The experience of osteoarthritis in older adults

Thesis

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THE EXPERIENCE OF OSTEOARTHRITIS IN OLDER ADULTS

A thesis submitted in partial fulfilment of the requirements of the
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SALOMONS
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ABSTRACT

Aims:
This study aims to explore the experience of osteoarthritis (OA) in older adults, drawing on concepts from the literature on chronic illness including social-cognition models (e.g. Self-Regulatory Model) and cognitive concepts (e.g. self-schema).

Design and Participants:
A qualitative research design and Phenomenological Interpretative Analysis Methodology were used. Sixteen participants were interviewed. Ten were recruited from an orthopaedic surgical waiting list source and six from a GP source: age ranged from 67 to 79 years, and history of osteoarthritis ranged from one to 35 years.

Measures:
A semi-structured interview schedule was designed and piloted, based on the research literature.

Results:
Analysis identified the following themes: Demands of OA (pain, impact on activity, and impact on mood); Perceptions of OA (onset/deterioration, cause, label, seriousness, prognosis); Strategies to manage OA (use of health services, changes in behaviour, psychological strategies, appraisal of strategies); Perception of Self (compared to past/future/others) and Contextual factors (age, co-morbidity, waiting list). Links between themes were reciprocal, and a tentative model of OA is presented.

Implications:
A comprehensive model of the experience of chronic illness could provide a framework to guide interventions for direct clinical interventions (e.g. adjustment to chronic illness, pain management, identification of psychological comorbidity) and indirect interventions (e.g. consultancy with other health professionals).
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1. REVIEW OF LITERATURE

1.1 Introduction

The prevalence of chronic illness is on the increase in our society, especially within the older age group who are the fastest growing cohort in the UK (Iliffe, Patterson and Gould, 1998). Chronic illness can impact on physical, social and psychological functioning, but little is known about older people's experience of chronic illness. In this review, some of the reasons why the area of older adults and chronic illness seems to have been neglected are discussed. Osteoarthritis is one example of a common chronic illness experienced by many older people. The nature, management and evidence of the impact of this condition on functioning is examined.

The physical and psychological functioning of people with chronic illness such as osteoarthritis varies widely. Health Psychology has attempted to develop models to explain individual differences in the experience and impact of chronic illness. The Self-Regulatory Model of illness provides a framework to integrate social and contextual factors with individual cognition and affect (Leventhal, Diefenbach and Leventhal, 1992). The evidence for specific components of this model, such as illness representations and coping are examined in relation to chronic illness and osteoarthritis. Finally, the study aims and rationale for a qualitative methodology are discussed.
1.2 Older Adults and the Experience of Illness: A Neglected Area

The terms ‘old age’ and ‘older adults’ seem somewhat arbitrary definitions for a portion of the lifespan. However, evidence suggests that examination of the needs of this portion of the population is warranted. The number of older people in our society is growing, especially in the eighty or over age group who are the fastest growing cohort in British Society (Hart, 1997). The majority of illness in older adults is primarily due to the high prevalence of chronic disease, with the majority of over sixty five year olds suffering from at least one chronic condition (Hart, 1990). These chronic conditions contribute to morbidity and mortality in older adults. The majority of people aged 65 or over suffer from at least one chronic condition and many experience two or more simultaneously. Poor physical health and disability constitute a risk factor for affective disorder in old age, and chronic conditions and mental disorder interact (Murphy, 1983). The World Health Organization’s definition of health is ‘a state of complete physical, mental and social well-being and not simply the absence of disease and infirmity’. Therefore, chronic health problems in older adults pose a challenge for the achievement of the goal of ‘health for all’ (World Health Organization, 1986).

In addition, Hart (1997) argues that negative stereotypes about elderly people held by health-care professionals and sometimes by older people themselves, can be barriers to the provision of optimal treatment for older people. Such stereotypes include a belief that old age is a time of inevitable decline, and that older people are non-compliant, unable to change lifestyles and behaviour, and over-use health services. Evidence to support these beliefs is scarce, however. Data related to bed occupancy
and number of prescriptions dispensed does support the view that older people are disproportionate consumers of health services in comparison to the rest of the population. However, the appropriateness and effectiveness of this utilisation is contentious. Many other studies have indicated an under-utilisation of health services, when seen in relation to their actual need, with older people tending to rely on self-management strategies in response to symptoms, rather than using formal services (Stoller, Forster and Portugal, 1993). Non-compliance is not a phenomenon unique to older people but the implications of non-compliance may be serious for older people due to polypharmacy and the balance of drug interactions. Research on medication compliance indicates that levels of compliance are low when an individual has little knowledge about the condition or the purpose of their medication. This highlights the importance of cognitive factors, such as beliefs about medication and illness. It also points towards the role of communication between health professionals and older people. Some research indicates that older people may be optimistic about their health when comparing themselves to their peers, or their own belief about age-associated decline (Jensen, Counte, and Glandon, 1992). This could have psychological consequences, since self-assessed health is the strongest predictor of life satisfaction in older people (Hart, 1997).

Hart (1997) suggests that interactions between biological, psychological, and social factors are most powerful in older people. Professionals should give recognition to the contextual issues and the impact of socio-economic factors and how physical difficulties are construed and evaluated in relation to the perceived availability of coping resources. Many older people experience concurrent life events such as retirement, bereavement and diminished social and financial status, along with illness,
pain and reduced mobility. Hampson and Glasgow (1996) have carried out a number of studies with older people examining the experience of chronic illness and conclude that,

"the experience of illness is an important but little studied aspect of the self for older persons and . . . . provides a valuable opportunity for applying basic theoretical concepts to real-life concerns". (p. 57)

According to this view, far from being an unrewarding area, illness in older adulthood may be an especially rich area to study.

1.3 Osteoarthritis: A Common Chronic Illness in Older People

Osteoarthritis (OA) is the most prevalent chronic condition in adults aged sixty-five or over, causing functional impairment, morbidity, and increased use of health care services. The condition is characterised by degradation of articular cartilage and formation of new bone, resulting in inflammation, loss of joint stability and mobility, and considerable pain (O’ Brien, Cousins and Horne, 1998). A series of events, partially understood, results in loss of cartilage and degeneration of biomechanical qualities. Cysts and sclerosis, or thickening of the bone, develop underneath the cartilage and new bone known as osteophytes are formed at the margins of the bones. As the disease progresses, other related tissues such as the synovial membrane also become affected. The most commonly affected joint is the knee, followed by the hip, but it also affects fingers, hand, foot and cervical and lumbar spine. A distinction has
been made between primary OA which has no predisposing factors, and secondary OA in which certain factors predispose the individual. Dekker, Tola, Audemkampe and Winckers (1992) suggest that OA is an end-stage condition which has multifactorial origin. Factors linked to osteoarthritis include obesity, regular participation in vigorous sporting activities and joint trauma (West and Rink, 1997).

There is a strong association between age and presence of OA and at 65 at least one joint group is affected in at least 50% of the population (Dekker et al., 1992). However, not all people will experience symptoms, and it has been estimated that only 30% of individuals with marked radiological OA will experience them. Pain is the principal symptom of OA and initially occurs after use of the joint and is relieved by rest. In later stages of OA pain may also be present during rest and sleep. Other symptoms include stiffness following rest and instability of the joint. Disability may depend on the joint involved and has been grouped into movement categories including mobility, bending down, dexterity, bending arm, and reaching up (Badley, Wagstaff and Wood, 1984). OA is also associated with limitations in performance of roles such as reduction in ability to work, performance of household work, shopping, leisure and recreational activities (Yelin, Lubeck, Holman and Epstein, 1987).

1.3.1. Treatment Responses to Osteoarthritis

Once OA has developed, the medical consensus is to maintain activity levels and avoid inactivity, joint stiffness, pain and depression. Treatment is primarily aimed at alleviating symptoms and prevention of deterioration, including drugs and physical
modalities (e.g. local heat). Surgical intervention involving joint replacement is now a well established procedure. Annually, throughout the world, more than 800,000 primary total hip replacement surgical procedures are carried out on arthritic joints. Joint replacement has been associated with improvements in quality of life and pain (Bernard and Zrinzo, 1999; Knutsson & Engberg, 1999). Current waiting list times for joint replacement surgery on the National Health Service in the UK can be up to two years. Therapeutic approaches include exercise and a small number of studies have examined psychological interventions (Dekker et al., 1992). There has been some evidence to support training in pain-coping skills to reduce the impact of OA (Keefe, Caldwell, Williams and Gil, 1990). However, there is mixed evidence on the effectiveness of educational and behavioural programmes to reduce the impact of OA (Kalfas, Kaplan and Ingram, 1992). There are few studies examining the efficacy of adopting healthier lifestyles in later life, although physical exercise in old age increases physical strength, mobility and cardiovascular status (Elward and Larson, 1992). Research targeting older people with OA has been an area of much neglect, with most studies tending to focus on people suffering from rheumatoid arthritis, rather than osteoarthritis (Barlow, Williams and Wright, 1997).

1.3.2. Impact of Osteoarthritis

A distinction has been made between the physical pain of OA, the psychological impact, and the level of physical disability. Weinberger, Tierney, Booher and Hiner (1990) have highlighted the impact of exposure to stressors on all these dimensions. Increased age is associated with greater physical disability, but not with pain or
psychological distress. Pain and disability are associated with amount of cartilage and bone degeneration, joint immobility and muscle weakness (Dekker, Tola, Aufdemkampe and Winckers, 1993). These authors also found that anxiety, certain coping styles and a tendency to focus on symptoms are also linked with pain and disability.

Dekker et al. (1992) have reviewed pain and disability in OA in relation to three levels including the articular level (i.e. changes in the joint), the kinesiological level (e.g. muscular changes) and the psychological level. The review highlighted that pain and disability was related to each of these three levels, but that each alone did not give a clear picture and that an interaction between the three was likely. For example, muscle weakness is associated with pain, but avoidance of pain related activities such as exercise contributes to this problem. They suggest that this avoidance is related to cognitive and emotional interpretations of symptoms. The review also highlighted the role of anxiety, coping style and depression on pain and disability in OA. Many studies in the review were not based on a conceptual framework of pain and disability. Although associations were observed between physical and psychological determinants of pain and disability there was little explanation of these associations.

Briggs, Scott and Steele (1999) compared the impact of OA in two elderly samples and found that people with OA had significantly lower scores than control patients in all quality of life domains, particularly for bodily pain and physical functioning. People with OA experiencing other co-morbid illness had poorer general and mental health. Lam and Lauder (2000) examined the impact of a range of chronic illnesses in the elderly including stroke, OA, asthma and depression. The results suggest that
limitation in daily activities for people with OA was comparable to those who had suffered stroke. OA of the knee had the greatest impact on health related quality of life and also increased the risk of ‘sub-optimal overall health’. In a review of several large surveys DeVellis (1993) found that levels of depression were similar in people with rheumatic type diseases compared to those with other chronic illnesses. Disease activity and severity have been positively correlated with emotional distress (Zautra, Burleson, Smith, Blalock, Wallston & DeVellis, 1995) but the relationship between disease status and psychological adjustment is complex. Therefore, although depression is related to pain, when pain is controlled for there is variation in psychological adjustment, and people with similar levels of pain vary in their adjustment (Pimm and Weinman, 1998). Understanding why some individuals are able to manage their illness and minimise pain, disability and distress could help identify areas for intervention.

1.4 Understanding the Experience of Chronic Illness: Health Psychology

The physical and psychological functioning of people with chronic illness varies widely, even within individuals suffering from the same condition (Heijmans, 1999). A number of psychological factors have been studied as determinants of outcome in chronic illness, but much of the work in this area has tended to focus mainly on younger adults. The area of Health Psychology has developed a number of social cognition models that aim to explain the relationship between illness and functioning. These models aim to examine how people create their own models of illness in order to make sense of and deal with their problems. Health-related behaviour is viewed by
the Health Belief Model (Becker, 1974) as the result of an individual's assessment of a number of factors including assessment of the perceived costs and benefits of treatment, perceived seriousness of the condition, and the ability to carry out the behaviour. Studies have provided some support for the health belief model, particularly in relation to compliance, but it has also faced a number of criticisms. Johnston (1994) argues that it may be difficult to separate knowledge of the disease from beliefs about the disease. Also, the focus of this model is on intention to act rather than action itself, and this may have limitations when translating to clinical settings. Williams (1997) suggests that, 'It is clear that there is a need to examine in detail the meaning of illness for the individual concerned'. (p.157). It seems, therefore, that an examination of illness representations and beliefs about illness is valuable in furthering our understanding of individual differences in response to illness and illness-related coping, as well as for the development of interventions to facilitate self-management of chronic illness (Heijmans and de Ridder, 1998).

1.5. The Self Regulatory Model of Illness: A Theoretical Framework

One of the more recent social cognition models is the Self-Regulation Theory (Leventhal, Meyer and Nerenz, 1980). This model aims to provide a framework to integrate social and contextual factors with individual cognition and affect (Leventhal et al., 1992). One of the main features of self-regulation theory is that it proposes two parallel processing systems, the cognitive and the emotional. These two processing systems are largely independent, one creating an 'objective' representation of a health threat and its coping and evaluative processes, and the other the 'subjective' or
emotional processing system creating emotion, coping and appraisal of the management of emotion (Williams, 1997). The two systems together represent a self-regulative system. Both systems are influenced by information from schematic memories of previous illness experiences, and conceptual knowledge of illness. Emotional reactions are given a prominent position in this model. However, there seems to be little evidence of examination of this parallel processing model, with many studies focusing on the cognitive aspect and failing to describe the emotional component.

Figure 1: Self-Regulation Model. Adapted from Leventhal et al. (1992)

1.5.1. Illness Representations and Chronic Illness

Leventhal’s model has been described as the ‘commonsense model’ of illness and defines illness representations as people’s own implicit, common-sense beliefs about
their illness (Leventhal et al., 1980). Work with a number of illnesses has identified five broad cognitive dimensions of illness representations. These representations include the following:

- the identity of the illness such as the label and symptoms;
- the cause of the illness;
- the consequence of the illness and impact on the person's life;
- the curability or controllability of the illness;
- the time-line or how long the illness will last (e.g. acute, chronic, cyclical).

These representations are thought to be derived from personal experiences of illness, information from professionals, and messages from the wider culture (Schiaffino, Shawaryn and Blum, 1998). There has been a great deal of interest in illness representations, or illness perceptions, and it is fair to say that this particular aspect of Leventhal's overall self-regulatory model has been the most widely examined empirically. Williams (1997) has examined the application of the self-regulatory model to a cognitive understanding of 'dysfunctional illness behaviour'. He argues that the Self Regulatory Model has limitations in its application as a clinical model to guide intervention as it ignores the 'self-schema'. He proposes an interesting model which incorporates beliefs about the illness, but also includes two further elements to produce an illness belief triad. This triad includes:

- Beliefs about the illness (illness representations).
- Beliefs about the self, others and the world (self-schema).
• Interaction between the illness representation and the other non-illness-related beliefs (elements of the illness representations likely to be influenced by other beliefs).

The relationship between the five dimensions of illness representations is also rather unclear, with some studies finding dimensions highly correlated (Hampson, Glasgow and Zeiss, 1994) and there is also a question of whether individuals use all five dimensions in their models of illness. Heijmans and de Ridder (1998) examined the relevance of the five-dimension illness perceptions model with Chronic Fatigue Syndrome (CFS) and Addison’s Disease (AD). They found that evaluations of illness were different depending on the disease experienced. For example, in both CFS and AD they found a four-factor solution which was slightly different in content for each disease. They conclude that dimensions of illness representation may merge according to what is relevant to the disease being studied and suggest the need for research from a disease-specific perspective, rather than the generic five-dimensional structure.

(i) Evidence on Illness Representations

A number of recent studies have examined the role of illness representations in chronic illness and illness related behaviour. These representations have been related to adherence to treatment in a variety of conditions (Leventhal, Deifenbach and Leventhal, 1992), emotional response to symptoms in cancer (Easterling and Leventhal, 1989), the decision to seek health care by people in a community sample (Cameron, Leventhal and Leventhal, 1993), older adults’ decision to attend HIV
testing (Siegel, Schrimshaw and Dean, 1999), older women’s utilisation of cancer screening (Savage and Clarke, 1998) and coping with chronic illness in people with diabetes (Hampson, Glasgow and Toobert, 1990). Moss-Morris, Petrie and Weinman (1996) examined the role of illness perceptions and coping in functioning in chronic fatigue syndrome (CFS). They examined illness perceptions as measured by the Illness Perceptions Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris and Horne, 1996). This measure was based on Leventhal’s model of illness representations and was designed to assess illness perceptions in the context of chronic illness and developed in the areas of diabetes, rheumatoid arthritis and chronic pain. Illness perceptions and emotion-focused coping were related to psychological adjustment and functioning. Illness representations in CFS were more strongly associated with adjustment and well-being than coping, with the ‘identity of illness’ component being the most predictive of well-being i.e. strong identity was related to poorer well-being. The authors did comment that individuals often have complex interactional models of causes of illness, and that to understand these attributions better there is a need to look beyond unidimensional measures. In terms of coping, seeking emotional support and positive re-framing were positively related to psychological adjustment. In a recent longitudinal study of people with psoriasis (Scharloo, Kaptein, Weinman, Bergman, Vermeer and Rooijmans, 2000), strong illness identity measured by the IPQ was associated with more visits to an outpatient clinic, depression and worse physical and social functioning at one year follow-up.

There is a small but developing literature exploring cognitive representations in rheumatic diseases. Hampson et al., (1994) examined the explicit aspects of OA using structured interviews. They identified the widely shared beliefs which they referred to
as ‘folk models’ of the disease as well as individual differences in beliefs among participants and their relationship to self management. The study highlighted the shared beliefs with the majority of participants reporting their OA as serious, unpredictable, chronic and incurable. Perceiving OA as intense (i.e. serious with high frequency of symptoms) was related to greater use of health services, negativity about treatment, and poorer quality of life such as pain, role limitation and health perception.

1.5.2. Coping and Chronic Illness

Adjustment to a chronic illness can require major behavioural, emotional and social changes for patients and their families. Loss of health can pose stressful adaptational challenges, restricted autonomy, limited access to social support and associated reduction in coping resources (Hart, 1990). The transactional model of stress, based on the work of Lazarus and Folkman (1984), has provided an influential framework for studying stress and developing understanding of individual differences. The appraisal process is the dominant feature of this model. The model postulates that a potential stressor arouses the appraisal process which includes both the assessment of potential for threat (primary appraisal) and the assessment of the person’s capability for coping with the threat (secondary appraisal). Stress results when there is an imbalance between the perceived demand and the perceived abilities to meet that demand. Therefore, there is an important distinction between ‘objective’ and ‘subjective’ interpretation, and it is the subjective interpretation of events which is important in predicting distress.
Literature on coping describes coping as a mediator of stress, accounting for the variation in responses between individuals in similar situations and within the same individual over time (Pearlin, Mullan, Semple and Skaff, 1990). Coping theory portrays individuals as active responders to stressful situations who attempt to minimise demand, increase capacity, or both, via problem-solving, cognitive efforts and emotion-focused efforts (Hinrichsen and Niederehe, 1994). The three main coping modalities have been described by Braithwaite (1990) as being efforts to:

- change and alleviate the situation;
- alter or reduce the perceived threats/ create a more positive perception;
- manage the symptoms arising from the situation.

Studies of coping have identified a relationship between coping strategies, functioning and outcome, and have been used to explain variability in response to illness. There is some debate in the literature as to what behaviours and cognitions qualify as coping, and whether this definition includes those strategies which may not be consciously selected by individuals (Newman, 1990). Broad definitions reflect the diversity of coping by including the things people do, either acting or thinking, to increase a sense of well-being in their lives or to avoid being harmed by stressful events (Nolan, 1990). Many models and classifications of coping strategies and resources exist in the literature. The Crisis Theory (Moos, 1986) describes coping as being dependent on three aspects:

- illness-related factors (e.g. severity, time-line, stigma, disability);
- background and personal factors (e.g. gender, role, age, beliefs, culture);
- the physical and social environment.
These all feed into the coping process which follows a pattern of cognitive appraisal of the problem, formulation of adaptive tasks, and coping skills.

The most well-known classification of coping has been postulated by Lazarus and Folkman (1984) who divide coping into problem-focused coping (adaptation of environment) and emotion-focused coping (adaptation to environment). These concepts were derived empirically by factor analysis and the Ways of Coping Questionnaire (Folkman and Lazarus, 1980) has this distinction embedded in its design. Studies using this approach have tended to use pre-conceived typologies and to categorise individuals accordingly. This approach has been criticised for having no clear theoretical basis and for being too simplistic: other research indicates that responses to the Ways of Coping scale form several factors, not just two, and that both problem-focused and emotion-focused coping can be broken down into distinct activities (Parkes, 1984, Aldwin and Revenson, 1987). In contrast, a later generic coping measure, the COPE, (Carver, Scheier and Weintraub, 1989) contains 13 scales which the authors describe as being conceptually distinct.

Debate exists in the coping literature over whether coping constitutes a dispositional orientation to life and willingness to use certain coping responses, or whether coping is situation-specific (Hooker, Frazier and Monahan, 1994). Early studies equated personality and coping styles, but more recently there has been a move away from trait type coping towards a transactional model looking at situation-specific coping. This model postulates that the assessment of coping requires an individual approach to determine which are the most effective strategies for which stressors (Nolan, 1990).
1.5.3. Limitations of coping models

There has been a strong tendency in the coping literature, which may be linked to the dominant western culture, to see problem-solving strategies as the most effective. However, when situations are not amenable to change such as in a chronic illness, these strategies may not be so useful. Lazarus (1993) suggests that all strategies are potentially useful, but that they need to be matched to the stressor. In terms of outcome, there is some evidence linking coping strategies with outcome such as psychological distress, but few studies have addressed this in detail. In relation to coping with illness, strategies such as self-blame and avoidance have been related to poorer adjustment, while positive reframing, social support and planning have been inversely related to distress (Carver et al., 1989). The examination of illness representations in relation to coping has also been scarce, although Chronic Fatigue Syndrome (Moss-Morris et al., 1996) and Addison's Disease (Heijmans, 1999) have been studied. Most studies are quantitative, however, and there appears to have been little exploratory work in this field.

Lazarus and Folkman (1984) have indicated that coping behaviour and emotional states mutually influence each other. A study by Saad and colleagues (Saad, Hartman, Ballard, Kurian, Graham and Wilcock, 1995) examined the relationship between coping and negative affect and indicated that coping strategies were mediators of depression in carers living with a person with dementia. In terms of coping efficacy, it is also necessary to identify at what point coping becomes effective. For example, there may be a time lag between the execution of a coping strategy and effect on
outcome. A related longitudinal aspect is whether coping efficacy changes over time in relation to the progression of illness severity. Townsend, Noelker, Deimling and Bass (1989) have identified two competing hypotheses regarding long term changes in coping. The first is the wear-and-tear hypothesis which suggests progressive deterioration as illness progresses. The second is the adaptation hypothesis which suggests adaptation to the demands of the situation.

An additional important point to consider in relation to coping is the availability of resources required to make certain coping strategies available. For example, in a study of elderly informal carers (Hodgson, 1997), participants communicated that they would seek help from friends and family if only there were any available or willing; or that they would maintain interests outside of caring if they had the time/opportunity to do so. Therefore, a clarification needs to be made between strategies which are being disregarded, and those which individuals do not have the internal or external resources to utilise. Hooker et al. (1994) argue that situation-specific coping ignores the role of internal personal resources, such as personality. They suggest that personality may help us to understand the predictors of coping, although few studies have examined both personality and coping concurrently. Illness-related factors, background and personal factors, and the physical and social environment, have largely been ignored in coping research. External resources such as support, personal resources such as personality, and personal factors such as culture, beliefs, and health and social cognitions should be acknowledged in coping models. Potentially, identification of risk factors in this way could enable intervention design and resource allocation specific to individual needs.
1.6 Summary

Although the prevalence of chronic illness is on the increase, there is little research on the experience of chronic illness in older adults. Osteoarthritis is the most prevalent chronic illness in older people, impacting on physical and psychological functioning and quality of life. Social cognition models, such as the Self-Regulatory Model, provide a framework for exploring individual differences in the meaning and experience of chronic illness. This model has been applied to a range of illnesses and focuses primarily on beliefs about the illness (five dimensions of illness representations), coping and appraisal of coping. The acknowledgement of contextual factors and addition of beliefs about the self (self-schema) could expand the model further and provide a comprehensive framework to understanding personal meaning, impact and response in chronic illness. Such information could help inform clinical psychology interventions on an individual and consultancy level with clients and health care professionals.

1.7 Rationale for Methodology: Interpretative Phenomenological Analysis

When there is a relative absence of previous research in an area, qualitative methods are often appropriate (Turpin, Barley, Beail, Scaife, Slade, Smith and Walsh, 1997). This study aims to explore the processes determining and maintaining the relationship between interpretation of symptoms, pain, disability, and distress of osteoarthritis in older adults by adopting a phenomenological approach or ‘insider’s perspective’.
Interpretative Phenomenological Analysis (IPA) draws on phenomenology, or an individual’s personal perception or account of an event, and symbolic interactionism, which argues that meanings occur through a process of interpretation as a result of social interactions (Smith, 1996). IPA can therefore be viewed as a qualitative methodology which facilitates co-construction between the participant and researcher emerging from the researcher’s engagement with the participants’ accounts (Osborn and Smith, 1998). The central premise of IPA is to allow the participant to tell their own story, in their own words, and attempt to explore meanings rather than facts. However, IPA also examines the relationship between account, cognition and behaviour or physical state, and therefore it shares links with the social-cognitive paradigms of health psychology, such as the self-regulatory model. IPA therefore differs from other qualitative methodology, such as Discourse Analysis, which focuses on the importance of language and cultural discourse rather than cognitions per se.

IPA has been used to explore the meaning of chronic illness, such as lower back pain (Osborn and Smith, 1998) and haemodialysis (Smith, Flowers and Osborn, 1997). Smith et al. (1997) have suggested that IPA can contribute to understanding of illness by exploring individual conditions (such as OA) and also the general concepts and constructs employed (such as beliefs about illness and coping). Therefore, IPA was adopted in this study to facilitate access to the personal meaning of OA for participants, and also to explore the concepts suggested by the literature on chronic illness.
1.8 Research Questions

The following questions guided the development of the interview schedule and information gathered during the interview.

- What are the demands of osteoarthritis?
- What are people's perceptions of osteoarthritis?
- What strategies do people use to manage osteoarthritis?
- How are management strategies appraised?
- What are the links between demands, perceptions, and attempts to manage osteoarthritis?
- What is the role of contextual factors in the experience of living with osteoarthritis?
2. METHOD

2.1 Design

The study employed a qualitative research design and a phenomenological interpretative analysis (IPA) methodology. A semi-structured interview schedule was designed to address the research questions and data were obtained from face to face interviews.

2.2. Participants: sampling and recruitment

Theoretical sampling in the form of variational sampling was employed (Strauss and Corbin, 1990). This aimed to maximise opportunities to elicit data from individuals along the dimensions of age, sex, and severity of illness. In an attempt to include participants with a range of illness severity, participants were recruited from two populations. Half of the sample were on the waiting list for orthopaedic surgery, and had been placed on the waiting list within the six months prior to the start of the study. These participants were selected as representing individuals with severe illness. The other half of the sample consisted of individuals known to a GP practice who were not awaiting surgery, and were selected to represent individuals with less severe illness.
The inclusion criteria for all participants were as follows:

- Aged 65 or over
- Diagnosis of osteoarthritis
- Non-hospitalised

The study excluded people with severe mental illness or dementia, for whom the interview process may have been distressing or who may not have been able to give informed consent (BPS, 1998). Also, severe mental illness could have introduced additional psychological processes not directly related to osteoarthritis.

The lead clinician of the Orthopaedic Department, and GP practices in a given locality were sent a copy of the research protocol and invited to collaborate in the study (Appendix 1, 2). One Orthopaedic Consultant and two General Practitioners agreed for their patients to be contacted about the study. Sixteen participants took part in the study. Ten were recruited from the surgical waiting list of an NHS Orthopaedic Department and six from a GP practice. Names and addresses of individuals meeting the inclusion criteria were supplied by the two GPs and obtained from the orthopaedic surgical waiting list. An introductory letter with tear-off consent slip (Appendix 3) and information sheet (Appendix 4) was sent to each of these individuals. Individuals who were interested in being involved in the study returned the tear off slip with contact details in a stamped addressed envelope provided. The researcher then contacted individuals directly by telephone to discuss the study and answer any questions before arranging a convenient time for the interview.
2.3. The interview schedule

A semi-structured interview schedule was designed by the researcher to address the research questions (Appendix 5). The development of the schedule was based on the research literature related to the experience of chronic illness, and focused on the broad themes of illness representations, coping and self-management. The structure of the interview was flexible, to allow the participant to include additional information and allow for evolution of the researcher’s theoretical ideas according to what emerged from the data.

The design of the schedule followed Smith’s model (1995) of identifying broad themes, sequencing themes in relation to sensitive areas, sequencing questions within each broad theme, thinking about possible probes and prompts, using open questions beginning with general questions and moving to more specific.

2.3.1. Piloting the interview schedule

The interview schedule was given to two professional colleagues for comments prior to the first interview and minor amendments were made. The first two participants interviewed were asked to give feedback about the interview process. The interview structure seemed to facilitate participants in expressing their views openly, and they did not have any suggestions for changes to the schedule or additions. Therefore no further modifications were made and the first two interviews were included in the analysis.
2.4. Procedure

2.4.1. Ethical issues

Ethical committee approval was sought and approved from the Local Research Ethics Committee (Appendix 6). Permission was also granted for the study to be carried out by the Chief Executive of the NHS Trust, and the Clinical Director (Appendix 7, 8).

The Older Adult Psychology Service and the Primary Care Counselling and Psychology Service in the area both take referrals for people in the 65 or over age range. The Heads of these services were sent a letter and protocol of the study to inform them of the research and to make them aware should referrals of participants arise during the course of the research (Appendix 9). The Ethics Committee also requested that the GPs of participants should be contacted to inform them of their patients' involvement in the study. This was done following the interview via a standard letter outlining the interview structure (Appendix 10).

It was anticipated that during the course of the interviews, participants would request further information or support in relation to their illness. The Arthritis Research Campaign is one organisation that provides information and support to people with arthritis. A written request was made, informing them of the study and asking for copies of their information booklet for people with osteoarthritis which was made available to participants (Appendix 11). The researcher also maintained clinical awareness throughout the interviews regarding the possible need for assessment of risk of harm. The limits of confidentiality were discussed with each participant before
the interview began, and the researcher took clinical responsibility in relation to the need for liaison with a general practitioner if risk of harm was identified.

2.4.2. Recruitment briefing information

The information sheet gave details about the nature and focus of the interview, the voluntary nature of involvement, and participants were informed that they could withdraw at any time without affecting their care. At the beginning of the interview, the nature of the study was explained once more and there was an opportunity to ask questions prior to the participant signing the consent form and the interview proper commencing.

2.4.3. Debriefing

This section explored how participants were feeling at the end of the interview and whether it had raised any difficult issues for them. They were asked if they would like to add anything further or had any further questions. Participants were again informed about the purpose of the research and asked if they would be interested in providing feedback on the emerging analysis. Participants were offered the Osteoarthritis information booklet from the Arthritis Research Campaign. Participants were also asked if they would like to receive a summary report of the research.
2.4.4. Researcher’s Impressions

Following each interview, the overall impressions, thoughts and feelings experienced by the researcher were recorded in the research diary (see Section 2.6.3.).

2.5. Data handling

Interpretative phenomenological analysis provides a framework of strategies for analysing interview transcripts. Smith, Osborn and Jarman (1999) provide a step by step account of analysis. As this study involved a large number of participants and transcript data, the model adopted was the one suggested for analysis of a larger sample, concentrating on exploring and theorising on shared experiences. The analytic stages are described below.

2.5.1. Initial Coding

The primary concern of the analysis was personal perceptions and understanding. However, there was a need at an early stage to identify themes mutually relevant to all participants. These then formed the basis of more detailed analysis. The first step involved reading each individual transcript a number of times, with initial thoughts and points of interest being noted. Each interview was then examined more closely and emerging themes noted. This initial coding was kept at a broad level. Once each transcript had been coded in this way, the codes were examined for ways in which themes could be grouped together. This was repeated for all sixteen transcripts until clusters of themes were generated for each participant.
2.5.2. Identifying Shared Themes

The next stage of analysis was a search for themes reflecting shared experiences for all participants, derived from the researcher's personal interaction with the interview data. All clusters of themes for each participant were examined together to look for general broad categories relevant to all participants, aggregating themes across accounts. Three broad themes were identified.

2.5.3. Analysing Shared Themes

Once general themes had been identified, the next stage involved more intensive analysis. This involved returning to the original transcripts and examining them once again to identify all extracts relating to each of the three broad shared themes. A word-processed file of each transcript was searched and abstracts relating to each theme were copied and pasted into a new composite file. Each transcript was examined in this way. This provided a new body of data for intensive examination.

The next stage of analysis was to examine the shared aspects of participants' experience in relation to each general theme. Extracts within each of the three themes were examined for the emergence of conceptual categories and given a provisional code until a list of provisional codes had been produced for all the extracts within each theme. This list was then examined to see if codes could be grouped together in a meaningful way. The next stage was to group extracts according to these new codes.
2.5.4. Searching for links between themes

The final stage was to explore patterns and links between themes to help understand further the participants’ experiences. Diagrams can capture relationships between themes. This initially requires an exploration of inter-relationships between the themes which have emerged from the analysis by examining each category in turn and how it is related to other categories, with a focus on the transcript to verify identified links.

2.6. Validity and Reliability

Standards of quality and rigour are increasingly being applied to qualitative research and are no less essential than with quantitative research (Stiles, 1993). However, it is important that appropriate criteria for judging qualitative research are selected. The aim of validity and reliability checks is to ensure that the analysis and account presented is a sound one which is warranted from the data (Osborn and Smith, 1998). This study employed respondent validity, inter-rater reliability and auditability to maximise the quality of the research.

2.6.1. Respondent Validity

Respondent validity attempts to assess the extent to which the analysis reflects participants’ experience and also examines the quality of the researcher’s interpretations. The themes, sub-themes and emerging analysis were fed back to five
participants (three from waiting list source and two from GP source) who were asked to judge the accuracy of the analysis and its applicability to their experience, and to make comments about the emerging framework.

2.6.2. Inter-rater reliability

Inter-rater reliability was carried out to assess consistency and repeatability of the analysis. Sections of transcript were selected from four interviews (two from the waiting list source and two from the GP source) for the purpose of assessing inter-rater reliability. An independent rater assigned codes to sections of text without sight of the researcher's own assignments, but using given definitions of codes. Inter-rater reliability was examined by comparing the codes assigned by the researcher and the independent rater and is reported in Section 3.6.

2.6.3. Auditability

The interaction between the researcher and the research produces the data (Charmaz, 1995) and therefore the researcher needs to be aware of potential biases or assumptions throughout the research. This interaction was monitored via a research diary kept by the researcher throughout the study which is available for inspection in Appendix 12.
3. RESULTS

3.1. Participant Details

Basic characteristics of the sixteen participants (ten from surgical waiting list source and six from GP source) are summarised in Tables 1 and 2. Pseudonyms are used throughout to maintain confidentiality and any identifiable information has been changed. There were thirteen female and three male participants, ranging in age from 67 to 79 years. History of osteoarthritis ranged from one to 35 years, and eight participants were experiencing concurrent health problems.

Table 1. Participant details: participants recruited from Orthopaedic surgical waiting list for joint replacement

<table>
<thead>
<tr>
<th>Participant Name</th>
<th>Gender</th>
<th>Age</th>
<th>Site of OA</th>
<th>History of OA</th>
<th>Time on waiting list</th>
<th>Living arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane</td>
<td>Female</td>
<td>68</td>
<td>Both knees</td>
<td>15 yrs</td>
<td>3 months</td>
<td>With husband &amp; daughter</td>
</tr>
<tr>
<td>Sarah</td>
<td>Female</td>
<td>73</td>
<td>Knee</td>
<td>11 yrs</td>
<td>2 months</td>
<td>With husband</td>
</tr>
<tr>
<td>John</td>
<td>Male</td>
<td>68</td>
<td>Hip</td>
<td>2 yrs</td>
<td>4 months</td>
<td>With wife</td>
</tr>
<tr>
<td>Jenny</td>
<td>Female</td>
<td>75</td>
<td>Knee, hip, spine</td>
<td>20 yrs</td>
<td>4 months</td>
<td>Alone (warden)</td>
</tr>
<tr>
<td>Lillian</td>
<td>Female</td>
<td>78</td>
<td>Both knees</td>
<td>2 yrs</td>
<td>3 months</td>
<td>Alone (warden)</td>
</tr>
<tr>
<td>Steven</td>
<td>Male</td>
<td>79</td>
<td>Hip</td>
<td>2.5 yrs</td>
<td>6 months</td>
<td>With wife</td>
</tr>
<tr>
<td>Julie</td>
<td>Female</td>
<td>73</td>
<td>Both hips, spine</td>
<td>2 yrs</td>
<td>6 months</td>
<td>With husband</td>
</tr>
<tr>
<td>Henry</td>
<td>Male</td>
<td>67</td>
<td>Hip</td>
<td>1 yr</td>
<td>5 months</td>
<td>Alone</td>
</tr>
<tr>
<td>Mary</td>
<td>Female</td>
<td>70</td>
<td>Hip</td>
<td>35 yrs</td>
<td>6 months</td>
<td>With husband</td>
</tr>
<tr>
<td>Katherine</td>
<td>Female</td>
<td>77</td>
<td>Both hips</td>
<td>1.5 yrs</td>
<td>6 months</td>
<td>With husband</td>
</tr>
</tbody>
</table>
Table 2. Participant details: participants recruited from GP Practice

<table>
<thead>
<tr>
<th>Participant Name</th>
<th>Gender</th>
<th>Age</th>
<th>Site of OA</th>
<th>History of OA</th>
<th>Living arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan</td>
<td>Female</td>
<td>73</td>
<td>Spine, both knees</td>
<td>22 yrs</td>
<td>With husband</td>
</tr>
<tr>
<td>Carol</td>
<td>Female</td>
<td>72</td>
<td>Knee</td>
<td>3 yrs</td>
<td>Alone (warden)</td>
</tr>
<tr>
<td>Rebecca</td>
<td>Female</td>
<td>78</td>
<td>Spine, hip</td>
<td>9 yrs</td>
<td>Alone</td>
</tr>
<tr>
<td>Mia</td>
<td>Female</td>
<td>70</td>
<td>Spine, both knees</td>
<td>35 yrs</td>
<td>With daughter</td>
</tr>
<tr>
<td>Dawn</td>
<td>Female</td>
<td>71</td>
<td>Both feet, both knees</td>
<td>10 yrs</td>
<td>Alone</td>
</tr>
<tr>
<td>Natalie</td>
<td>Female</td>
<td>79</td>
<td>Knee, hip</td>
<td>30 yrs</td>
<td>With husband</td>
</tr>
</tbody>
</table>

3.2. Results of the analysis: themes and conceptual categories

Using the method of analysis described earlier, individual transcripts were read and re-read, and over 200 initial codes were identified. These codes were organised into clusters for each participant, and commonalities examined across the transcripts. Three broad general themes were identified from this initial stage of analysis. Within each of these three themes, clusters of codes facilitated the identification of conceptual categories. Full results of the analysis and coding in relation to all themes and categories are displayed in Appendix 13. A detailed example of coding of an interview extract can be seen in Appendix 14.

In the following text, themes and their categories are described. The number of respondents who made expressions related to each of the themes is presented. Exemplary quotations have been used to illustrate the themes, and quotations can be
identified by the use of quotation marks. Links between themes are then examined and discussed and concepts linking themes are presented. Links between themes are also presented in diagram form. The results from the respondent validity study and inter-rater reliability study are also presented.

Three initial general themes were identified from the analysis. These were labelled as the demands of OA; perceptions of OA; and attempts to manage OA. Conceptual categories were identified within each general theme. The three general themes and related sub-themes are summarised and displayed in Table 3. Each is then presented in turn.

Table 3: Themes and conceptual categories

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual categories</th>
<th>No. participants citing theme (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demands of OA</td>
<td>• Experience of pain</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>• Impact on activity</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>• Impact on mood</td>
<td>13</td>
</tr>
<tr>
<td>Perceptions of OA</td>
<td>• Onset and deterioration</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>• Cause</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>• Label: condition and mechanism</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>• Seriousness</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>• Prognosis</td>
<td>16</td>
</tr>
<tr>
<td>Attempts to manage OA</td>
<td>• Medical/health strategies</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>• Behavioural strategies</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>• Psychological strategies</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>• Appraisal of strategies</td>
<td>14</td>
</tr>
</tbody>
</table>
3.2.1. The demands of osteoarthritis

When discussing the impact of osteoarthritis and the demands it places on people’s lives, participants discussed a range of issues. The main categories included pain, impact on activity (including mobility, activities of daily living and social activity), and impact on mood.

(i) Pain

All 16 participants talked about pain as a symptom of their osteoarthritis. Three main categories emerged when participants talked about pain: the intensity of pain, the pattern of pain and factors related to pain. These are summarised in Table 4.
Participants used a variety of terms to describe their experience of the intensity of pain. Ten participants used the word ‘ache’ to describe their experience of persistent pain.

‘It’s like, you could say, like a toothache, you know, it’s gnawing.’
(Katherine)

‘More of an ache, it’s there all of the time, yes. It doesn’t come and go. I suppose you would say it’s a sharp pain, it’s like having tooth ache all the time.’ (Lillian)

Many also described a second kind of pain, such as ‘sharp’ or ‘stabbing’ to describe specific incidences of pain experiences, often in addition to the experience of ‘aching’.

‘Well, when I get the pain here it feels like somebody digging, digging a, digging a knife or something in you, you know.’ (Jane)

‘This in my leg here, there is a dull ache, but I get like a really sharp stabbing here, well I describe it as a red hot poker there.’ (Julie)

When describing the pattern of pain, nine participants described pain as continuous and described the experience of persistent pain.

‘Oh, it’s with me every day dear. Every day, just like a toothache it never goes away.’ (Jenny)
‘It’s always there, it aches and burns all the time, even sitting here I’m aware of it. It’s never completely gone. It’s still there.’ (Mary)

Others described a cyclical pattern of pain with periods of relief, followed by periods of pain.

‘But if I manage to get comfortable, nothing brings it on until I’m ready to get up, and then it’s a problem.’ (Sarah)

‘But, um, I must admit I don’t feel I have the continuous pain that some people seem to get with it. I’m lucky that I can sit with it, and normally in bed it’s not too bad, depending how you sort of wake up sometimes.’ (John)

Participants described pain in relation to a number of factors which they identified as exacerbating pain. This included walking, standing, twisting, lying down and bending.

‘Yeah, I could force myself to walk. But it was so painful.’ (Henry)

‘And if you’re walking along, you know in the town, and people, er, walk in front of you that you’ve got to pull up sharp, that really, you could cry out then.’ (Jane)
‘Bending, very bad. I bend in the middle of the floor and unless I’ve got something to, it’s not only difficulty with bending it’s pain with bending, it’s painful.’ (Rebecca)

(ii) **Restricted Activity: Mobility/Activities of Daily Living/Social**

Comments about the impact of osteoarthritis included a range of factors related to reduced activity, including difficulties with mobility, activities of daily living, and social activity. These are summarised in Table 5.

**Table 5: Categories generated for impact of OA on activity**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual categories</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demands of OA: Impact on Activity</strong></td>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(i) standing</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(ii) walking</td>
<td>16</td>
</tr>
<tr>
<td><strong>Activities of daily living</strong></td>
<td>(i) self-care (e.g. bathing)</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>(ii) shopping</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(iii) housework</td>
<td>10</td>
</tr>
<tr>
<td><strong>Social activity</strong></td>
<td>(i) general social contact</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(ii) attendance at formal activities (e.g. bowls)</td>
<td>6</td>
</tr>
</tbody>
</table>

Participants discussed the impact on mobility in relation to inability to stand for long periods, and the inability to walk distances. Eight participants described the need for an aid such as a wheelchair or a stick when walking. Activity had been curtailed considerably as a consequence.
Well I would hate to have to walk down the road to post a letter now. I wouldn’t be able to get back. Not unless I sat on the wall, if I had two or three sits on the wall’ (Steven).

‘Not very good I’m afraid. I can’t walk very far. Can’t go up the town or nothing. I’m more or less housebound, you know.’ (Mia)

Difficulties with mobility and flexibility were also discussed in relation to activities of daily living, such as shopping, housework, and self care. Fourteen participants described difficulty with bathing, due to reduced flexibility of joints.

‘I can’t get into the bath, because you’ve got to get over into the bath, and I can’t lift my legs over the bath. And there’s a shower and all there but I can’t get out when I’m in the bath, which is a nuisance that.’ (Lillian)

‘I just cannot get in the bath. That’s what I would love to do, when I feel particularly tired and painful, to sit in a bath and soak, but I just cannot get in there. And if I got in there I couldn’t get out’ (Julie)

Participants also discussed how reduced mobility impacted on the amount of social contact and social activity participants were engaging in. Some expressed a sense of isolation.
‘Well, as I say, I don’t go out a lot. I used to go to a club that runs Thursday afternoons at (place). It was a knitting club, I used to go there but I can’t get there now.’ (Susan)

‘And they have wonderful visits to all sorts of exciting places. And, of course, I’m now saying, ‘no that’s a whole day out, I can’t do it’. So, yes, I have cut down on those longer things’ (Sarah).

‘But then, my social life was, really, bowls, apart from your normal family social life. Um, and it was my last sporting stop, if you like (laughs). And to have that taken away was hurting.’ (John)

(iii) Mood

Thirteen participants described the impact of osteoarthritis on their mood. The main themes that arose when talking about mood were feelings of anger, frustration, irritability, low mood, and anxiety. These are summarised in Table 6.

Table 6: Categories generated for impact of OA on mood

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual categories</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demands of OA: Impact on Mood</td>
<td>Anger/ frustration</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Fear/ anxiety</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Low mood/depression</td>
<td>9</td>
</tr>
</tbody>
</table>

39
Participants described anger and frustration in relation to limitations in ability to engage in activities, and sense of helplessness.

‘Just, I say I get annoyed at the things I can’t do, but I don’t think I’m bitter about it, you know.’ (Jane)

‘Well I feel like throwing things (laughs). Oh, terrible, yeah, God. She says, ‘Mother, calm down’, you know. But, um, you can’t stop it. Oh, and sometimes you feel weepy. And the pain’s really bad.’ (Mia)

‘You get frustrated because you can’t do what you er, and you don’t feel like you’d like to feel, and I think it’s a bit of everything.’ (Katherine)

Fears and anxiety were related to current concerns and sense of vulnerability, especially in relation to fear of falling or slipping, as well as anxiety about the future and possible deterioration or increased dependence on others.

‘And because I can’t relax, I hold this so tight (trolley), and I should just be able to hold it lightly and that should take me, but I’m taking that. It’s because I’m afraid of falling. My hands are all red where I hold everything so tight.’ (Lillian)

‘I’m afraid of falling, or slipping off the stool, or something.’ (Jenny)
'But I feel that if I have to, can’t cope here, I’d have to get in a sheltered place. I’m hoping against hope that if I can keep no worse than I am I can manage, yes.’ (Rebecca)

Some participants described feeling low in mood at times, and four described features of depression. Assessment of risk was carried out with these four participants, and one participant expressed active suicidal ideation, prompting liaison with GP and referral to mental health services.

‘Um, it shows sometimes, you think, well what have I got to get up for today, I might as well lie here.’ (John)

‘But it’s just this osteoarthritis that’s getting me down. And I just, I just can’t stick it.’ (Jenny)

‘Because it does, it really gets you down, and you think you cannot go on any longer. And there doesn’t seem to be anything to help you.’ (Lillian)

3.2.2. Perceptions of osteoarthritis

A number of themes emerged when participants’ talked about their understanding and perceptions of osteoarthritis. These themes included perceptions about the onset and deterioration of the condition; the cause of the condition; the label of the condition
and mechanism behind the symptoms; the seriousness of the condition; and prognosis for the future.

(i) Onset and deterioration

Many participants had a clear idea and memory of the onset of their osteoarthritis, and beliefs about the deterioration of the condition. Categories related to perceptions of onset and deterioration are displayed in Table 7.

Table 7: Categories generated for perceptions of onset and deterioration

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual categories</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceptions of OA: Onset and deterioration</td>
<td>Onset</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>(i) sudden</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>(ii) gradual</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Speed of deterioration</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>(i) fast</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>(ii) gradual</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Evidence of deterioration</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(i) Pain and immobility</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(ii) Medical evidence</td>
<td>2</td>
</tr>
</tbody>
</table>

Seven described the onset as sudden in nature, with no forewarning or prior symptoms. Many pinpointed a particular day when they first noticed symptoms.

'See, when I first had, I had no pre-warning at all when I first got it is in my back it was just that my daughter was born, and then next morning I couldn’t move'. (Susan)
‘But, er, I understand that ten or eleven years ago, I was walking down the drive, on my way into the office, and my knees collapsed under me. And that was the first real sign that I’d had’. (Sarah)

‘It just come on me. And the different residents in here, they can’t understand, because I was all right one day, crippled up the next. It came on so sudden’. (Lillian)

Eleven participants talked about how their condition had deteriorated. Many discussed deterioration in relation to perceived levels of mobility and reduction in activity levels.

‘But, um, it’s been getting stiffer and stiffer. And the last year it has absolutely astounded me how immobile I’ve become. It’s literally all happened, seriously, in the last year’. (Sarah)

Two participants used medical information as evidence of deterioration.

‘I went to the doctor’s he had it x-rayed, he said, ‘Yes, it’s going’ and then had it x-rayed again and he said, ‘It’s completely gone’’. (Steven)

The speed of the deterioration was also commented on:

‘It really is getting bad, the last few weeks have been really bad. I mean it’s been around for years but the last three years I suppose it has got worse, and
now it’s getting, and it was week by week, but now it’s almost day by day.’

(Mary)

(ii) Cause

The majority of participants seemed to be searching for reasons to explain the cause of their osteoarthritis, although many were uncertain about cause. Five felt that they had no ideas about cause. Causes included a range of factors including previous lifestyle, wear and tear, other health conditions, inheritance, age and injury. The causes mentioned by respondents are displayed in Table 8. Many seemed puzzled about the cause and were searching a variety of possibilities simultaneously.

‘Well I’ve got my own theories, but the Consultant said largely my size . . . which is believable. But I think a lot of it is probably lifestyle. Um, you knock yourself about at sport, obviously . . . I don’t think it’s injury as such. You know, purely wear and tear’. (John)

Table 8: Categories generated for perceptions of the cause of OA

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual Categories</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceptions of OA:</td>
<td>Previous lifestyle (diet, sport, manual labour, kneeling).</td>
<td>11</td>
</tr>
<tr>
<td>Cause of OA</td>
<td>Hereditary</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Other conditions (nerves, fibrositis)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Multiple causes</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Injury</td>
<td>3</td>
</tr>
</tbody>
</table>
When talking about their symptoms, participants described their understanding of the condition on two levels: firstly, the label for the condition as a whole, and secondly the mechanism of the condition. Categories related to the perceptions of label of OA are summarised in Table 9.

Table 9: Categories generated for perceptions of label of OA

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual categories</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceptions of OA: Label</td>
<td>Condition (i) arthritis (ii) osteoarthritis</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Mechanism (i) crumbling/cracking/corroding bones (ii) degeneration of joint</td>
<td>7</td>
</tr>
</tbody>
</table>

Fifteen participants had ideas for the name of the condition. Nine participants used the terms ‘arthritis’, and only six of these mentioned ‘osteoarthritis’. When describing their understanding of what was meant by the label they used for the condition, participants described a range of ideas about the mechanism of the condition. A number used vivid terms such as ‘crumbling’ to describe what is happening to their bones, and others described ‘corrosion’ and ‘cracking’.

‘And I saw the x-ray of my hips, and it didn’t look a bit like a hip, it just looks like a squashed mess. Because the bones crack and they crack all the time. It’s a wonder how I’ve got any bones left’. (Lillian)
‘Er, I would think if I didn’t know any better, I would think that the pelvis is cracking up because the way it cracks sometimes.’ (Steven)

‘Well my knee cap is going, it’s worn and it’s crumbling, right. My hip is pulling away and it’s crumbling (laughs).’ (Natalie)

Participants also had images of what was happening to their joint or bones while they were walking.

‘but the way it feels, as if I’m walking and then it feels as if it’s completely come out of it’s socket and it just won’t go.’ (Mary)

‘in fact sometimes if I’m, when I’m out walking, I can’t do a lot of walking really, I just feel that my leg, from here is going to snap.’ (Julie)

(iv) Seriousness

Fifteen participants felt that their condition was serious and only one felt that their osteoarthritis was not serious in its consequences. The categories relating to perceptions of the seriousness of OA are summarised in Table 10.
Table 10: Categories generated for perceptions of seriousness of OA

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual categories</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceptions of OA: Seriousness</td>
<td>Seriousness</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>(i) serious</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(ii) not serious</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Appraisal of seriousness</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>(i) comparison to others</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(ii) impact on quality of life</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>(iii) need for surgery</td>
<td>1</td>
</tr>
</tbody>
</table>

The means by which people evaluated the seriousness of their condition involved a number of factors. These included reduced mobility, impact on activities of daily living such as bathing, pain, impact on others, and need for surgery.

‘Well, I think it’s quite bad. I have to er have a wheelchair, I’ve got a wheelchair. And I can’t get down in the bath.’ (Susan)

‘Well, I suppose they must be serious for me to have a knee replacement mustn’t they? So I suppose it must be serious, mustn’t it?’ (Jane)

‘I think it’s very serious, because not only am I restricting myself, and what I can do. But I’m causing great inconvenience to other people.’ (Sarah)

Some used comparison with others as a means to assess seriousness. This included comparison with others, and also comparison with other “self” in the past. Some
simultaneously compared themselves to others and past 'self' to describe their own subjective experience of the impact of their illness.

'Well I don’t consider it very serious. Um, I suppose I better qualify that because I’ve seen people with hip that have got a deformity as well. Yeah, so I think there’s quite a, there’s a range of people a lot worse than I am. Um, but personally it’s serious to me because I can’t live the life that I’ve been used to.’ (John)

(v) Prognosis

Eleven respondents talked about their ideas about the future prognosis of their illness. Categories related to perceptions about the prognosis of OA are summarised in Table 11.

Table 11: Categories generated for perceptions of prognosis of OA

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual categories</th>
<th>No. participants citing theme</th>
</tr>
</thead>
</table>
| Perceptions of OA: Prognosis | Assessment of poor prognosis  
(i) deterioration of symptoms  
(ii) spread to other joints | 10  
2 |
| | Surgery as indicator of good prognosis | 7 |
All eleven participants described a poor prognosis including fear about future deterioration of their symptoms, and progression of the condition to other joints.

‘I can’t see that, um, it can, I mean I’m seventy-three, I can’t see that I will lose it. I’m hoping that, er, I don’t know I presume it doesn’t spread, it’s a funny word to use. I can’t see that I’ll ever lose it.’ (Sarah)

‘Well I don’t think it will ever go away quite honestly, not all together. I’m just hoping that the left one won’t be as bad as the right one.’ (Carol)

A number of participants mentioned hopes regarding the outcome of surgery, when discussing their future. Many felt that surgery was the only way that symptoms would improve in the future.

‘I mean if I don’t have it done, I’ll probably end up not being able to walk, sort of in a few years time wouldn’t I?’ (Jane)

‘Well, it’s not going to get any better without an operation, that’s for sure. It’s steadily getting worse.’ (Steven)

3.2.3. Attempts to manage osteoarthritis

A wide range of strategies were mentioned as attempts to manage the impact of osteoarthritis. These strategies clustered under a number of themes including use of
health care and medical interventions, changes in behaviour and psychological strategies. They also talked about their appraisal of strategies.

(i) Use of Health Services:

Participants had used a number of strategies related to medical and health services. These are summarised in Table 12.

Table 12: Use of health services as strategies to manage OA

<table>
<thead>
<tr>
<th>Theme</th>
<th>Strategies adopted</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempts to manage OA</td>
<td>Medication</td>
<td>16</td>
</tr>
<tr>
<td>Use of health services</td>
<td>Physiotherapy</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Hydrotherapy</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Osteopathy</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Pain Clinic</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>TENS machine</td>
<td>2</td>
</tr>
</tbody>
</table>

All sixteen participants had used medication at some stage, such as painkillers or anti-inflammatories.

‘Um, I’m getting to be a regular medicine chest really. I’m not a hypochondriac, but it seems like it when I look at this list of stuff!’ (Steven)

‘Well other than that, all I’ve had is the tablets the Dr gives me, coproxamol I take actually. Yes, painkillers.’ (Dawn)
(ii) Behavioural Strategies

Participants described a number of changes in behaviour as attempts to manage their symptoms. These are summarised in Table 13.

Table 13: Changes in behaviour as attempts to manage osteoarthritis

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual category</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempts to manage OA:</td>
<td>Rest/activity cycle</td>
<td>10</td>
</tr>
<tr>
<td>Changes in behaviour</td>
<td>Task adaptation</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Activity/exercise</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Setting limits to activity</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Practical aids</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Maintaining interests</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Heat source</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Reading</td>
<td>4</td>
</tr>
</tbody>
</table>

Ten participants described trying to find a balance between rest and exercise. Many were breaking tasks down into small stages with resting in between.

‘You see, I go out there and do the potatoes I’ve to come back, sit down. Then go and put it in the microwave, then sit down again. I have to do it bit by bit, I can’t do it anything otherwise.’ (Jenny)

Many also described adaptation of tasks to involve less movement.

‘But whereas the old days you probably pick one up, dry it and put it away, you now put it in neat piles ready to move round the kitchen and, er, and put it away. That’s, and I think that, whatever you do, you tend to think along those lines.’ (John)
Many were also adapting a task to make it more manageable by using mobility aids or practical aids.

“Well, I had to buy one of these little plastic step stools to get in and out of the bath. But our bath, there’s a ledge, I get right to the end and bring myself up each side, sit myself on that ledge at the end you see.’ (Katherine)

Participants also made links between immobility and stiffness, and were attempting to keep mobile.

“But if I can get up and walk a little bit about, it’s more stiffness is when you sit too long.’ (Mia)

(iii) Psychological strategies:

Participants described a range of strategies which were psychological in nature, and are summarised in Table 14.

Table 14: Psychological strategies as attempts to manage osteoarthritis

<table>
<thead>
<tr>
<th>Theme</th>
<th>Conceptual category</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempts to manage OA: Psychological strategies</td>
<td>Acceptance</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Creating a positive perception of problem</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Social comparison</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Drawing on experience of illness/ difficulties/ loss</td>
<td>7</td>
</tr>
</tbody>
</table>
Seven participants described acceptance of their difficulties, which seemed to be related to acceptance of the lack of control they have over their symptoms:

‘It’s just something you know you get from time to time, and you just sort of accept it don’t you, you know. Not much you can do about it is there.’ (Jane)

‘I mean I just accept it. You can’t do much about it so you’ve got to make the best of what you’ve got.’ (Dawn)

A small number (four) attempted to see a bright side to their situation and attempted to create a positive perception.

‘I suppose, think that tomorrow it won’t be so bad.’ (Sarah)

Five compared themselves to people in a worse situation as a form of social comparison to evaluate or minimise their own difficulties.

‘I suppose at least I can get about, whereas there’s lots of people that can’t get about. People that are crippled up with it, you know. Must be awful. I know how they feel, you know, but because, as I say they’re worse off than I am, so.’ (Jane)

‘Now one lot whose got cancer very badly, there’s nothing they can do, he’s slowly dying. So when you look at that and, er, you know, compare yourself, in a way you haven’t got any problems.’ (Natalie)
Some drew on their experience of dealing with concurrent or past illness, difficulties, or losses in the past.

'Well, I suppose it's like a lot of things in life isn't it. We've all got some problems or other, and the older you get probably worse. And I suppose we've learnt to cope some way or another, and to find that we've just got to get on with these problems. It's not always easy, it's not always easy.' (Julie)

(iv) Appraisal of strategies

Participants described a number of ways of assessing the efficacy of strategies to manage their symptoms. Evidence of efficacy seemed to be related to whether strategies improved symptoms, prevented deterioration, or caused negative side effects. Categories relating to appraisal are summarised in Table 15.

Table 15: Categories generated from appraisal of attempts to manage OA

<table>
<thead>
<tr>
<th>Theme: Attempts to manage OA</th>
<th>Conceptual category</th>
<th>No. participants citing theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appraisal of strategies</td>
<td>Evidence of efficacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(i) symptom improvement</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>(ii) distraction from symptoms</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>(iii) preventing deterioration</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>(iv) duration of improvement</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Evidence against efficacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(i) side effects</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>(ii) concerns about medication</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Source of appraisal evidence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(i) self</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>(ii) others: health professionals</td>
<td>5</td>
</tr>
</tbody>
</table>
Assessments of strategies consisted mainly of reduction in pain or increased mobility, and distraction from the symptoms.

‘And by the end, I’d started to have a taxi along to (name) Road from here half the time, and in the end I was able to go about even without the stick.’ (Carol)

‘And the warmth. It’s warmth, you get that little bit of ease. Yes, you know, you can walk a bit better when they’re warm.’ (Mia)

‘Oh, it makes you think, because I can get wrapped up in a book, particularly if it’s a good one, and I can find if it’s really good I’m wanting to pick it up all the time, and that’s my salvation.’ (Carol)

Four participants mentioned one way of appraising strategies with no immediate benefit was to consider what would be the outcome if they did not adopt the strategy.

‘Because, as is always, you forget some day, ouch, and then you remember, you forgot your pill that morning. So I think it’s probably keeping the pain under control.’ (Sarah)

‘So it hasn’t really solved the problem. But I do stick with it, because as somebody said to me, I could be a lot worse if I didn’t use it.’ (Rebecca)
The length of effectiveness was mentioned and most strategies were assessed as having an impact that was short lived only.

‘Just for a week or two, and then it seems as though your body gets used to it. And you go back as you were. It’s only short lived.’ (Susan)

‘It (bath) eases you for a little while but it doesn’t last very long, but I mean for an hour or so after it feels quite good.’ (Mary)

The negative impact of strategies such as medication and exercise were mentioned, and participants had particular concerns about taking medication.

‘My thing is, if I go and swallow those now, and then later what am I going to do and anyway it makes your head fuzzy, I don’t want that.’ (Natalie)

‘Well, you know, um, it’s easy to get overdoses isn’t it? Paracetomol.’ (John)

‘It’s worse after that, yes. I have tried that, so all this business of exercise. If I really thought it would do good I would do it, but it doesn’t seem to do any good. It’s just wearing it out faster.’ (Steven)

Evidence to appraise strategies was derived from participants’ own experience of trying different strategies, as well as evidence from Consultants, GPs and other health professionals.
‘Not a lot of help, to be honest. In fact, the last lot I had a few years back, the physiotherapist themselves said, ‘There’s no point in you coming, I’m just not doing any good at all’. (Mary)

3.3. Links between themes: building a model

Each of the three themes and related conceptual categories were examined in turn for evidence of links within themes and between themes and categories. Additional themes were then identified, linking and spanning the original themes. This section examines these links in detail and proposes a tentative model to describe the inter-relationship of themes.

3.3.1. Reciprocal links between themes

Examination of the links between the three core themes identified inter-relationships and reciprocal links within and between all three themes via links between the individual conceptual categories. Limited space restricts a detailed examination and presentation of every relationship between each of the many individual conceptual categories. Therefore key examples of links between themes are presented here, and diagrammatical representations used to illustrate intra-theme and inter-theme relationships further.
For example, looking at links within themes, there was evidence of reciprocal relationships between the categories of pain, mobility, and mood within the Demands of OA theme.

An illustration of these reciprocal links is presented in Figure 2, which highlights the relationship between categories within the Demands of OA theme.

![Diagram of reciprocal links between categories within the Demands of Osteoarthritis theme.]

**Figure 2: The Demands of Osteoarthritis: a diagrammatical representation of links between categories.**

Links were also evident between individual themes. For example, there was a relationship between the themes of the Demands of OA and Perceptions about OA. Pain and immobility were used as indices to assess the seriousness of the condition and poor prognosis was a factor in feelings of frustration and anxiety expressed. Perceptions of the cause and mechanism of OA, including crumbling or corroding
bones, were related to immobility in some cases where participants felt that mobility or exercise was contributing to the problem.

There was also a relationship between Demands of OA and Strategies to Manage OA. For example, pain and immobility prevented some people from engaging in exercise. There were also links between Perceptions of OA and Strategies to Manage OA. For example, perceptions of poor prognosis prevented engagement in strategies, and beliefs about the cause and nature of the condition affected the choice of strategies adopted.

3.3.2. Appraisal

Appraisal initially emerged as a sub-theme related to Strategies to manage OA. However, closer analysis identified appraisal as featuring across the three themes in terms of appraisal by themselves and others of symptoms, perceptions about the nature of the condition, and the effectiveness of strategies adopted.

3.3.3. Perception of the self

Detailed examination of the relationship and links between themes facilitated the emergence of a new super-ordinate theme, spanning the three core themes. This theme was labelled as the experience of the self. As participants described the experience and impact of OA such as pain and immobility and their perceptions of the condition,
they often compared themselves to other selves (i.e. other people) and also to other forms of themselves in the past and in the future. The comparison of self to other people has been presented earlier in the results. Therefore, the following section concentrates on comparison of self with other selves in the past and future, and specifically highlights associated issues of loss and threat.

Many participants described the impact of OA in terms of loss in relation to themselves in the past, such as past roles, relationships, activities and pleasure.

‘And I mean gardening, I used to love the garden. And I’m not a person who takes very kindly to sitting down a lot or watching television either.’ (Julie)

‘Well yes, I mean I’ve always been a walker really. Walking, wouldn’t think nothing of walking round the shops, but just now I just can’t do it.’ (Jane)

‘We’ll be honest about it, it has affected our sex lives for one thing. We’ve always had a very good active sex life, and I feel unhappy now because I can’t do it so much, because I feel it’s unfair to my husband.’ (Mary)

Some described loss of independence and increased reliance on other people:

‘Because I always done my own shopping and everything, now I have to get other people to do it for me.’ (Lillian)

Others described themselves in relation to their perception of age related factors:
‘Old, and as a consequence, disappointed. It’s because I hadn’t expected to be so old so early (laughs)’. (Sarah)

‘Oh don’t get old. You get older, and as I say, you don’t, you feel the same in your mind. But it’s your body just, er, gets old doesn’t it?’ (Jane)

‘Erm, well bearing in mind my age, I suppose I don’t do too badly. But I mean, I don’t, I don’t think I am in such good health as I was a few years ago. I shall be 78 in (month), so you don’t expect to feel like you did several years back.’ (Katherine)

Others defined themselves in relation to fears and hopes about themselves in the future.

‘But that’s the only one thing, I kind of feel, I don’t want to be in a wheelchair and all that . . . But I sort of dread that day.’ (Natalie)

‘If it’s true what they say, that once the hip operation’s done there’s no pain . . . no reason why I shouldn’t start walking round the block with a couple of sticks or whatever.’ (Steven)
3.4. A model of the experience of osteoarthritis

The results of the analysis of themes and conceptual categories, and the relationship between themes were organised into a framework for understanding the experience of osteoarthritis. A diagrammatical representation of the model is displayed in Figure 3. This model highlights the nature of the three core themes and related conceptual categories, and illustrates reciprocal relationships between the Demands of OA, Perceptions of OA, and Strategies to manage OA. Perception of the self (past, present and future) and Appraisal (by self and others) span all three themes. Contextual factors such as age, concurrent illness and the nature of the waiting list for surgery surround the model.
Figure 3: A Model of the Experience of Osteoarthritis: Links between Themes
3.5. Results of the respondent validity study

Five participants (three from the surgical waiting list source and two from the GP source) were re-interviewed and asked to give feedback on the accuracy of the themes and categories generated from the analysis. They were also asked whether the emerging model reflected their experience. Overall, all five participants reported that the analysis reflected their experience. The findings of the respondent validity study are summarised in Appendix 15.

3.6. Results of the inter-rater reliability study

Out of 71 text units, there was agreement on the coding assigned to 66 text units, giving an inter-rater agreement of 93%. The corresponding Cohen’s Kappa value was 0.9 (Siegel and Castellan, 1988).