; and (2) for people who chose not to participate in the RCT. The logistics and planning required to carry out the research were complicated by the researcher living in the North Island and the research project being based in the South Island (see chapter five, section 5.7, Limitations and Strengths). The two recruitment strategies required two different research administrators in the South Island to be directly involved in the process of recruitment on behalf of the researcher. Flow charts of both strategies (see Figure 3.1 & Figure 3.2) give a clear outline of the processes involved. Recruitment Strategy 1, for RCT participants, was successful with few problems encountered. Recruitment strategy 2, recruiting a small number of people who declined to take part in the RCT, was problematic and required more contact time with the clinical research nurse involved (see chapter five, section 5.7 Limitations and Strengths). All participants subsequently contacted by the researcher (following the initial invitation by the research administrators) agreed to participate in the study. It is not known how many participants declined the invitation to take part when asked by the research administrators.

Invitation/information packs were generated for both recruitment strategies. These packs included an invitation letter (Appendix Four), an information sheet (Appendix Five), consent form (Appendix Six), blue reply slip and a pre-paid reply envelope.

The forms for each strategy were essentially the same with word changes where appropriate. For recruitment strategy 1 (RCT participants) a batch of twenty invitation packs were initially sent to the RCT clinical research administrator for distribution. In the case of recruitment strategy 2 (people who chose not to participate in the RCT), the recruitment process required the researcher to post the invitation packs.

Figure 3.1: Recruitment Strategy 1

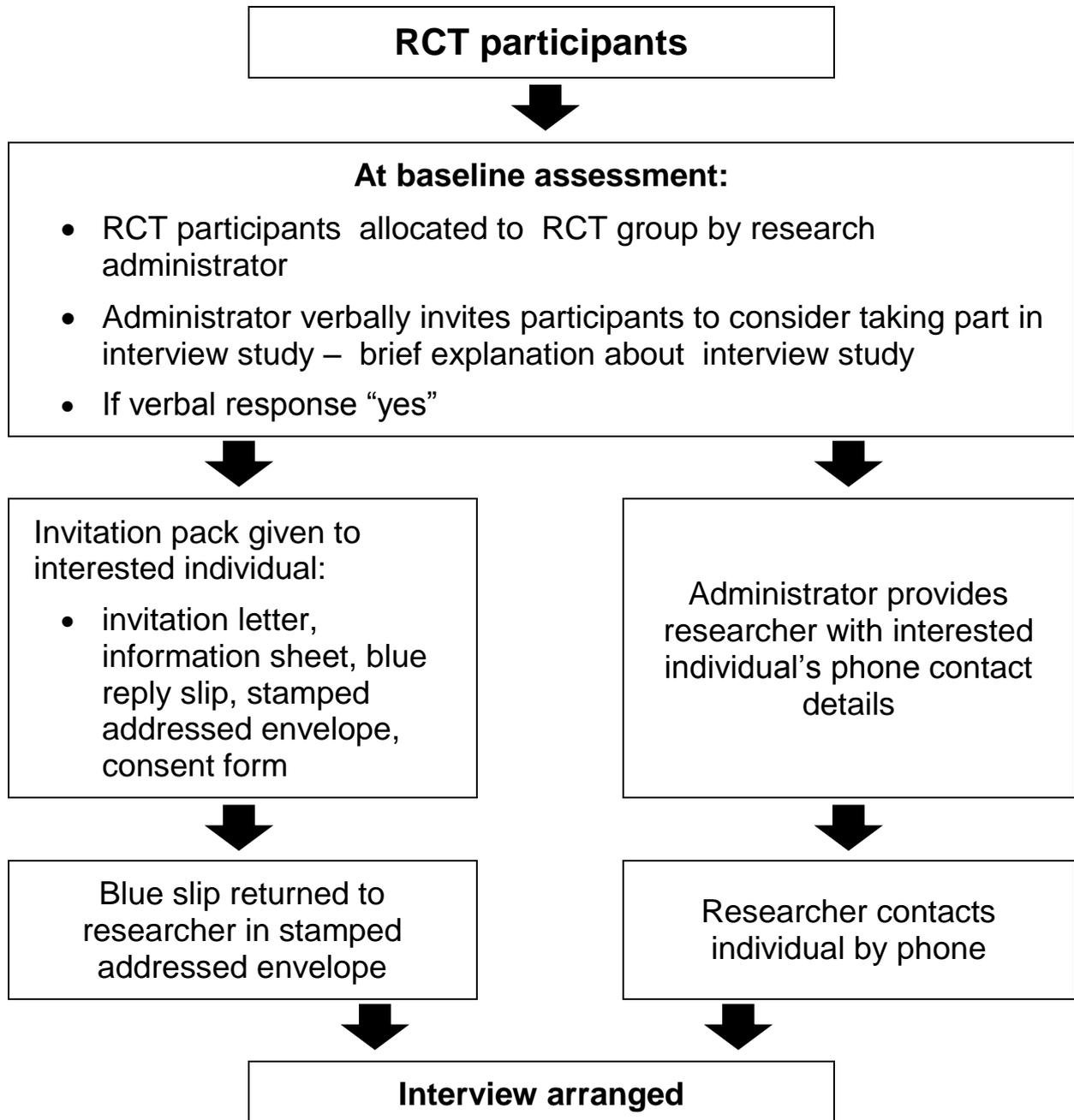
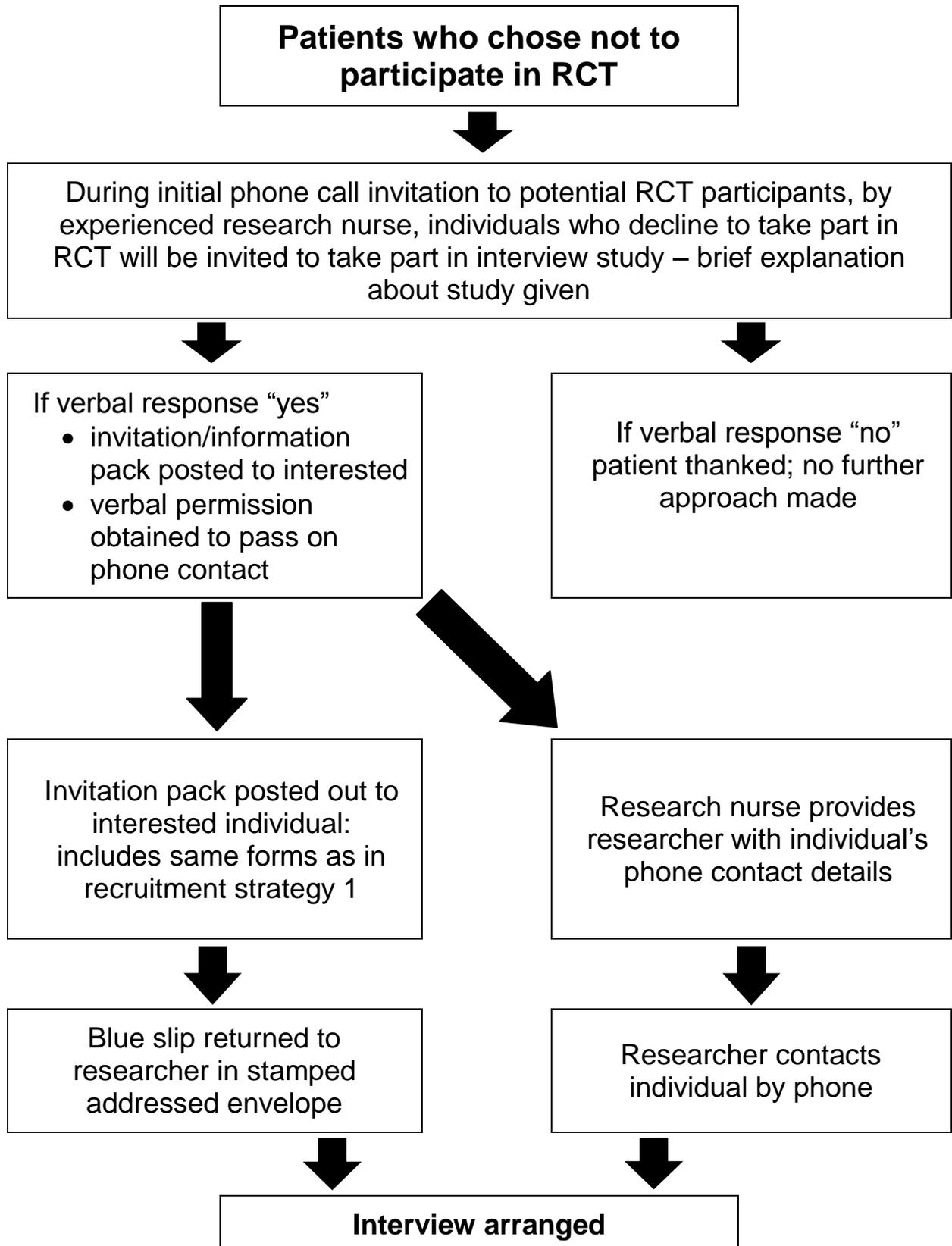


Figure 3.2: Recruitment Strategy 2



3.3.4 Data collection

An overview of the number of completed data sets collected and an indication of the collection timeframe is presented in Table 3.1. The interviews took place over a six-seven month period with five researcher visits to the South Island. A complete data set for the RCT participants comprised two interviews: for the non-RCT participants a complete data set comprised one interview. For participants in the four intervention arms of the RCT, the interviews were scheduled as Phase I or initial interviews; that is while participants were in the early stage of the programme. The Phase II or follow-up interviews took place following completion of the nine week intervention programme (depending on the timing of their second interview, some RCT participants had also received the two booster treatments at this stage). The non-RCT participants were interviewed once at any time during the Phase I and Phase II interview cycles. Narrative descriptions of the process are given in the following section.

Table 3.1: Overview of Data Collection

Interview Phases	RCT Participants				Non-RCT participants
	Exercise	Manual Therapy	Combined Therapy	Usual Care	
Phase 1 June - August	5 *	4	4	4	1
Phase II October- December	4	4	3 ∞	4	4
Complete data sets	4	4	3	4	5

* Interview data for one participant was lost due to technical failure

∞ One participant withdrew from RCT.

Stage 1: Scheduling the Interviews

Once the research administrator/s received an ‘expression of interest’ from a participant with verbal consent to pass on their contact/phone details, the information was forwarded to the researcher via email. At least one week was allowed for a participant to read the information

contained in the pack and return the blue reply slip prior to the researcher contacting them. In most cases the week time-frame was extended for practical reasons. The researcher then created participant 'groups of convenience' when scheduling interview dates to minimise travel (financial considerations) and time away. To provide a reminder, each participant was phoned one week prior to the week assigned for interviewing by the researcher and a convenient time and location for the face-to-face interview was arranged. For the initial interviews, this scheduling was worked around the participant's physiotherapy intervention session to minimise any inconvenience. Most Phase II and RCT non-participant interviews were conducted in the participant's home.

Stage II: Conducting the Interviews

All interviews were conducted in English by the researcher. For Phase I interviews the participants (included RCT participants and RCT non-participants) signed a written consent form prior to being interviewed. Participants were also given full information about the research, and it was made clear they had the right to stop the interview process at any time. For Phase II interviews, verbal consent was obtained and recorded prior to the interview. Participants then took part in a 35-45 minute audio-taped interview, based on the corresponding semi-structured interview schedule (Appendices One & Two). At the Phase I initial interviews the researcher obtained basic demographic information such as age, employment status and other joints affected by OA (Appendix 7). The Phase II or follow-up interviews were conducted once the participant had completed the physiotherapy intervention programme (approximately three months). A digital recorder with internal microphone was used when recording the interviews. If required, field notes were recorded immediately after each interview.

Data Management

The digital-recorder audio files generated by the interviews were downloaded onto a laptop computer before the researcher returned to the North Island. Thus the files were stored in two locations to ensure their safety. The audio files were subsequently emailed to an independent person who transcribed them verbatim after signing a confidentiality agreement; each transcript was checked and verified against the audio file by the researcher. Pseudonyms were used to protect confidentiality, electronic data were assigned passwords and transcripts were stored in a locked filing cabinet. The data were managed both manually and using

NVivo 8 (QRS International Pty Ltd). As a novice researcher with no experience of NVivo software, managing the data both manually and electronically facilitated a better understanding of the process.

3.3.5 Data analysis procedures

Data were analysed using IPA (Smith, 2008). Interpretative phenomenological analysis is not a prescriptive approach; rather it provides a set of flexible guidelines that can be adapted by the researcher in light of their research aims (Smith & Osborn, 2008). All transcripts were typed using a participant pseudonym to ensure anonymity and confidentiality. Data were analysed using a layered interpretative analysis to explore the issues across the cases. This is an inductive and idiographic process used in the early stages of IPA. It starts with a content analysis or typology of responses and then continues on to refine the themes using an iterative technique to examine and interpret the data (Smith, 2008). Information is organised into smaller categories to enable the emergence of a larger representation of shared experiences that are common across participants.

The process of analysing data from Phase I and Phase II interviews was staged separately and later combined. The first analytic stage involved close reading of the Phase I transcripts by the researcher. Key words and phrases were highlighted in the text and annotations made in the margins of the transcripts. Repeated readings of the texts provided a list of emergent themes; clustering related themes provided the initial super-ordinate themes. The re-reading of transcripts (iterative process) ensured ideas and themes remained context-specific. The researcher then verified the emergent 'descriptive themes' with a supervisor experienced in qualitative research. The supervisor had independently coded the same transcripts; themes for each transcript were verified by the researcher and supervisor working together.

Readings of the Phase I transcripts helped clarify (and inform) the questions and prompts for the second interview schedule. Text extract/s that strongly reflected a specific issue for a participant in the first interview was used to shape individual questions in the second schedule. During the analysis process the researcher attended a day course to learn the basic skills of using Nvivo 8. Consequently, the analysis process was continued using Nvivo software (earlier coded texts were transferred to the software programme). The process of coding and highlighting relevant text extracts was continued for the Phase II transcripts with the same process of theme verification as Phase I. The NVivo software provided a flexible

tool for the process of coding, organising, integrating and interpreting the data. The hierarchical organisation of themes - termed a 'tree node' which contained themes ('nodes') and subthemes ('children') - brought flexibility to the process of refining and reorganising themes within and across cases.

Although the researcher utilized NVivo software, the continual refining of initial themes and interpretation of the data was a mechanical process. The researcher became familiar with the data by creating whiteboard diagrammatic representations of the superordinate themes, their interconnectedness and the related subordinate themes and ideas.

3.3.6 Assessing the quality of the research

Yardley (2000) has offered three broad principles for assessing the quality of qualitative research. These are: (1) sensitivity to context; (2) commitment, rigour, transparency, and coherence; and (3) impact and importance. The following paragraphs will discuss how the researcher attempted to establish quality in the work of this thesis.

Sensitivity to context is demonstrated by references to relevant and up-to-date literature that reflected the research topic and 'unanticipated topics and themes' that emerged during the analysis (Smith, 2004). Context sensitivity is also demonstrated by the researcher's attention to the theoretical foundations of the methodology adopted for this project. It is also shown in the use of verbatim transcript extracts to support the themes.

Commitment refers to the degree of engagement in the project. This was clearly demonstrated in the researcher choosing to organise and carry out research despite being based at a distance. Rigour refers to the thoroughness of the study; this was shown in the in-depth knowledge of the texts and the interpretative analysis of the data. Transparency and coherence refer to how clearly the research process is outlined in the write-up of the study and was demonstrated in descriptions of how participants were recruited, the data collection process and the steps used in data analysis.

Yardley (2000) also noted that regardless of how well the research project is conducted, it is important to assess whether or not it said anything useful. The extent to which this research project achieved impact and importance will be discussed in chapter five.

Chapter Four

Results

4 Results

This chapter will begin by providing a description of the participants and then the nature of the data collected will be given. The remainder of the chapter will present the themes with supporting verbatim extracts from the interview transcripts.

4.1 Overview of Participants

A purposive sampling method (Smith and Osborn, 2008) was used to recruit participants from the four groups of the RCT population. In total, a subgroup of seventeen RCT participants then took part in the Phase I interviews: sixteen RCT participants took part in the Phase II interviews (see Table 2.1, p.42). The interviews were audio-taped and lasted approximately 35-45 minutes. A complete data set comprised Phase I and II interviews; fifteen data sets were analyzed in the results. One interview was lost due to equipment failure. One participant declined the Phase II interview after withdrawing from the RCT. Five participants who chose not to take part in the RCT were recruited and interviewed on one occasion only; their data were included in the overall results.

The median age of the 20 participants interviewed was 65 years, with ages ranging from 53-86 years. It was interesting to note that half the participants still worked either full-time or part-time (seven and three respectively). The group also comprised the same numbers of females and males. The duration of years with OA ranged from two years to twenty-five years or more. A significant number of participants reported having either one other joint involved or a 'systemic-type' of OA. For example Rachel spoke of her hip, knees, feet and fingers being affected (see Appendix 7 & 8).

4.2 Interview Data

In the Phase I interviews the RCT participants were asked to tell the story of their OA and their expectations of the clinical trial physiotherapy programme. Where necessary prompts were used to help guide the interview and elicit relevant information, such as when and how

their OA started; symptom behaviour; how the condition affected their lives; previous treatment experiences; ongoing management and coping strategies. Other interview questions included perceptions of exercise, expectations of the physiotherapy programme, how they saw the future and what they thought of surgery. In the phase II interviews, RCT participants were asked to reflect on their experience of the research programme, what it was like doing the exercises, how the programme impacted (or not) on the management of their condition and whether or not it had changed their perception of the future and/or surgery.

Questions during the Phase I interviews primarily focused on participants' experience and management of their OA condition. However, many participants were keen to talk about their beliefs around joint replacement surgery (JRS), hospital waiting lists and the health system. At the Phase II interviews participants' narratives reflected a positive experience of the physiotherapy programme citing improvements in managing their condition, but again the focus came back to JRS.

The non-RCT participants were similarly asked to talk about their experience and management of OA; they were interviewed during either Phase I or Phase II (see Appendix One, Phase I Interview Schedule). In addition they were also asked to talk about why they chose not to take part in the RCT.

The remainder of this chapter will outline the themes and subordinate themes in more detail, with supporting verbatim extracts from the transcripts. Pseudonyms are used throughout; alterations to clarify meaning are denoted by round brackets (). Longer quotations are indented after paragraphs, but shorter quotations are embedded within paragraphs using quotation marks “ ” to assist with flow. Occasionally, quotation marks are also used within paragraphs to draw attention to precise words used by participants. Some cases will be highlighted if they stand out as being particularly interesting or illustrative of the topic being discussed.

4.2.1 Overview of themes

Stories from both interview phases contributed to the three superordinate themes that emerged from the data: *The OA Story*, *The Research Story* and *The Surgery Story*. Participants' accounts of their experience of OA, the significance they ascribe to their signs and symptoms, and their perception of the inevitable consequences of their worsening condition, for many,

shaped their beliefs and expectations around their involvement in the research project and what they thought of JRS. Each theme contained two subordinate themes (see Table 4.1) and they will all be described in more detail in the following sections.

Most participants believed joint JRS was necessary to “fix” their joint condition; one participant spoke of surgery as “the light at the end of the tunnel”. Surgery was seen by many participants as not only the treatment of choice for their condition but an inevitable outcome of their deteriorating OA. For some, when it became evident that surgery was not readily available, the only alternative was to give the physiotherapy programme a go otherwise “that would have been the end of it”. Thus the *The OA Story* theme is central to both *The Surgery Story* and *The Research Story* theme. The subordinate theme titles are quotes from the text and reflect the dominant thoughts of the participants.

The stories from the non-RCT participant interviews have been incorporated and well represented by *The OA Story* theme and *The Surgery Story* theme. The findings from the interview data were unremarkable in that they were very similar to the trial participants’ stories. Essentially, there were no identifiable differences between participants in the clinical trial, and those patients who chose not to participate in the RCT.

Table 4.1 Summary of Themes and Subordinate Themes

Theme	Subordinate Theme
The OA Story	No Way Back Life Goes On
The Research Story	Give it a Go Shown a Signpost
The Surgery Story	Light at the end of the Tunnel Waiting ‘n’ Hoping

4.2.2 The OA Story

This theme was titled *The OA Story* as it provides a narrative of the participants’ history and current experience of their condition, starting with their descriptions of the onset, how they managed with the consequences of increasing functional restrictions and pain, through to their

ability to doggedly carry on in spite of their problems. OA was perceived as something that had insidiously crept into their lives and was impacting more and more on social, recreational and work activities. Participants' stories highlighted the emotional and mental cost of living with increasing physical limitations and pain. Participants spent a lot of time describing the escalating effects of reduced mobility and function particularly with everyday tasks. The consequences of living with a pervasively deteriorating condition focused their views on what the future held. The first subordinate theme, *No Way Back*, describes participants' experience of living with a deteriorating, painful and restrictive joint condition. The second subordinate theme, *Life Goes On*, referred to how they managed to carry on in spite of their difficulties.

No Way Back

This subordinate theme was titled *No Way Back* to reflect participants' descriptions of living with a progressive, worsening, painful joint condition. Sally's statement, "once your hip starts to degenerate there's no way back" encapsulates the pessimistic viewpoint held by many of the participants. Their stories reflected a pervasive negativity in coping with their OA and phrases such as "it's getting worse and worse", and "I just can't do it" were commonplace. For some, the management of their OA had reached a desperate point in that they perceived there was "nowhere to go" and "it's all downhill". Their belief that deterioration was an inevitable consequence of having OA was one factor underpinning their low expectation of the physiotherapy programme and therefore the need for surgery.

The onset of OA tends to be gradual and focused within a particular joint. Nevertheless a number of participants identified old sporting injuries which seemed to precipitate the onset of joint problems. Several participants talked about an interplay of factors that contributed to the problem; an initial joint injury followed by years of aggravating the problem through work or hard physical activity. Other participants described a more typical pattern of insidious niggles and twinges followed by increasing physical restrictions and pain. Several participants identified a crisis point whereby they became "suddenly" aware of the severity of their condition:

...it's about a year...because it had been niggling and suddenly I thought this is not, you know, I need to find out actually what is wrong with it...from just being a niggle, knowing that there's something wrong, to suddenly now taking panadol every four hours.

(Rachel)

Throughout *The OA Story* participants focused on the increasing disruption that their condition caused to their lives. They spend a lot of time describing the effects of their OA condition on performing everyday tasks such as getting dressed, doing housework, and supermarket shopping. Mary alluded to her frustration with the loss of function on a daily basis:

I've noticed increasing difficulty with other things; getting in and out of the car, getting out of bed in the mornings, stairs, but cold weather makes it worse; getting dressed of course, putting shoes and pantyhose on...it's more loss of function which is frustrating for me.

(Mary)

As well as struggling with basic tasks, participants voiced their frustration at being unable to take part in a broad range of life domains including social, recreational and work. Increasing pain levels and decreasing mobility restricted their participation in previously enjoyed activities. Many participants expressed a sense of loss at what they "used to do" and now "can't do it". Emily and Gary despaired at what they could no longer do:

...I can't do the garden, I've got to get somebody in to give me a hand with that and cut the lawns, it's just beyond me that now...well I think it's just the pain and frustration of not being able to join in – well I play bowls – well I can't; I find now that I just can't do that very much.

(Emily)

I can't go to a rugby match now, I can't stand up for the length of a rugby match, or I can't go to the test match or I can't play bowls now like I used to.

(Gary)

While some participants identified strongly with the loss of social and recreational interaction, others spoke of the struggle to work. The average age of participants was 63 years consequently many wished to either remain employed or return to full employment. Greg was 62 years old and anxious to get back to work:

I'm unemployed, I can't work because of the pain and I'm really getting to the stage where, to put it mildly, I'm getting pissed off, because I'm 62, I want to get back into the work force...

(Greg)

Rebecca was 55 years old, worked fulltime, and was one of the youngest participants. She had been actively involved in sport until her diagnosis of "acute arthritis of the hips" seven years ago. Rebecca had made significant adjustments in her lifestyle "to make my life easier" but talked about progressively doing less over the years. For her the impact of OA on her "whole lifestyle really" was profound and affected her physically and mentally":

...initially it was hard to comprehend that this was going to affect my, you know, well my whole lifestyle really which it did...as the years have gone on less and less things that I did before that I can't do now or I do them with help, even putting shoes on...I mean it's not life threatening or anything like that but when you're used to being physically fit and well it takes a toll on you mentally as well.

(Rebecca)

The frustrations of living with physical limitations and pain on a daily basis had significant effects on participants' emotional and mental wellbeing. They described being tired, weary and slower; everything they did required a "bit more of an effort". The pervasive nature of OA meant they could never get away from it:

Yeah I'm cranky...oh yes, it's always there in the back of your mind...and by the time I'm finished, I'm getting around like a half shut pocket knife, you know, I'm all bent over.

(Rachel)

Several participants spoke about how coping with pain and physical restriction made them feel depressed. Gary had experienced knee problems for 45 years and was desperate to get "the knee fixed" by joint replacement surgery. The following extract is an example of the extreme frustration participants sometimes felt when coping with the severity of their condition. His mind/body dissonance reference serves to reinforce his feelings of overwhelming frustration:

Some days you just feel like going away and getting the car and putting the hose on the exhaust and feeding it – you just get depressed. Cos you know you can do whatever you want to do but your body's not letting you.

(Gary)

Participants managed their pain in a variety of ways: pain medication; rest; pacing their activities to include rest periods; and constantly adjusting their activities to cope with known symptom behaviour. Rebecca spoke of the latter as “self preservation”:

...what I tend to do anyway, is save myself if I think I've got to stand for a long time, I won't go. So you – or if you go somewhere, and you know, there's a few chairs there, I just aim straight for the chair. Whereas before I would have just stood up...but I think now, if I don't sit down, I will either not be able to get home, or I won't be able to walk the next day. So it's sort of like self preservation really.

(Rebecca)

Ultimately many participants relied heavily on pain medication to keep their pain at tolerable levels in order to stay active, keep working and maintain their lifestyle. They spoke about the large quantity of medication they were taking on a daily basis:

Well I'm on paracetamol, I take that two tablets, four times a day; codeine, one or two tablets, four times a day and aproxin, one or two tablets, three times a day and basically that's how I manage it...so I'm basically a rattling pill barrel.

(Greg)

Panadol was the preferred medication with many participants regularly taking the maximum dosage of eight per day. Rebecca spoke about “living on panadol” both before and after during the exercise programme while Rachel exclaimed she would be “shot” if she did not take two panadols every four hours. Mark, who was working fulltime and experiencing a lot of knee pain, said he was tempted to use a “bit of home-bake” for pain relief over and above his usual eight panadol a day:

It's getting to that state where I'm almost tempted...if the pain gets much worse and I want to keep working, I'm seriously thinking about it...

Life Goes On

The title of the subordinate theme, *Life Goes On*, reflects participants' desire to persevere and endure with their normal daily activities as much as possible in the face of gradual, insidious joint deterioration, worsening pain and increasing loss of function. Staying active and "keeping up your social contacts" were seen as being important for coping and maintaining mental wellbeing. Unfortunately the continual demands of balancing and adjusting their daily activities in order to cope with the pain and physical restrictions were becoming more difficult and life was "getting harder" for many participants. In the following extract, Michael's comment that "life goes on" could be interpreted as perseverance or acceptance, or that participants did not see they had any choice:

... it's getting worse and worse and worse all the time...and arth –whatever it is has crept into it and it's just cause me problems...and at night time it's just like a giant toothache in the leg... it's starting to wake me up now at night, two or three times at night, some nights... restricts me in doing sort of most things I used to do, but you sort of learn to work around it, you know, and sort of guard it...but I try and use it best I can but other than that, life goes on.

(Michael)

Participants' accounts of the consequences of living with OA on a daily basis indicated that many participants were struggling. And yet they alternated between talking about the disruption in their lives as being severe and worsening, and positive ways to cope. Running through participants' accounts was a stoical attitude of "learning to live with it"; concomitantly they sought out positive ways to adapt in order to maintain their work, hobbies, or daily functional activities. The belief that "there's always a way around it" was expressed by Emily in her first interview and was reflected by other participants. For some this took the form of a practical solution; Richard wore knee pads at work, Sally and Bridget had built raised beds to avoid kneeling while gardening, and Tom used a mobilised trolley for the golf course. Other participants adopted the coping strategy of continuing their usual activities but with some limitations in place:

There's always a way around things, and I mean no matter how awkward, or how difficult it is, you'll always find a way to do it...you sort of work out a way of doing it.

(Emily)

Despite actively seeking ways to adapt and cope with their OA, for some participants stoicism underpinned their approach to the ongoing management of their condition. Mark felt he had to “just carry on”, while Richard spoke of being able to “put up with a lot of pain you know, put up with a lot of pain actually”. Emily and Sally both indicate that stoicism often prevails:

I have to cope with it, have to take each day as it comes, and you know, but I really haven't done – I suppose I should have tried to do something.

(Emily)

I can't walk any distance or it hurts and doing down hills is quite painful so, but you learn to live with your limitations, so I do what I can do.

(Sally)

A walking stick is known to be a useful coping tool for lower limb (knee or hip) OA but it can also be seen as a visible sign of some disability. Although most participants' presented to the Phase I interviews with either a limp or a rolling gait, their stories reflected a reluctance to using a stick; there appeared to be a definite stick stigma. Bridget had developed “a bit of a gait” and did not like the way she walked but was too proud to use a stick. This appeared to be true for many of the participants at the Phase I interviews. Gary was fearful of developing reliance on a stick:

I try not to...Jesus, I don't know what'd happen if I had to start using the stick...if you use them once and then you think oh, that wasn't bad so you use them all the time and then you forget how to walk without sticks.

(Gary)

At the Phase II interviews several participants had changed their mind and were now happy to use a stick when walking. This change in attitude appeared to relate to further deterioration of their condition with increased pain levels and, for two female participants, a need to feel the

security afforded by walking with a stick. Using the stick enabled participants to stay active and for Gary, persevere with walking:

I take it when I'm walking (the stick)...because I've got to walk.

(Gary)

..I'm relying more and more on the stick, more for security than anything, and like sort of on a windy day, well I'm blimmin sure I'd have my stick.

(Louise)

4.2.3 The Research Story

The Research Story captures participants' experiences of being involved in the randomised controlled trial (RCT), their reasons for being involved, what their expectations and hopes of the programme were and, where appropriate, their experience of the physiotherapy programme. The title of the first subordinate theme, *Give it a Go*, was a phrase used by several participants in response to the invitation to take part in the research project (the RCT). It encapsulates how many participants approached the research project. The second subordinate theme, *Shown a Signpost* reflects on participants' expectations and hopes of the programme, their experience of it, and their views on surgery and the future.

Give It a Go

In response to the invitation to take part in the research project, "I'll give it a go" was overall a positive approach; it portrayed the view that there was nothing lost by trying, but it also has an element of not being too surprised if it does not work out. Participants did not perceive there were many alternatives for treatment of their OA; several saw the research programme as a lifeline, given they had been taken off the surgery list again (participating in the study did not affect what happened with the waiting list). For many participants other physiotherapy options were seen as being expensive or not particularly effective whereas surgery, while perceived as being the most beneficial option, was not available to them. Even though participants were prepared to "give it a go", they were ambivalent about how effective the physiotherapy programme would be for them; their responses often included a sense of desperate buy in to the programme. On the one hand the programme embodied the idea of

hope, that it may help them, even though they were at the same time unsure this would be the case:

So I thought, oh well, I'll give it a go anyway, I mean I'm prepared to almost give anything a go now, you know, just to see if it does help.

(Emily)

On the other hand, many participants held the altruistic belief that other people might benefit from their participation in the research programme even when they themselves had doubts that it would benefit them:

Can't do any harm, have a crack, yeah. It may help me, if it doesn't help me, may help somebody else.

(Michael)

I just decided well I've got nothing to lose, and this may help me and it may help other people too, which is a good thing.

(Rebecca)

Shown a Signpost

In the Phase I interviews participants' hopes and/or expectations of how the research programme would benefit them were influenced by several factors; their beliefs, perceptions and experience of their OA condition, their uncertainties relating to the programme and their beliefs about joint replacement surgery. Participants were unsure how the programme would impact their OA but many believed surgery would ultimately be required to fix their condition and facilitate their return to normal activities; this strongly influenced their hopes and expectations of the programme. Participants often juxtaposed their hopes for the programme with their beliefs about surgery. Greg believed that getting his knee operated on would enable him to return to work; this hope was embedded in a vague altruistic reference to the wider OA community:

I hope that it will give me easing of the pain and also that the research that these people are doing on osteoarthritis, I hope that they can get it together and be able to go to the orthopaedic department and say, this osteoarthritis on people is a lot worse than you think it is; apply for extra funding to get these operations done...

(Greg)

At the Phase I interview Mark was quite clear in relating his hopes and expectations of the programme to his belief that he would be receiving surgery:

Hopefully it will help me regenerate some muscle; I would like to have some muscle regenerate before I have surgery cos I believe that would aid recovery.

(Mark)

At the completion of the programme, Mark was “managing a lot better than what I was”; he had almost halved his pain medication with the exercises and he was “coping with it better”. Despite these changes, Mark was still adamant he needed surgery.

Mary stood out as being the only participant with a specific goal in mind for the programme; this was to get back to horse riding; “riding was a central part of my life since I was a child”. She played down her goal and its physical demands to demonstrate the enormity of the goal for her. For Mary being able to ride again was an important outcome and a way of judging the programme success for her:

I’m quite goal directed so if I feel that I can, if it’s going to give me something that I can achieve...if I could achieve getting on a quite little pony and just having a quiet little pony and just having a quiet hack around I’d, that would be a huge achievement for me”...I think my hopes were too high, I think perhaps that’s – perhaps I – and you know, just – I really really really wanted to get back on a horse again...and then when I could see it wasn’t even going to start to address that, then I - so probably my expectations were unrealistic, really.

(Mary)

Even though many participants were sceptical about the possible benefits of the programme, the overall impact was positive. Greg’s comment “the further that treatment went on, believe it or not, the better it felt” reflected how many were surprised by the improvement they gained from the programme. Mark summarised what most participants felt...“I’m managing a lot better than what I was”. Participants described a range of functional improvements; for Tom being able to get in and out of a chair was a “big improvement” while Bridget had become “more conscious of how to walk up and down stairs”; improvements in gait were often linked

to increased confidence with physical activity. Almost all participants discussed the psychological benefits of the programme using expressions such as “restored confidence, being “more aware”, “more in control” and being in a “better mental state”. A combination of having more knowledge about their condition and improvements in physical functioning enabled participants to feel more confident. For Kirsty the programme had been “a sign post in the right direction”; she talked very positively about the effects of the programme and felt she had regained some measure of control over her life:

...it was the signpost of what to do and where to go that was the biggest benefit that I got... and given me a great deal more confidence, because I might have avoided doing things even more if I hadn't been assured...through education I manage it better now and as far as doing things... it puts me in control, in a way.

(Kirsty)

Bridget, Mary and Rebecca all felt they had benefited from the programme in different ways but for them it was “too late”. Rebecca and Mary had fully engaged with the programme in the early stages and had both spoken positively about the programme and the impact of the prescribed exercises. At the Phase I interview Rebecca had been particularly enthusiastic about the difference it was making for her:

The programme's already showing me that I am capable of doing more than what I was doing and I can have a better quality of life if I keep the exercise up and keep moving. I can't do the things that I used to be able to do, but I can still be active.

(Rebecca)

At the Phase II interview Rebecca provides a rationale for why the programme had not worked for her. Her initial enthusiasm regarding the impact on her life had changed to disappointment; she reflects on her underlying, unspoken hope that the programme would fix her hip:

...unfortunately I think it was too late for me...but I don't think there can be any long term benefit from it because my hip's in such a bad condition to start off with...initially I felt so good and I felt so wonderful that I thought yeah this is it. And that's probably why – I've just reached a plateau now and the benefits are not

what I thought they would be at the end of the programme because I felt so good at the beginning of the programme...I guess that's a realisation too, when you come to the end of the programme that okay you, I have improved heaps, but it's – doesn't fix it, and I guess that's probably what I wanted, it fixed.

(Rebecca)

Gary entered the programme with little expectation of any change and a fixed belief about how his knee would be helped. At the Phase I interview he was sceptical of making any improvement with the programme but hoped that it might “free it up a wee bit”. Concomitantly he held a strong belief that “I'm at the stage where both my knees have got to be replaced”. He engaged with doing some exercises but also believed that activities such as walking up and down stairs also counted as “doing my exercises”. On completion of the programme his assumption that it probably wouldn't make any difference to his symptoms was confirmed:

Oh I suppose it was alright [on being asked how he found the programme]. My knee's no different, it's no different now to what it was when I started...if anything, it's got a bit slower...same amount of pain. Because you know, I know myself, it's not going to get any better until they operate on it.

(Gary)

Despite being sceptical about gaining any improvement from the exercises, many participants spoke positively about the impact of the exercises on their life. At the Phase I interviews participants described the exercises as “just making a difference” and were noticing improvements in gait, confidence, functional activities, mobility and strength. At the Phase II interviews, many perceived it was still worthwhile to continue with them and cited maintaining mobility and function as the main reasons. For most, the difficulty was maintaining the motivation to continue with formal exercises without the structure of the programme. When questioned about ongoing exercises many participants were defensive and quick to equate general physical activities with doing exercises.

Mary was allocated to the combined therapy group and spoke about being “very lucky” because “I'm in the group that has both the manipulation and the exercises”. At the Phase I interview she was very positive, describing functional improvements and felt that the programme was “just making a difference... benefiting me even just within a month”. Mary

maintained the exercise regime (for both hips) while she was in the programme and attributed her progress to the passive manipulation rather than the active exercises based on her previous experience of physiotherapy:

and it became clear to me that the manipulation was probably contributing more to effectiveness, cos I've had physio before and done some exercise and things, so the manipulation, I'd come out of there feeling freer....

(Mary)

Once the programme was finished, Mary lost her motivation to continue with the exercises citing she had not made enough progress; “you need to see some progress for coping with the pain, cos the exercises were painful”. She voiced her disappointment with her own lack of commitment to the exercises and once again emphasized the value of manipulation:

...the programme showed me was that the physiotherapy he gave me could be helpful, particularly the manipulation part of it...I have been slack about doing the exercise...the manipulation has freed me up, but without that, it's actually painful.

(Mary)

Michael had also been in the combined therapy group and when questioned about what he thought the benefits of the project were, referred to the perceived impact of manual therapy:

...well the one I was on, the actual manual physio on it, that was good, that helped, you know, I'm sure that helped it quite a bit too. That combined with the exercises and yeah, it was good.

(Michael)

All participants were enthusiastic and positive when discussing their experience of being in the research project: Kirsty exclaimed that she “had plus plus plus attention and benefit, right from the word go”; Rebecca found that “they were always on time, well organised...it was brilliantly run” and Tom described the programme as being “absolutely excellent”. The physiotherapists involved were described as inspirational, helpful and motivational. In Bridget's case, her motivation for staying in the programme was based around the physiotherapist's expectations rather than her own:

to be perfectly honest, if it hadn't been for Max...I probably wouldn't have kept going...and because his expectation was, you know, he expected you to do it, you rose to the occasion and did it...he's the best thing they've got going for that study.

(Bridget)

The majority of participants in the three treatment arms of the RCT appeared to have engaged with the programme. It was an overall positive experience for most participants with many developing better coping and management skills. Despite this, the majority of participants in the interview study (RCT and non-RCT participants) still believed that JRS was necessary for their OA hip or knee condition.

4.2.4 The Surgery Story

The third superordinate theme, *The Surgery Story*, describes participants' perceptions, beliefs and expectations of JRS and the issue of being at the 'mercy' of the health system. At the Phase I interviews participants were asked their views of surgery in the context of managing their OA (non-RCT participants included). At Phase II, the questions focussed on the impact of the physiotherapy programme in changing, or not, their views of JRS. The title of the first subordinate theme, *Light at the end of the Tunnel*, was a quote chosen to reflect how many participants believed JRS to be the solution to their problems; the "fix-it" that would allow them to return to some level of normalcy. In addition, the need for surgery was often verified by a medical opinion in conjunction with observable X-ray changes and for most, worsening symptoms. The second subordinate theme was titled *Waiting 'n' Hoping* to represent participants' sense of powerlessness and resignation in relation to surgery. There was confusion with how to get on the hospital waiting lists, how to stay on the waiting list and the subsequent frustration of waiting on the waiting list.

Light at the end of the Tunnel

The perceived benefits and expectations of surgery did not appear to be related to the relief of symptoms alone, although for some participants, pain relief and restored function were the primary outcomes. Most participants believed surgery would allow them to regain some measure of control over their lives and facilitate a return to their usual activities. Louise at fifty-nine years of age and living on her own, was worried about age discrimination in the

work force and believed surgery would enable her to return to work. She was frustrated with being taken off the waiting list because for her the operation had meant “some light at the end of the tunnel”, a chance to “get my life back together”. She articulated what many participants felt:

Well if I get the operation, I reckon I can cope with things...well I can get my life back into control... be in charge of my life again.

(Louise)

Kirsty had spoken positively about the impact of the programme and how she had regained some measure of control over her life. However at seventy-nine years old and living on her own she had concerns about becoming dependent and did not want to “finish in a chicken house” (retirement home); she believed surgery would help her maintain independence and quality of life:

So I would certainly take any work (surgery) that would make my quality of life better...do anything I can so that I’m independent...I wouldn’t turn it (surgery) down. Certainly not, I would go for it.

(Kirsty)

Greg had initially been sceptical about the benefits of participating in a research programme but at the Phase II interview he talked positively about the physiotherapy, the researchers, how he enjoyed the research and that it had “most definitely” changed his attitude in relation to coping with his OA. At a functional level he reported minimal change. In spite of this he continued to do the exercises regularly because it helped give “that wee bit of mobility” but ultimately there was no change to the pain. Greg was anxious about being unemployed at age sixty-two, so for him surgery was about relieving the pain and being able to work:

I’m unemployed, I can’t work because of the pain...I’m pissed off. Because I’m sixty-two, I want to get back into the work force but I can’t until I get my knee operated on.

(Greg)

Some participants described their hope of being able to return to recreational activities after surgery. Bridget and Emily expected it might give them a bit more mobility, but were

undecided about the outcome. Bridget, along with other participants, felt surgery was inevitable but expressed doubts about surgery being the cure after talking to other people who had experienced joint replacement surgery:

I know that surgery's not the answer either, it doesn't cure everything. It might alleviate some of the pain and discomfort, but it still has it's own problems...cos I've talked to people who have had joint replacement.

(Bridget)

In contrast Rebecca had no qualms and her expectation of surgery was strongly linked to relief of pain symptoms:

No I don't want to delay it, why do you have to live in pain..? If they said to me I could have it tomorrow, I'd be in there tomorrow.

(Rebecca)

Participants' beliefs about the need or inevitability of surgery were confirmed by a range of factors. For some, expert medical opinion had seeded the idea of surgery at an early stage. Gary was told when he injured his knee 45 years ago that "you're going to have trouble with it in fifty years, they said"; Bridget's expectancy of surgery grew from being told seven years previously that "what was there was eventually going to need to be replaced". Greg's belief about his knee deteriorating was confirmed by what the doctor had said and the X-ray results:

My doctor has recommended from day one the knife...he told me right from day one, once he got the first X-ray back, that my knee was, to put it mildly, stuffed, and that it would never get any better; and it hasn't.

(Greg)

Participants talked about a specific medical diagnosis (OA), confirmed by X-ray that determined the need for surgery. X-ray findings were viewed as "objective" evidence of the reality of their condition. However, some participants recognised that the diagnosis, X-ray changes and symptoms did not always marry-up. Mary was aware that although her X-ray changes were quite severe she knew it did not necessarily equate with "what you're experiencing with your function". Conversely Rachel was "surprised" that the second X-ray findings were not noticeably worse than those eighteen months previously, given her current

worsening symptoms. Sally's belief in the X-ray finding as a strong diagnostic indicator of surgery was evident when she reflected on her symptoms in relation to the X-ray:

I mean they X-rayed it and they could see that it needed to be done on the the X-ray, so that was obvious. So why it's taken so long to get any worse; maybe because I'm not doing as much walking as I used to do, I don't know. So I can see that eventually I'm going to have to have it replaced.

(Sally)

Waiting 'n' Hoping

The theme *Waiting 'n' Hoping* highlights the lack of control many participants experienced while being on a waiting list; they were in an invidious position of just waiting and hoping that they would get surgery. Many were confused and frustrated by the seemingly nonsensical approach to surgery and the waiting lists. There was often a discrepancy between the specialist suggesting the participant would benefit from surgery and a letter from the hospital stating the participant did not meet the criteria:

I've just got a letter from the manager, saying that although both surgeons thought that I was suitable for and would benefit from hip surgery, I'm sorry I didn't meet their criteria to go on their waiting list.

(Mary)

He said I would benefit by an operation, but not bad enough to go on the waiting list...now can you understand that? It's double Dutch, isn't it?

(Emily)

All participants had a story about the hospital waiting lists, whether it was the difficulty of getting on the list, staying on the list or the length of time waiting. Rachel was ambivalent about surgery because her priority was caring for her 100 year old mother at home. She talked about having to "think of her first and then myself and you just do what you got to do to get on and don't wallow in it". Despite her stoical attitude Rachel had visited the orthopaedic surgeon and been told she would need a new hip but just not yet. For Rachel it was about the safety net of being in the system, although she also expressed some doubt about how easy it would be:

...but anyway, I said well, I just wanted to see you because I wanted to be in the system and he said oh well, when you feel that you need a new hip you come and see us, and I thought well it won't be that easy, I don't think.

(Rachel)

Sally had a similar story; she thought surgery was not imminent but rationalized keeping the orthopaedic appointment on the basis that her hip could deteriorate suddenly therefore she needed to keep herself in the system:

But I don't know what it'll be like six months down the track, which is the reason I haven't taken myself off their list, because you never know; what if it might suddenly deteriorate and you don't want to be – have to start all that process from the beginning again.

(Sally)

4.3 Summary

Data from the interview transcripts emerged into three main themes, namely *The OA Story*, *The Research Story* and *The Surgery Story*. *The OA Story* provided a narrative of the participants' experience of their condition, highlighting the emotional, mental and physical cost of living with a painful, deteriorating joint problem. *The Research Story* reflects the experience of participating in a clinical trial physiotherapy programme and how it influences (or not) their ongoing management and perception of their condition. *The Surgery Story* captures the participants' stories of powerlessness, frustration and their hopes of what the health system might deliver - surgery. The following chapter will discuss the results in relation to the literature.

Chapter Five

Discussion and Conclusion

5 Discussion and Conclusion

This chapter begins by proposing some links and relationships between the themes and subordinate themes identified in this study. The findings are then discussed in relation to existing literature. Relevant theme or subordinate theme titles will be put in brackets () to assist the reader in connecting the discussion to the findings. The researcher will comment on limitations and strengths of the study, followed by a summary of key findings and suggestions for future research. The chapter will conclude with a summary of the research project.

5.1 Introduction

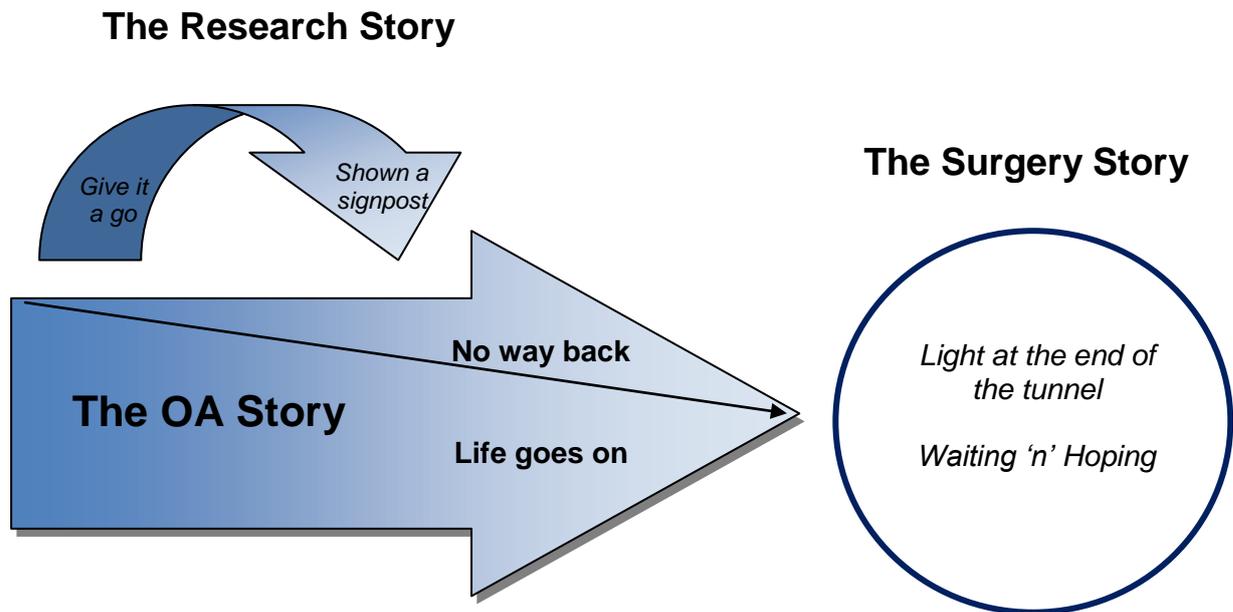
The primary aim of this qualitative study was to allow participants in a clinical trial of physiotherapy to describe from their own perspective what they believed and expected the impact of the programme would be on their OA condition. Participants were interviewed in the early phase of the physiotherapy programme and on completion of the programme. Results show that being in the trial did not significantly alter participants' perceptions of the trajectory of their condition or the need for JRS. However, the programme did make a difference in that it changed their ability to cope and better manage their condition: they described improvements in physical functioning with subsequent psychological benefits and improved quality of life. Although participants engaged with the programme they concomitantly constructed personal meanings of their knee or hip OA which influenced their perception of the need for surgery. Horne, Weinman, and Hankins (1999) stated that patients form their own implicit models of illness which are strongly influenced by their interpretation of symptoms; similarly the symptoms experienced may influence beliefs about treatment. For participants in this study the day-to-day lived experience of OA as a progressive, painful, disabling condition, in combination with medical opinion and observable X-ray changes validated their expectations of surgery. Their overall response to the physiotherapy programme was modified by the perceived severity of their condition, their beliefs around long-term outcomes, and the expectation of surgery already implanted either by expert medical opinion or perhaps simply as a result of being listed for surgery.

The sampling strategy for the main research question of this study comprised participants from each of the four intervention arms of the RCT. The RCT participants received either: (a) an exercise therapy programme; (b) a manual therapy programme; (c) both exercise therapy and manual therapy; or (d) no trial physiotherapy. The sampling strategy for the secondary question comprised people with OA who were eligible for the RCT but who chose not to take part; this makes up the fifth group. For the current study, the sampling strategy did not make a difference to the results. It was clear from the data analysis there was no thematic differences between the five groups of participants, therefore they were analysed together as a single data set. Although it was possible to detect subtle differences between groups' lived experiences, *The OA Story* was common narrative of all five groups.

5.2 Relationships between Themes and Subordinate Themes

Chapter three outlined the three main themes and subordinate themes that answered the research question, with quotations from participants' narratives. The analysis indicated a trajectory of OA that culminates in total JRS. Throughout the narratives participants used descriptions that shaped the picture of a one-way journey. Phrases such as "it's all downhill", "no way back" and "no where to go" metaphorically presented their condition as a one-way road with the physiotherapy programme as a 'temporary detour'. Not all participants perceived their condition as necessarily being on a downhill trajectory, nevertheless for most, the journey was the 'one-way road' with surgery at the end. The diagrammatic representation below does not portray a model or theory, nor was it the intention of this study to do so, but its purpose is to assist the reader in seeing the overall picture of how the themes and subordinate themes fit together.

Figure 5.1: Relationships between Themes and Subordinate Themes



The concept of describing illness experiences or processes as a journey is not new to health care literature. Marcinkowski et al. (2005) in their study of the patient perspective of total knee joint arthroplasty, described undergoing surgery as being “like a carefully navigated major journey” (p.206). In the figure above, the dominant theme, *The OA Story* is represented by a large horizontal arrow to reflect the centrality of this theme to both *The Research Story* and the *The Surgery Story*: it also represents the ‘road’ to surgery. The internal downward sloping line reflects, for some, the perceived downhill trajectory of their OA condition. Participants’ belief that deterioration was an inevitable consequence of having OA (*No Way Back*) was a predominant factor underpinning their expectations not only of the physiotherapy programme but of the need for surgery. The pervasive and progressive nature of arthritis symptoms (*No Way Back*) and their effect on physical, social and occupational activities was creating significant disruption of their lives. Activities of daily living in addition to work and leisure pursuits were increasingly limited and compromised; pain management was becoming increasingly important to maintain a level of function; for many the physical and mental costs were taking its toll. Nevertheless, despite their ongoing difficulties and frustrations, most participants had developed coping mechanisms and adapted to “find a balance” in order to carry on (*Life Goes On*). They described a stoic need to “plough on” with life, persevering with a positive attitude of adapting and coping.

The Research Story is depicted by a smaller arrow which initially curves away from the central *OA Story* theme but eventually feeds back into it. For participants in the physiotherapy intervention groups (whose stories contributed to *The Research Story* theme), their beliefs about the deterioration of their condition and the severity of their symptoms meant they were initially both ambivalent and sceptical of what could be accomplished by participating in the clinical trial programme (*Give it a Go*). Despite these initial doubts, their overall response to the physiotherapy programme was extremely positive. They had not expected to experience significant improvement in their condition and were surprised that while in the programme, it “made a difference” (*Shown a Signpost*). The combined effects of education and exercise appeared to improve their ability and confidence to perform everyday activities which concomitantly produced psychological benefits associated with better functioning. For some, the exercise regimes also resulted in decreasing pain levels and pain medication. Overall these participants appeared more confident in their ability to manage their condition (*Shown a Signpost*). Following completion of the programme this response began to decline once contact with the programme was withdrawn. In a trial examining the efficacy of a chronic disease management programme for OA knee, Lamb, Toyne, and Barker (2008) noted that being on a waiting list for surgery could be one factor that affects continuing adherence to a programme. The programme of prescribed strengthening exercises was delivered by a physiotherapist and progressed on a weekly basis. In the patients on the waiting list, the response began to decline once contact with the physiotherapist was withdrawn. This contrasted with people who were not on a waiting list; they continued to show a positive response to the programme (Lamb et al., 2008).

The Surgery Story is represented by a circle, being the end-point of *The OA Story* journey. In spite of the positive effects of the programme, the majority of participants expressed either the wish for joint replacement surgery (JRS) or suggested that it was ultimately inevitable. Surgery was seen as the solution (*Light at the end of the Tunnel*) to their problems, whereby their lives would return to some level of normalcy; several participants spoke of surgery facilitating their return to work. Meanwhile, the frustrations of living with a debilitating condition were mirrored by the frustrations of being on the waiting list and waiting for surgery (*Waiting ‘n’ Hoping*). The perceived vagaries of the waiting list system had an impact on their mental health. In an interpretive-phenomenological study examining the lived experience of being on a waiting list for total hip or knee joint surgery, Sjolting, Agren, Olofsson, Hellzen, and Asplund (2005) found that caring-suffering occurs when peoples’

caring needs are unmet. The system which is ultimately supposed to help them is the cause of suffering (see section 5.5.2, A Life on Hold).

In the following sections of this chapter, the findings will be discussed in relation to the existing literature. To assist the reader, the three main themes from the results, *The OA Story*, *The Research Story* and *The Surgery Story* will be used with interpretation points as subtitles.

5.3 The OA Story

The findings of the *The OA Story* complement the quantitative literature (and other qualitative literature) that identifies factors such as pain, immobility and difficulty with daily activities as important problems for people with OA.

5.3.1 Disrupted biographies

In the sociology literature ‘disrupted biographies’ is a term that has been used to represent the experiences of people with chronic illness: it embodies how they perceive illness and disability as a profound disruption to their life stories (Sanders, Donovan, & Dieppe 2002). In the current study, *The OA Story* illustrates how participants experienced their symptoms as a source of biographical disruption; their daily lives and life choices were increasingly hampered by the impact of disabling symptoms, in particular joint pain. An interpretive sociology study by Sanders et al., (2002) examined the way in which people experienced symptoms of OA and the implications for the management of symptoms. They explored the significance and consequences of OA symptoms in a cohort of people aged between 51 and 91 years; a similar age range to the current study (53 to 86 years). They found that older participants often experienced their symptoms as both a normal part of their story and as a source of biographical disruption, whereas younger participants (those in their 50’s and 60’s) did not refer to their joint problems as being natural and degenerative, or as being inevitable. They did not perceive their symptoms as being normal, which influenced their approach to management and their determination to get formal treatment. The findings in relation to the younger participants are illustrated in the current study: participants’ experience and interpretation of their OA symptoms, and the perceived consequences of these symptoms (*No Way Back*), influenced their expectations and beliefs of the programme and future treatment.

In the Sander et al. (2002) study older participants, although acknowledging the disruptive impact of symptoms, also subscribed to the notion of disability being a normal part of old age and tended to play down the significance of their problem. Osteoarthritis was something to be tolerated while the experience of joint pain and disability was perceived as part of getting old. Other studies have shown similar findings whereby older adults who view arthritis as a normal and expected part of ageing, modify social roles and activities accordingly. In many cases the older adults have perceived this as justification for avoiding surgery (Ballantyne, Gignac, & Hawker, 2007; Clark et al., 2004; Sanders et al., 2002). In contrast, participants in this study, whilst actively engaged in adapting and modifying their lifestyles to manage their OA, focused more on what they believed would be the curative aspects of joint replacement surgery to restore their lives to normal (see section 5.5.1, Desire for Surgery).

5.3.2 The ICF construct

The notion of disrupted biographies is mirrored in the quantitative literature on the International Classification of Functioning, Disability, and Health (ICF). *The OA Story* findings complement the quantitative literature that identifies many factors, such as pain, physical restrictions, reduced participation in societal activities and depressive mental state as common features of OA, particularly knee OA (Botha-Scheepers et al., 2008). The ICF is a general health status framework traditionally used in arthritis research and is seen to comprehensively represent the breadth of possible experience of patients (Rat, Guillemin, & Pouchot, 2008). The ICF aims to provide a basis to understand and study health states, as well as their consequences and determinants (Rat et al., 2008), however as Rat (2008) noted, “it emphasizes *what* has to be measured but not *how* to measure” (p.1719).

Within the ICF framework disability is recognised as a dynamic and complex interaction between the disease, personal and environmental factors. Disability is seen as the outcome of the relationships between deviations from normal body function or structure (impairments), difficulties in executing activities (activity limitations), limited involvement in life situations or roles (participation restrictions), and contextual factors (environmental factors and personal factor). Contextual factors such as health system and comorbidities reflect the fact that human beings and consequently their level of functioning and disability are seen in interaction with their context (Weigl, Cieza, Kostanjsek, Kirschneck, & Stucki, 2006). Environmental factors are physical geography and health system, while personal factors can include psychological factors (e.g. learned helplessness, pain-coping, self-efficacy) as well as co-

morbidities such as depression and coping styles. When applied to OA, the disease can lead to impairment (e.g. joint pain) which gives rise to limitations in activities such as walking and self-care. These in turn, may restrict participation in broad roles and societal activities such as employment, leisure and social involvement (Hawker & Gignac, 2006).

Throughout the *OA Story* the interaction of the three central ICF components (participants' impairment, activity limitation and participation restriction) was widely represented in the narratives. Participants described increasing pain levels and reduced function which contributed to restricted participation in wider societal activities that gave their life meaning. For most, staying active, maintaining work status, and "keeping up social contacts" was perceived as being important for coping and mental wellbeing (*Life Goes On*). Loss of leisure activities with the accompanied loss of social contact impacted their emotional wellbeing. Evidence in the wider arthritis literature shows that people with arthritis often give up or limit important roles or activities (Beaton, 2000, cited in Hawker & Gignac, 2006; Sanders et al., 2002). Hawker and Gignac (2006) argued that maintaining valued roles like social involvement is very important for people with arthritis and suggested there is a need for interventions which focus on increasing peoples' levels of participation in such roles.

The impact of psychological co-morbidities such as distress, frustration and despair in creating disability among people with OA is well documented in both the qualitative and quantitative literature. Recent quantitative studies have weighted the importance of contextual factors (environmental and personal) in modifying the association between first level ICF components thus presenting a more 'holistic' account of the OA experience (Botha-Scheepers et al., 2006; Weigl et al., 2006). Participants in this study described (at length) the struggle and frustration of increasing physical limitations and pain, focusing on what they were no longer able to do. A study by Katz and Yelin (2001) which investigated what activities matter most for people with arthritis, found that the loss of abilities to engage in recreational and social activities, significantly increased the risk of depression. Consistent with the current study, everyday struggles, frustration and depression were associated with the participants' experience of pain and ongoing disability. A study by Botha-Scheepers et al. (2006) evaluated the effect of illness perceptions (including perceptions of likely chronic duration of their condition, belief in control over their condition and whether it can be cured or not) and mental health on self-reported activity limitations in the lower extremities. Patients who believed OA had a large impact on their functioning and who believed in the chronic duration of their condition reported more limitation in activities than expected, based

on clinical evaluation of impairments. This finding supports work by Hampson (1997) who found that people who report more symptoms and more pain also perceive their arthritis to be more serious, in the sense of being long term and having negative consequences.

In the current study participants discussed making significant adjustments in their lives to accommodate the increasing pain levels and activity limitations (*Life Goes On*) but as Rebecca in this study pointed out, the impact of OA was on her “whole lifestyle really” which ultimately “takes a toll on you mentally as well”. The pain, reduced function, loss of activities and reduced social contact were difficult to cope with: participants described emotional and psychological states of being “frustrated”, “cranky”, “miserable”, “annoyed” and “depressed”. These consequences of OA are also described in other qualitative studies that have explored patients’ experiences of OA knee (Hall et al., 2008; Tallon, Chard, & Dieppe, 2000; Toye et al., 2006). In Hall et al.’s (2008) study investigating the physical and psychosocial consequences of living with OA in daily life, the most predominant emotions experienced were depression, frustration, inadequacy, fear and embarrassment. Consistent with findings in the current study, frustration was coupled with no longer being able to continue with the simplest activities that they once engaged in. In their study investigating the health experiences and priorities of individuals with OA knee, Tallon et al. (2000) found that psychological impacts such as anxiety and depression were a major issue to many individuals.

5.3.3 The centrality of pain

Pain is inextricable from function

Pain was a constant intrusive presence and was qualified with reference to effects such as reduced mobility and increasing restrictions. Participants did not talk about pain directly and very few participants described their pain, but referred to the effects of pain in terms of how it impacted their functioning. This has been found in other qualitative studies looking at the pain experience of people with chronic OA of the hip or knee joint (Hall et al., 2008; Hampson, 1997; Gooberman-Hill et al., 2007; Maly & Krupa, 2007; Toye et al., 2006). In a qualitative study involving six focus groups Gooberman-Hill et al. (2007) explored the pain experience of people with chronic pain of the hip or knee. They found that participants’ description of pain was inextricably linked to their discussion of function: participants were very aware of the role of position and movement in triggering or exacerbating their pain

which necessitated adapting or avoiding certain activities. Goberman-Hill et al. (2007) identified three key elements: pain affected by physical position, pain triggered or exacerbated by certain physical movements and pain that was related to activities that involved difficult positions or movements. These three elements were widely represented in the current study and often resulted in participants expressing reluctance to engage in particular activities (social, recreational or everyday tasks) because of the position or movements required. In addition, participants often emphasised the difference between then and now; between present and past selves. Throughout the narratives statements of activity limitation were often prefaced with “I can’t...” or “I used to...”: “I can’t stand up for the length of a rugby match...” and “I used to dance” (*No Way Back*). Snelgrove & Lioffi (2009) suggest that these descriptions serve as an index of the degree of disability caused by pain... “the physical pain was accompanied by a sense of loss as participants described the discrepancy between present and past selves” (p.742).

Pain-coping mechanisms

Although pain was a barrier in the lives of the participants, pain also provided meaningful information particularly in relation to pacing activities (Maly & Krupa, 2007). Pacing involved either an *a priori* decision to limit activity to avoid subsequent problems or ‘an in the moment’ decision because pain was present during the current activity. In this study Rebecca described making *a priori* decisions based on the behaviour of her knee pain and known consequences: she would not go places where she was required to stand for any period because “I will either not be able to get home or I won’t be able to walk the next day”. Her constant monitoring and adjusting activities to avoid aggravating the pain was described as a form of “self-preservation”. Whilst pacing was a reasoned decision made by some participants, others chose to avoid the possibility of pain altogether by avoiding certain activities. Participants emphasized the importance of adjusting and adapting activities in order to maintain a certain level of functioning and to stay involved (*Life Goes On*).

Adaptive behaviour involved a range of both passive and active pain coping strategies similar to those illustrated in a study by Perrott et al. (2008). Perrott (2008) found that passive pain coping strategies (resting and limiting activities), were significantly higher in patients with knee OA than in patients with hip OA. Active pain coping strategies such as reducing demands – that is the maintenance of usual activities with limitation of intensity - were widely employed by participants in the current study. Participants also took a pragmatic approach to

copied positively and adapted situations in order to maintain their activities: for example using raised garden beds to avoid bending or a mobilised trolley at the golf course to reduce the amount of walking (*Life Goes On*). In a focus group survey of patients with OA knee, Tallon (2000) found a wide variety of coping strategies were used to manage their knee problems: carrying on regardless, taking medication as required, using aids to daily living, restricting movement and resting were reported to be the most helpful strategies, which is consistent with the findings from this study. In the current study the use of a walking stick was not readily adopted as a mobility aid. The use of such aids can be perceived as embarrassing and associated with old age (Sanders et al., 2002; Tallon et al., 2000). Zola (1982) suggested that many people living with disabilities, in striving to ‘successfully adapt’ are prepared to endure uncomfortable aspects of their condition, such as limping. (Zola 1982 cited in Sanders et al., 2002).

The mantra “learning to live with it” embodied not only passive and active coping strategies employed by participants but also a stoical attitude towards their situation. “Life goes on” and “learn to live with your limitations” were typical expressions used to describe their experience of coping with OA on a daily basis. This stoical attitude has also been observed by others who have studied people’s views about health and illness. The construct of stoicism has been found to be related to both positive and negative adjustment to illness (Yong, 2006). In some studies denial and stoicism have been linked with underestimating health needs while in contrast, stoic acceptance has been reported to have a positive association with quality of life. In the current study, the ability to cope was underpinned by a degree of stoicism and as Mark noted, you have to “just carry on”, which could be interpreted as having both positive and negative connotations. Other authors have found, in studying older peoples’ views about illness that stoicism is often prevalent in this population and may result in underreporting of symptoms, particularly pain (Yong, 2006; Sanders et al., 2002).

5.3.4 Disease progression

In a study by Toye et al. (2006), patients’ personal meanings of knee OA and total knee replacement (TKR) were important in that they affected decisions regarding the need for TKR. Included in participants’ ‘personal meanings’ were important beliefs about the progression of OA. In the current study, participants strongly identified with the belief that their OA condition would only worsen: the downhill trajectory of their condition (*No Way Back*). Consistent with Toye et al. (2006), contact with health professionals, in particular

surgeons, reinforced the idea that OA is progressive; many participants described being told they would “need an operation”. Greg’s belief about the trajectory of his condition was strongly affirmed by medical opinion ...“my doctor has recommended from day one the knife”. Evidence of disease progression was also reinforced by increasing pain levels and the uncertainty of any real change in their condition with the physiotherapy programme. Greg engaged with the programme and was routinely doing exercises, which he acknowledged helped, but “it’s not going to take the fact away that it’s got to be done”. Hall et al. (2008) in their study of peoples’ expectations of TKR described a “breakpoint” in the trajectory of living with OA knee. The experiences of pain, loss of functional and social activities, and the emotional consequences culminated in a “breakpoint” which led them to seek TKR.

5.4 The Research Story

The findings of *The Research Story* have been verified in other qualitative literature that discussed the benefits of an exercise intervention, specifically improvements in function that facilitate better mood states and feeling more in control.

5.4.1 Expectations of the intervention

Participants’ expectations of the trial were not based around an assumption that they would significantly improve or be cured. Most stated they hoped to achieve some benefit but were diffident about having any real expectations of improvement (*Give it a Go*). These findings are supported by Stone, Kerr, Jacobson, Conboy, and Kaptchuk (2004) who explored patient expectations in placebo-controlled RCTs. Similar to the current study they found that participants made a distinction between *hoping* for benefit versus any *real* expectation of improvement. As noted in similar studies, expectations or “patient anticipatory processes” (Stone et al., 2004. p.77) are not fixed but are continually shaped by inputs that include experience and information received both before and during the trial (Goossens, Vlaeyen, Hidding, Kole-Snijders, & Evers 2003). In the current study, there was discernable uncertainty about what could be hoped for, which, for some participants, could be attributed to not understanding their condition (Thorstensson, Roos, Petersson, & Arvidsson, 2006): as Kirsty exclaimed... “I’m thinking and hoping it will repair whatever”. In their study of expectancy Goossens et al.(2003) suggested that expectancy in pain control (how much do you expect to improve) may be functionally more related to affective processes similar to those involved in hope. When entering a new treatment, hope has been found to explain some

of the effects of expectancies. Given that participation in the RCT was voluntary, it is possible to reason that patients hoped to benefit from the programme.

Goossens et al. (2003) looked at a model of changing expectancies over the course of a cognitive-behavioural intervention and observed how this influenced treatment outcomes in chronic pain. Influences on pre-treatment expectancy are based on available information (including past experiences of ineffective treatment; input of health professionals) and may be high or 'too hopeful'. As a consequence they can have immediate positive effects on treatment outcomes. In the initial phase of treatment, factors such as relationship with therapist, the initial amount of information provided and an increase in self-efficacy can influence expectancy. At follow-up post-treatment expectancy can be influenced by post-trial experiences, relapses and therapeutic improvement (or not). If patients attribute therapeutic change to external factors, such as therapists' techniques, post-treatment improvements may be short lived and can easily become negative treatment outcomes.

The following section is an example of expectancy as a function of experiences before, during and after the trial. It demonstrates issues that influenced Rebecca's hopes and expectations of the programme, and the impact of the programme.

Rebecca entered the trial after being taken off the surgical waiting list again. She "was more than delighted" to be involved in the programme, "because if I didn't have this programme here that would have been the end of it". Given that the surgical option had again been taken away, there was no other perceived option available. Rebecca's unspoken hope was for the programme to "fix it" (that is her OA condition). She engaged fully with the programme, mastered the exercises and was routinely performing the exercises in spite of the pain because "the end result is good". Previous physiotherapy and exercises (she attended a private clinic) had not worked for her. Rebecca's explanation for the different outcomes was around focus: the previous physiotherapy "wasn't really focused" whereas with the current intervention she exclaimed... "I think it's so different now because it's just one-to-one focused". While in the programme Rebecca's ability to manage her condition improved dramatically: she felt more "capable", "confident", and "had a better quality of life if I keep the exercise up". Insightfully, she commented on why she might be functioning better on a physical level... "I mean it probably is psychological". On completion of the programme she expressed her disappointment in unmet hopes and expectations and reasoned that it was "too late". Although Rebecca was more confident managing her condition, "felt a lot freer" and spoke

positively about functional improvements, she had reached a “plateau” and was “despondent about getting any further”. She had increased her pain medication but was more confident in managing her pain which she attributed to the education aspects of the programme.

5.4.2 Benefits of programme

Physical

Being in the trial did not necessarily alter participants’ perception of the trajectory of their condition, however there were definite benefits from taking part in the programme that they were aware of and reported. Most participants were better able to manage their condition and as Bridget noted “it has made a difference” (*Shown a Signpost*). In the trial, prescribed exercise was a core part of the physiotherapy programme and all participants in each of the three active intervention arms received an individualized home-programme of exercises. The specifics of the exercise regimes depended on the intervention arm protocol (Abbott et al., 2009). In the current literature, exercise is seen as being effective in increasing function and decreasing pain particularly in knee OA (Thorstensson et al., 2006), although the specifics of an optimal regime are not clear. Most of the participants, while involved in the physiotherapy programme, bought into the philosophy of managing their OA through exercise. They ascribed improvements in pain levels, mobility, and general physical functioning to “doing these exercises”. The combined effect of education and information (*Shown a Signpost*), with improvements in physical functioning, empowered participants to manage their condition and as Kirsty states...“it puts me in control, in a way”. Thorstensson et al. (2006) found that being in control improved patients’ ability to handle their situation and cope with the problems related to knee OA. Similar to the current study, experiencing improvements in physical functioning, symptom relief and receiving guidance with exercises were important concepts for middle-aged patients engaged in an exercise intervention. Patients were aware of the health benefits from regular exercise but also believed that ongoing supervision was a prerequisite for exercise.

In the current study nearly all participants from the three clinical trial intervention arms adhered to the exercise regimes while in the programme but most struggled to continue with regular exercise once the physiotherapy sessions stopped. Many remained positive towards the perceived benefits of exercise but found it difficult to accommodate the exercises into daily routines; some rationalised that general physical activities equated to doing exercises.

These results are consistent with Campbell et al. (2001) who examined the reasons for adherence and non-adherence with home-based exercise regimes by patients with OA of the knee. In their study, all respondents initially adhered to the exercise regime while still seeing the physiotherapist, but found it difficult when the face-to-face sessions stopped. Campbell et al. (2001) suggests that continued adherence to exercises is contingent on the individual's perception of their symptoms, assessment of their effectiveness and their willingness and ability to incorporate the exercises into everyday life. A perceived positive outcome of the exercise intervention is also often a prerequisite for continued participation in exercise programmes (Campbell et al., 2001).

As in Campbell et al. (2001) study, participants' decisions to continue the exercises were reasoned and rational: maintaining mobility, reducing pain and as a coping-strategy while waiting for surgery were cited. Rebecca demonstrated that the reasoning underlying continuation of the exercises in the longer term was often more complex. At completion of the programme, Rebecca felt her condition had reached "a plateau now" and despite not liking the exercises and feeling she was not "getting any further" she had incorporated them into her daily routine. By contrast Mary discontinued the exercises post-programme. She had initially subscribed to the benefits of exercise while in the programme but rationalized that "you need to see some progress for coping with the pain, cos the exercises were painful". Rejeski, Ettinger, Martin, and Morgan (1997) in their study of knee OA and exercise suggest that changes in knee pain are critical outcomes of physical activity programmes given that pain is central to a person's health perception, and pain is the primary reason patients seek medical care.

It has also been suggested that ongoing adherence to physical activity programmes may be influenced by patients being on the waiting list for surgery (Lamb et al., 2008). Their study looked at the effects of a management programme for people with severe knee OA. The programme included a prescribed strengthening regime, supervised and progressed by a physiotherapist on a week-by-week basis over six weeks. For people on a waiting list for knee arthroplasty there was a significant drop off in response once contact with the physiotherapist was withdrawn. The majority of participants in this study were either on the waiting list or waiting to get back on the waiting list, which may have been a factor influencing ongoing exercise adherence.

The influence of psychological constructs

It is unlikely that improvements in function over the period of the intervention would be only due to physiologic adaptations (Rejeski et al., 1997; Jette & Keysor, 2003) or changes in the disease process. As mentioned above, functional improvements, being able to do more walking, negotiating stairs and driving, as well as reduction in pain medication, were effects participants attributed to the exercises and education delivered by the physiotherapists. Previous studies have suggested that improvements in function that occur with exercises may be more due to patients' confidence in their abilities (i.e., self-efficacy) to change performance-related disability, than physiologic adaptations (Rejeski et al., 1997; Marks & Allegrante, 2005). Self-efficacy is a prominent psychological theory popularized by Bandura (1977) who asserts that behaviour is the outcome of an interaction between cognitive processes and environmental events. In effect it emphasizes personal experience and that the patients' beliefs are more influential in their recovery than the severity of the illness (Lau-Walker, 2006). In social cognitive theory outcome expectancy and self-efficacy are two key psychological constructs that are discussed in relation to health behaviour and therapeutic interventions (Lau-Walker, 2006; Marks & Allegrante, 2005; Barron et al., 2007). Outcome expectancy is "a person's estimate that a given behaviour will lead to certain outcomes" whereas self-efficacy refers to "the conviction that one can execute successfully the behaviour that is required to produce the outcome." (Bandura, 1986, p.391 as cited in Barron et al., 2007). The two constructs essentially operate together, although outcome expectancy can be seen as a precursor of self-efficacy (Lau-Walker, 2006).

In the current study, participants' confidence and ability to manage their chronic condition (self-efficacy) was enhanced by the interaction with the physiotherapist. *Skill mastery* and *persuasion* have been identified as sources known to enhance efficacy expectations (Bandura, 1997 as cited in Marks & Allegrante, 2005). In the current study, participants' descriptions of learning and performing the exercises implied they were simple exercises and easy to master - "a piece of cake". They variously described the physiotherapists involved as being inspirational, helpful and motivational. Bridget highlighted the persuasiveness of the therapist when she said..."he expected you to do it; you rose to the occasion and did it". Consistent with Marks and Allegrante (2005) study, the physiotherapists provided education and information alongside persuasive communication to promote the adoption of the exercise regime. Rebecca was confident that "through their education I manage it better now" and Michael felt the programme had "made me more aware of doing the right things...". Overall

the experience of being in the physiotherapy programme was positive with many participants better able to manage their OA.

Favourable self-efficacy beliefs can potentially mediate the outcomes of physical activity programmes for people with chronic arthritis (Rejeski et al., 1997; Marks & Allegrante, 2005). In the context of arthritis (that is a chronic disease requiring ongoing management), higher pain self-efficacy beliefs have been found to be predictive of higher levels of physical functioning, adaptive coping efforts, less disability and depression, and reduced avoidance behaviours; ie individuals are more likely to persevere. Given that exercise is perceived as an important intervention for promoting health among persons with chronic arthritis and the construct of self-efficacy is known to make a difference in how people *feel, think* and *act* (Lau-Walker, 2006), effective physiotherapy programmes need to be aware of the psychological needs of the patient as well as their physical needs (Jette & Keysor, 2003).

5.5 Surgery Story

Serendipitous findings are a major part of using a qualitative approach according to Turner et al., (2002). Although the focus of this study was on participants experience of their OA and the impact of the physiotherapy programme, many participants chose to give detailed descriptions of issues relating to JRS, such as being on the waiting list, staying on the waiting list, getting back onto the waiting list and referrals to specialists.

5.5.1 Desire for surgery

Contrary to the current literature, participants in this study perceived total joint replacement surgery as the primary solution to their OA condition (*Light at the end of the Tunnel*). In an editorial by Hawker and Gignac (2006) she noted that “studies consistently indicate that among people living with disabling arthritis in whom total joint replacement (TJR) is indicated, there is significant unwillingness to consider TJR as a treatment option” (p. 526). A Canadian population-based survey of individuals with disabling hip or knee arthritis by Hawker, Wright, Badley, and Coyte (2004), found that the majority of participants felt that arthritis pain and disability should be extreme before TJR was considered. These findings were corroborated by O’Neill et al’s.,(2007) qualitative meta-synthesis of decision-making for total knee replacement surgery. Patients assumed they needed to be in constant pain and virtually unable to move before seriously considering surgery. These misperceptions were

mirrored by the opinions of the family physicians, who also waited until their patients' symptoms and disability were extreme before referring on to a specialist. Other studies of older adults' experiences of OA (see section 4.3.1, Disrupted Biographies), note that symptoms were often viewed as a natural part of ageing, therefore surgery was not seen as an option. Their decisions to avoid surgery were often reinforced by their interpretations of discussions with health professionals (Ballantyne, Gignac, & Hawker, 2007; Clark et al., 2004; Sanders et al., 2002).

The Surgery Story theme identified two distinct groups within the study; the first was the fatalistic "it's inevitable" group and the second, the "it's got to be done" group. For participants in the former, surgery was the only perceivable solution and outcome to the long term, downward trajectory of their condition; as Emily stated... "I'll have to have it done sooner or later". For those in the latter group, there was a sense of urgency around their wish for surgery based on returning to work and fixing the pain. Louise spoke for several participants when she said... "if I get this done, well I can get my life back into control, get back into the workforce, get off the benefit and be in charge of my life again...at the moment it's the pain that's controlling my life".

The perceived benefits and expectations of surgery did not only relate to relief of symptoms. Participants' reasons for deciding they needed surgery were multifarious and often reflected a desire to get back to a 'former identity' (Ballantyne et al., 2007), and to normalizing their lives: getting back to work, getting back to recreational activities, fixing the pain and taking control of their life again were significant factors that influenced this viewpoint. Their focus was on what could be accomplished following surgery (*Light at the end of the Tunnel*). These findings are similar to a New Zealand study of patient perspectives of total knee joint arthroplasty (Marcinkowski et al., (2005). In their study they described a process of "getting back to the future" which meant getting back to a life without pain and disability, something participants could only do by looking forward. Some participants in their study viewed surgery as the only way to carry on leading a normal life. The tools within the process of getting back to the future came under three categories - "enduring", "thinking twice," and "keeping faith". Many of the concepts within the "enduring" category are illustrated in the current study: concepts of struggling, frustration and looking ahead to surgery, so that they could get back to a meaningful life denied them by pain and disability. Participants' desire for surgery was shaped by their present circumstances of coping with a chronic disabling condition on a daily basis. As Dieppe et al. (2009) suggested, given the disparity between

clinical and radiographic findings, the need for surgery is more a reflection of the impact of the condition on their lives that dictates the need for surgery. Their present circumstances were not only defined by their symptoms but what they could do beforehand.

5.5.2 A life on hold

In New Zealand, patients are scored for publicly funded total JRS according to their degree of urgency for surgery. Patients placed on waiting lists are awarded a clinical priority access score by their surgeon. The higher the score, the greater the disease, indicating to the waiting list administrators how urgent a patient's surgery may be. The higher the score, the higher their priority on the waiting list (Fielden et al., 2005; Marcinkowski et al., 2005). The score is not validated which may result in a varying score for patients with the same level of disability and potentially variable waiting times (Fielden et al., 2005). Marcinkowski suggests that waiting list management for publicly funded joint replacement is politically topical given the degree of suffering in those on the lists, the known benefits of total knee joint arthroplasty and information known about timing for best surgical outcomes.

In 2005, Derrett carried out a research report on booking systems for elective services for the New Zealand National Ethics Advisory Committee. She noted that the booking system was very complex and information given to patients about the booking system was incomplete and variable. The original intent of the booking system had been to provide certainty about whether or not patients were to receive surgery, accompanied by indications of the length of waiting time. Derrett (2005) confirmed that ongoing uncertainty in waiting lists systems and false hopes of surgery leading to adverse effects was a prompt for moving to a more explicit booking system.

The health system, and by implication the booking system that operated in the region where the participants in this study lived appeared to provide inconsistent information regarding surgery. A recurring scenario described by participants was one where a specialist assessment of their OA hip or knee was made and surgery recommended; a follow-up hospital letter was received two- three weeks later usually suggesting they had insufficient points to be on the waiting list. As Louise explained, after the promise of surgery the "dear John" letter arrived to say "our waiting list is too long, you're off it". To get back on the list most participants described a process of going back to their General Practitioner for a letter of referral back to the specialist to be reassessed; for Rebecca this appeared to be a "hopeless situation".

Participants perceived a need to be on the waiting list and stay on the waiting list (*Waiting 'n' Hoping*). Despite the ongoing frustrations with the system, staying on the waiting list was seen as important, given they did not trust the system. O'Neill et al. (2007) suggested that patients find it difficult to live with both the uncertainty that underpins the course of their condition and the uncertainty caused by the indeterminate waiting time of surgery. In their meta-synthesis O'Neill et al. (2007) noted that "expectations of treatments are shaped by the balance between living a life on hold, and the perceived risks associated with surgery" (p.5). In the current study very few participants made reference to possible risks or problems they might encounter with surgery. They were focused on the perceived benefits of surgery but struggling with the lack of information and seemingly nonsensical delays. The paradoxical situation many found themselves in was summed up by Emily... "he said I would benefit by an operation but not bad enough to go on the waiting list...it's double Dutch".

Sjoling, Agren, Olofsson, Hellzen, and Asplund (2005) conducted an interview study in Sweden exploring the lived experience of being on the waiting list for arthroplastic surgery. The findings reveal that almost every aspect of daily life is affected by the indeterminate wait for surgery and the related experiences of pain and disability. The respondents' expressed a deep sense of lost dignity, powerlessness and frustration, which becomes a form of suffering. Sjoling et al., (2005) talked about caring-suffering which occurs when individuals caring needs remain unmet and when patients feel disparaged and neglected by the health service. The Swedish experience is reflected in the current study wherein 'the system' which is ultimately supposed to help them, becomes the source of struggle and cause of suffering. Dealing with a faceless system for some became a disempowering process, as Mary observes... "it's just like you're treated as nothing, really, you know, they just set you up".

5.5.3 Medical model

The participants' medical beliefs are apparent throughout the accounts in this study. A medical diagnosis confirmed by X-ray was important in confirming and identifying the need for surgery. These findings are consistent with those of Toye et al. (2006) who found that participants stressed the importance of X-rays as a way of defining the disease. Given the subjective nature of pain, radiographic changes provide an objective medical test for the participant to legitimize their symptoms and to some extent, their health behaviours (Kleinman, 1988, cited in Toye et al., (2006). This is an important issue given the evidence

suggests that the correlation between symptoms (pain) and X-ray changes is poor (Bedson & Croft, 2008; Dieppe et al., 2009; Toye et al., 2006; WHO, 2003). Bedson and Croft (2008) examined the OA knee literature and found a wide variation in the degree to which knee pain relates to radiographic knee OA and vice versa. They concluded that discordance between X-rays and symptoms is influenced by the number and type of X-ray views, the definition of pain and the characteristics of the study population. In a recent large prospective cohort study undertaken by a consortium of twenty orthopaedic centres in twelve different European countries, patients presenting for total hip replacement showed a wide variation in disease severity (Dieppe et al., 2009). Although most patients coming to surgery had severe structural hip changes, there was no correlation between clinical severity and radiographic severity. The authors stressed the need to assess patients on the basis of the impact of the condition on their lives, and not on X-ray severity, when considering them for surgery.

5.6 The Non-trial Participant Story

The secondary aim of this qualitative study was to explore the perceptions of a group of patients with osteoarthritis hip or knee who did not wish to participate in the clinical trial physiotherapy programme. The participants in this group were interviewed on one occasion. The participants reasons for not enrolling in the trial were largely based around practical issues: perceived transport difficulties, demands on time with fulltime work, not convenient - moving house, perceived inability to attend regular sessions or exercise regularly and severe co-morbidities which precluded attending and participating in the physiotherapy sessions. In an overview of literature pertaining to why patients do not take part in cancer trials, Cox and McGarry, (2003) noted that many factors of non-participation relate to practical issues such as those outlined above, in addition to lack of interest and the duration of the trial.

5.7 Limitations and Strengths

As for all research, there are limitations and strengths associated with this study. This was the first time that the researcher had embarked on a research project. Although experienced in clinical interviewing techniques, this novice qualitative researcher had to adapt to a different model of interviewing which may have influenced data collection. The researcher noted that some choices of language used in the interview potentially influenced participants' responses and their choice of language, and ultimately the interpretation of the data. For example, use of the word "hope" when asking about expectations of the trial; similarly when asking about

surgery, use of the word “inevitable”. Overall, the questions posed were open-ended which allowed participants to introduce new topics and ultimately provide some rich data. Within this context of a Masters thesis by a novice researcher, it was possible that qualitative data analysis did not achieve full depth. Smith (2004) suggests that a student new to qualitative analysis should be thinking of producing an analysis which is ‘good enough’.

It is important to note that it was outside the scope of this Masters project to include all areas of the analyzed data. The findings reflected what was important for these participants and valuable data were collected regarding their experience of living with OA and for some, their experience of a clinical trial physiotherapy programme. There were other areas that could be explored that would add value to this study; the impact of the medical opinion in shaping peoples’ actions; participants’ experiences of previous physiotherapy; and the impact of manual therapy. Although these topics were discussed at the interview, they did not present as important themes during the analysis.

The logistics of coordinating and carrying out research from a distance were both a strength and weakness of this study. The researcher was organized with the practicalities of recruiting participants from a distance and scheduling interviews. The early phase interviews took place at the same location as the physiotherapy intervention sessions and were scheduled either before or after the session to minimize inconvenience to participants. At the second stage interviews, many participants were willing to be interviewed at the same location. Two different research administrators were required for the recruitment of trial and non-trial participants. Recruitment of participants who declined to be in the RCT was problematic: the clinical nurse researcher self-selected participants for this group to provide a range of ages, given that most of the participants were very elderly with over-riding co-morbidities. It required ongoing discussion and contact with the clinical nurse researcher over a prolonged period.

Initial technical difficulties with the audio-equipment meant that two interviews were lost although one was retrieved by conducting a follow-up telephone interview. Other limitations to be considered are the use of NVivo 8 (QSR Ltd). The researcher was new to the software but could have made better use of it; there were also issues restricted access to the software by the university.

Nesting this qualitative study inside a randomized controlled trial was considered a strength of the study. The homogeneity of the population sample for the main research question was prescribed by their inclusion in the larger MOA trial. Similarly, the participants who chose not to be in the RCT but agreed to be interviewed already met the inclusion criteria for the trial.

Although this study aimed to include participants' experiences of both hip and knee osteoarthritis, the literature predominantly used in the discussions chapter related to patients' experiences of OA knee. A recent study by Gooberman-Hill, French, Dieppe, and Hawker, (2009) examined the differences in hip and knee experiences of OA and noted that although all participants described common concerns with activity limitations and pain management, the details of their concerns differed. For people with knee pain, stairs, weight, and stiffness assumed a greater prominence in their lives, while those with hip pain were more concerned with sidedness and groin pain (Gooberman-Hill et al., 2009).

5.8 Summary of Key Findings

Osteoarthritis is the most common form of joint disease and the leading cause of pain and physical disability in the older population worldwide. As with all western countries New Zealand's population is ageing and by the late 2040s, the proportion of the population aged 65 years and over will have doubled. This study aimed to capture the experiences of patients with OA participating in a physiotherapy clinical trial programme designed to reduce disability and pain. A qualitative study was conducted: interviews were used because they allow us into the world of the individual to see the content and pattern of daily experience. Sixteen individuals were recruited from the four intervention arms of the RCT and interviewed twice: once in the early stages of the intervention and post-intervention. A further five individuals who chose not to participate in the RCT were also interviewed on one occasion. Data were collected from the face-to-face interviews using open-ended questions. These were transcribed verbatim and analysed using interpretative analysis. Interview data contained three main themes, each with two subordinate themes. Theme one, *The OA Story*, provided a broad narrative of participants' experience of their OA condition. The pervasive nature of OA was impacting more and more on their daily lives. The first subordinate theme *No Way Back* reflected how they experienced living with a progressive, deteriorating, painful joint condition, while the second subordinate theme, *Life Goes On*, embodied the stoicism and perseverance required to cope with normal daily activities in the face of worsening pain and

increasing loss of function. Theme two, *The Research Story*, captures participants' experiences of being involved in the randomised controlled trial. This theme comprised two subordinate themes: *Give it a Go* represented the uncertainty of what the trial intervention could offer them; *Shown a Signpost* illustrated the positive impact participating in the trial had on participants. The final theme, *The Surgery Story* described participants' beliefs and perceptions of total joint replacement surgery and the problems they encountered with the health system. The subordinate theme, *Light at the end of the Tunnel*, symbolised surgery as the cure-all option for their chronic osteoarthritis condition; *Waiting 'n' Hoping* reflected the frustration and uncertainty of either being on a waiting list or hoping to get on a waiting list for surgery.

Many of these findings supported the existing literature related to patients' experiences of osteoarthritis, treatment expectancy, coping strategies and experience of exercise. An unexpected finding was participants' perceptions and willingness to consider total JRS as the 'cure-all' option for their OA hip or knee. Participants' were optimistic about the benefits of surgery and had very positive (perhaps unrealistic) expectations of their post-operative pain and level of function. This finding contributes a challenge to existing knowledge about willingness to have surgery: it contrasts to the current literature that consistently indicates significant unwillingness among people living with disabling OA to consider JRS as a treatment option (Hawker et al., 2004).

5.9 Future Research

This study provided some insight into how and why participants in a physiotherapy trial for the management of OA conceptualized their situation, and their subsequent actions or responses to treatment. Similarities and differences to contemporary literature were noted in the discussion chapter. Many of *The OA Story* findings supported qualitative and quantitative studies of peoples' experience of living with OA; the physical and psychosocial consequences; and the constant adaptations required to live with pain and functional limitations on a daily basis. Similarly many of *The Research Story* findings verified what has been described in the literature; the benefits of exercise interventions, specifically improvements in function that facilitate better mood states and a greater sense of control. For *The Surgery Story* findings, there were similarities to the international literature, but also a noted point of difference in that patients were keen and willing to consider TJR as a treatment option. Although the focus of this study was on participants' experience of their OA and the

impact of the physiotherapy programme, many participants chose to give detailed descriptions of issues relating to JRS: physiotherapy became an ‘interim’ measure while waiting for surgery.

This highlights some potentially interesting and important areas for future New Zealand-based OA research such as further investigation into why New Zealanders believe joint replacement surgery is inevitable and necessary; peoples’ perception of physiotherapy as an effective intervention for OA – will it mitigate their symptoms and reduce the need for surgery; and exploring the influence of beliefs in people with OA, with particular reference to the health system. These areas of research lend themselves to a qualitative approach.

The already significant economic burden of OA in NZ and the projected increasing cost of chronic conditions like OA with an ageing population require a multi-faceted approach. In terms of more general recommendations for future research understanding more about the patients’ processes may be valuable in informing therapeutic interventions for OA and provide a deeper perspective on the results of quantitative trials. As previously noted, qualitative studies can reveal a richer, more complete understanding of complex interventions such as those required for the treatment and management of OA. There is a growing recognition in the literature of the need to take account of contextual factors and individual differences when developing and evaluating the efficacy of complex interventions such as physiotherapy programmes.

5.10 Implications for Physiotherapy

The findings of this study also have implications for how physiotherapists interact with these types of patients, the influence of the highly motivational therapist and the timing of treatment and ability to provide regular follow up.

The following bullet points provide some reflections on physiotherapy practice that have come out of this study:-

- To enhance the efficacy of physiotherapy interventions and fully engage the patients, it is important to have an understanding of patients’ beliefs and their own implicit models of illness; if we know their perspective we can challenge their perspective. Understanding more about the patients’ process may be valuable in informing physiotherapy interventions (further qualitative research).

- As noted in the study, the construct of self-efficacy is known to make a difference in how people *feel*, *think* and *act* (Lau-Walker, 2006). In the current study, participants' confidence and ability to manage their chronic condition (self-efficacy) was enhanced by the interaction with the physiotherapist. In clinical practice, how aware are physiotherapists of the psychological components of the interaction that influence the outcome?
- Given the chronic nature of the condition and the gradual deterioration, how is physiotherapy going to keep in contact with these OA patients over time? Speculating from the data, this may require community-based group programmes perhaps jointly developed by the physiotherapists and the wider OA community to incorporate their needs.
- Physiotherapy may also need to reflect on what type of services will be provided (and marketed) to this group of people and at what stage of their condition so that the services continue to have relevance in their lives. The study highlighted the importance of continued participation in wider societal activities for people with OA and how this impacted their ability to cope and their mental wellbeing. Speculating on this, the long-term nature of the condition may require a change in mindset for physiotherapists and patients; for the physiotherapist, perhaps when to stop providing intervention; looking at what is required to maintain peoples' continued participation in the wider community; and for patients to be actively involved in maintaining their own wellbeing.

5.11 Conclusion

Interpretative phenomenological analysis aims to capture and explore the meanings that participants assign to their experiences. This research provided some understanding from the patients' perspective of the complex reasoning and processes associated managing a chronic OA condition; beliefs about the need for JRS; the effectiveness of physiotherapy and exercise; and ultimately their own health behaviours.

Being in a trial of physiotherapy did not change participants' perceptions of the trajectory of their condition or their perceived need for surgery.

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Appendix One:

Phase I Interview Schedule

Phase I Semi-structured Interview Schedule

Examples of open-ended questions and prompts for trial and non-trial participants

The following is a draft of potential in-depth face-to-face interview questions. The researcher might not use all of these question but these are examples of question that might be used to prompt fuller responses.

Section 1: Questions for all participants

General introduction questions:

Name, age last birthday, gender

Osteoarthritis related questions:

- Will you tell me about your osteoarthritis (OA)?

Prompts could include:

How long have you had OA?

Is there any family history?

How did it start?

Can you describe how it feels to have OA?

Will you tell me about your symptoms?

How do you cope with your OA?

What do you think makes it worse?

What do you think makes it better?

How has your OA/your symptoms changed over the time you've had it?

Will you describe how OA affects your life? – physical, mental, emotional

What treatments have you had for your arthritis?
Did previous treatment match your expectations?
What has been your experience of physiotherapy?

Exercise related questions:

- Will you tell me what you think about exercise?

Prompts could include:

Do you do exercise or any other type of activity?
What do you think about exercise: is a good thing or a bad thing?
Are you less active now than you used to be?
Have you had physiotherapy exercises before? How was it?
What sort of advice have you had about exercise?

Section 2: Questions for trial participants

Clinical trial related questions:

- Will you tell me about why you chose to participate in the clinical trial?

Prompts could include:

Do you see it being different from physiotherapy you could get elsewhere?

Physiotherapy programme related questions:

- What do you hope the physiotherapy programme will do for you?

Prompts could include:

What do you hope you will achieve with doing the physiotherapy programme?
Do you feel it will affect the outcome of your hip/knee OA over time?
Do you feel the physiotherapy will affect how you manage your condition?
What do you think the physiotherapy programme will involve?
What do you see as the best and worst things that are likely to arise from the sessions?

Have you had other kinds off physiotherapy before? How was it?

- How do you see the future?

Prompts could include:

How do you feel about the ongoing management of your condition?

What do you expect will happen with your hip/knee osteoarthritis over the next few years?

Do you think you can have any control or influence over what will happen with it?

Do you think joint replacement surgery is inevitable?

Would you avoid it or delay it if you could? Can you tell me why?

What do you think might help avoid or delay the need for surgery?

When I come back I will be knee to know what you thought about the trial programme – the good things and the not so good.

Section 3: Questions for non-trial participants

- Are you willing to tell me about your decision regarding taking part in the clinical trial?

If answer “yes” prompts could include:

What were your reasons for not taking part?

What might have helped you to take part?

What do you think hindered you from taking part?

Do you have any advice to give about taking part/or not taking part in research trials or exercise programmes?

Appendix Two:

Phase II Interview Schedule

Phase II Semi-structured Interview Schedule

Examples of open-ended questions and prompts for trial participants only following completion of the physiotherapy intervention

You have just completed the physiotherapy programme will you tell me what you think about it?

Prompts could include:

- How did you find the programme overall?

What were the good parts for you?

What were the not so good parts for you?

- Will you tell me if the programme has changed how you manage your OA?

In what way(s) has this happened?

- In what way did the programme meet your expectations (or not)?

Will you explain why (or why not)? (refer to their expectations in the initial interview)

- Do you think it has made a difference to how you cope with your OA

If yes, will you tell me how?

If no, will you tell me why?

- Do you think it has changed how you see the future with your OA?

Now that you have finished being in the programme what do you think about the exercise programme you were given?

Prompts could include:

- You were asked to do the exercises twice a week: lots of people find it hard to fit in a exercise programme twice weekly.

What made it easy for you?

What made it difficult for you?

- What was it like doing the exercises?

Was it difficult? Will you tell me why?

Was it easy? Will you tell me why?

When you were in the clinic for treatment, they showed you how to do the exercises you were required to do at home.

Prompts could include:

How did you find learning the exercises?

What would have helped you to remember them?

What was it like recording what you had done each time?

What was it like doing the exercises regularly over the nine weeks?

How did you find the advice given to you by the therapist?

Was it helpful?

How did you find the advice given to you on the instruction sheet?

Was it helpful?

What did you think about exercises sheets given to you?

Was the information on the sheets helpful?

Do you think the exercises have made any difference?

Will you tell me in what way?

Now the programme is finished what do you think about continuing on with exercises ?

What advice would you give to a new patient coming in to do this exercise programme?

What advice would help them engage in this programme?

What advice would you give to the research team to help them run a better programme?

Will you tell me if the research physiotherapy programme has changed your views on having surgery for your joints?

In what ways has it changed your ideas?

Do you think being in the research physiotherapy programme has helped avoid or delay surgery?

How do you see the future now?

Individually tailored questions

In the first interview you said that you hoped that.....how do things compare now?

Will you tell me what it was like to be in the research project?

Prompts could include:

Were there things you didn't like about being in the research project?

Will you tell me about them?

What were the good things about being in a research project?

Would you recommend participating in a research project to other people?

Will you tell me why you would (or wouldn't)?

How are you doing with your OA now?

Is there anything else you would like to say about taking part in the research project?

Is there anything else you would like to say about and taking part in the research physiotherapy programme?

Questions for Usual Care group

Will you tell me how you have been coping over the past three months?

Have there been any changes with your OA?

If so how has it changed?

Have you made any changes to how you are managing your OA?

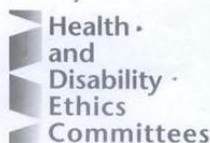
If so, what have they been?

Surgical question (or not)

In your first interview you said...

Appendix Three:

Letter of Ethics Approval



Lower South Regional Ethics Committee

Ministry of Health
229 Moray Place
PO Box 5849
Dunedin
Phone (03) 474 8562
Fax (03) 474 8090

8 May 2008

Jill Nalder
25 Kotari Rd
Days Bay
Eastbourne
Wellington

Dear Jill

Project Key: LRS/08/10/EXP

Full Title: Patient's experiences of a clinical trial physiotherapy programme for chronic hip or knee osteoarthritis.

Investigators: Jill Nalder, Dr. Sarah Dean, Dr. Sheena Hudson, Dr. J Haxby Abbott.

The above study has been given ethical approval by the **Chairperson** of the Lower South Regional Ethics Committee.

Approved Documents

Information sheet and consent form version no. 1 dated 6 May 2008. *- fooku*

Progress Reports

The study is approved until **30 June 2009**. The Chairperson will review the approved application annually and notify the Investigator if they withdraw approval. It is the Investigator's responsibility to forward a progress report prior to ethical review of the project in **6 May 2009**. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised if the study does not commence, or is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. The organisation may specify their own processes regarding notification or approval.

Yours Sincerely,

Riria Tautau-Grant
Ethics Committee Administrator
Lower South Regional Ethics Committee
email: riria_tautau-grant@moh.govt.nz

Appendix Four:

Invitation Letter

(letterhead deleted)

Greetings

I am writing to ask if you would consider volunteering to be involved in an interview study being conducted by the University of Otago Rehabilitation Teaching and Research Unit in conjunction with the Centre for Physiotherapy Research.

The enclosed information sheet has all the details of the interview study and what would be required from you.

If you are interested in taking part please fill out the attached blue form and post it to us in the pre-paid envelope and we will contact you about taking part in the study.

Please note that by sending in this form you are not consenting to taking part in the study- only that you would like to discuss the study further before deciding whether or not you would like to take part.

Thank you for taking time to read this information.

Yours sincerely,

Jill Nalder

Masters research student

University of Otago Research and Teaching Rehabilitation Unit

Wellington School of Medicine and Health Sciences

Appendix Five:

Information Sheet

(letterhead deleted)

Project Title

Patients' experiences of a clinical trial physiotherapy programme for chronic hip or knee osteoarthritis

Invitation to take part in the study

You are invited to take part in our interview study. This information sheet is about the interview study that involves people who have chronic osteoarthritis of their hip or knee and who are currently taking part in the clinical trial physiotherapy programme. We are interested in talking to people about their experience of the physiotherapy programme, as someone who is taking part in the clinical trial. We wish to find out more about how people view the physiotherapy programme, what the impact might be for them in managing their osteoarthritis and their experiences with being involved with the clinical trial.

My name is Jill Nalder. I am a Masters student with the University of Otago Rehabilitation Teaching and Research Unit. I am the main researcher organizing this study, working with several experienced researchers and supervisors, Dr Sarah Dean, Dr Sheena Hudson and Dr Haxby Abbott. We are interested in finding out more about your experiences of a clinical trial physiotherapy programme.

We would be very grateful if you would agree to take part in this interview study.

Participation

For this interview study we would like to recruit sixteen people with osteoarthritic hip or knee who are taking part in the clinical trial.

People who would like to take part in this interview study will be asked to give up to forty five minutes of their time to meet with the researcher on two occasions. The first occasion

will be during the first few weeks that you take part in the larger trial. The second occasion will be shortly after you have completed the trial.

The meetings can be arranged at a time and place that suits you, either in your home or at the Physiotherapy Clinical Centre. I will ask you some questions about your osteoarthritis, how you manage your condition and how you view the physiotherapy programme as someone taking part in the trial.

There are no right or wrong answers. The interview will be on a one-to-one basis and will be audio-tape recorded. This recording will be typed out and looked at by the researcher and supervisors.

We will be looking for common themes that people with chronic osteoarthritic hip or knee say about their experience of the condition, and their experiences as someone taking part in a clinical trial physiotherapy programme. You will be asked if you would like to look at your typed out interview and to make any comments about it. We will do this by sending you the typed copy in the post, you can either send your written comments back in the pre-paid envelope or we will arrange to telephone you to hear your comments.

A summary of the findings from the study will be sent to you if requested. However, there is often a significant delay between collecting the information and publication of the results.

Confidentiality

Your name will be changed on the typed copy so no one, apart from the research team, will know who made a particular comment. You will be asked if you would like to have your audiotape at the end of the study, if not the tape will be destroyed. All other information collected for this study is confidential and kept secure and no material that could personally identify you will be used in any reports on this study.

Benefits, risks and safety

This study is non-therapeutic. However, the benefits of taking part in this interview study will be to hear the views and opinions of people with chronic osteoarthritis. The results from this interview study might identify ways of improving physiotherapy treatment options for osteoarthritis.

There is no cost involved with taking part in this interview study and if you choose to be interviewed at an arranged venue, these travel expenses will be refunded.

While we welcome your involvement, you are under no pressure to take part in the study. If you do decide to take part, you are free to decline to answer a question, free to stop the interview and free to withdraw from the study at any time. Changing your mind about taking part in the study will not affect you continuing to receive health care now or in the future.

For further information

If you are interested in taking part please fill out the attached blue form and post it to us in the pre-paid envelope and we will contact you about taking part in the study. *Please note that by sending in this form you are not consenting to taking part in the study – only that you would like us to discuss the study further before deciding whether or not you would like to take part.*

In addition, please feel free to contact the main investigator if you have any questions about this study:

Jill Nalder

Dr Sarah Dean

Dr Sheena Hudson

Dr J Haxby Abbott

This study has been approved by the Lower South Regional Ethics Committee. If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate, (03) 479 0265 or freephone 0800 377 766 or freefax 0800 2787 7678. If there is a specific Maori issue/concern please contact Linda Grennell at 0800 37 77 66.

Thank you for taking the time to read this information.

Appendix Six:

Consent Form

(letterhead deleted)

This consent form was designed for participants taking part in the clinical trial 2008.

A separate consent form with similar material was adapted for the non-trial participants.

I have read and I understand the information sheet dated 2008 for volunteers taking part in the study designed to explore peoples' experience of a clinical trial physiotherapy programme for osteoarthritic hip or knee. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have any questions about the study.

I consent to my interview being audio-taped Yes / No

I would like to be sent a summary of findings from the study. Yes / No

I _____
(full name) hereby consent to take part in this study.

Signed : _____ **Date:** _____

Researchers: Jill Nalder
 Dr Sarah Dean (main supervisor) Dr Sheena Hudson Dr J Haxby Abbott

Project explained by: _____

Project role: _____

Signature: : _____ **Date:** _____

Appendix Seven:

RCT Participant Characteristics

Pseudo	Age	Gender	Employment Status	Primary joint	Other joints	Original casual belief	Years with OA	Trial Group
Richard	65yrs	M	Work FT	Knee	Nil	Unknown	3	MT
Gary	62yrs	M	Volunteer driving 2 days	Knee	Other knee	Dislocated knee - rugby	25+	MT
Greg	62yrs	M	On benefit -unemployed	Knee	Other knee	Playing rugby	10	MT
Kirsty	78yrs	F	Retired	Knee	Nil	Twisted knee prolonged limp	2	MT
Tom	73yrs	M	Retired	Knee	Other knee	playing golf	4	CT
Mary	60yrs	F	Work FT	Hip	Other hip, hands	Unknown	5	CT
Michael	63yrs	M	Work PT	Knee	Other knee	Jumped off back of truck	12	CT
Rachel	66yrs	F	Work PT	Hip	Other hip, knees, feet, fingers (systemic)	Unknown	25+	UC
Louise	59yrs	F	On benefit –unemployed	Knee	Hands, knees, feet (systemic)	Fell 2 yrs ago	2	UC
Emily	69yrs	F	Retired	Knee	Both hips	Unknown	25+	UC
Sally	69yrs	F	Retired	Hip	Other hip,hands, feet (systemic)	Unknown	4	UC
Mark	62yrs	M	Works FT	Knee	Other knee	gymnastics and running	12	EX
George	83yrs	M	Retired	Hip	Nil	Unknown	5	EX
Rebecca	55yrs	F	Work FT	Hip	Other hip	Unknown	6	EX
Bridget	62yrs	F	Work FT	Knee	Nil	Recurrent falls since12yrs	17	EX

Appendix Eight:

Non-RCT Participant Characteristics

Pseudo	Age	Gender	Employment status	Primary joint	Other joints	Original casual belief	Years with OA	Reason for declining
Ron	80yrs	M	Retired	Knees	Shoulders, hips, feet (systemic)	Tramping	18	Not think able do regular exercise programme or attend regularly; not sure exercise helpful
Nicole	86yrs	F	Retired	Hip	Not sure	Noticed niggles	11	Keen to participate but not able because of transport issues and loss of confidence
Jill	84yrs	F	Retired <i>In a home</i>	Hip and Knee	Other hip, knee, hands, feet (systemic)	Unknown	25+	Not sure remember being asked; unwell at time; heart condition dictates what able do
Reg	65yrs	M	Retired	Hip	Hands	Intermittent twinge	5	Moving house – timing not good
Mandy	53yrs	F	Fulltime	Knees	Hands, feet Shoulders (systemic)	Unknown	3	Works fulltime –too busy-didn't know what it involved