The experience of osteoarthritis in older adults

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The Experience of Osteoarthritis in Older Adults

A thesis submitted in partial fulfilment of the requirements of the Open University for the degree of Doctor of Clinical Psychology

November 2000

Salomons
Canterbury Christ Church University College
4. DISCUSSION

4.1. Overview

The results of the study are discussed in relation to each of the original research questions. Results are compared to the existing research, acknowledging the similarities and differences in the findings. Next, the model developed from the results of this study is discussed in comparison to existing theory. Methodological issues and limitations are considered. Finally, the clinical implications of the study and recommendations for further research are presented.

4.2. Personal model of osteoarthritis

Personal models of illness have been defined as people's representations of their illness, including disease-related beliefs, emotions, knowledge and experience (Skelton and Croyle, 1991). The results of the current study indicate that participants hold multidimensional personal models about their experience of OA. This study suggests that participants could be viewed as 'experts' on the experience of their illness, having rich and complex ideas about the demands the illness places on their lives, their perceptions about the illness, and experience and appraisal of a repertoire of coping strategies. This is consistent with the research of Hampson and Glasgow (1996) who carried out a comparison study of personal models of illness in older people suffering from OA and non-insulin-dependent diabetes. They found that
models of illness became more complex as a result of personal experience of illness, and that personal experience of illness may be linked to expertise.

Participants held perceptions of their condition in relation to each of the five illness representations identified by Leventhal and colleagues in the Self Regulatory Model of illness. For example, they had personal perceptions about the identity or label of the condition, the cause, timeline, cure or prognosis and the consequences of their OA. However, the complexity and detail of each of the five representations did vary, with participants expressing most complex perceptions about the consequences, or impact, of OA. This emerged as a theme in its own right during analysis, and was the area which participants talked about the most. There is some evidence to support the view that the five-dimensional structure of the Self Regulatory Model may vary in structure and complexity according to the condition. Heijmans and de Ridder (1998) compared illness representations in two chronic conditions (Chronic Fatigue Syndrome and Addison’s Disease) using the Illness Perception Questionnaire. They examined the factor structures underlying beliefs about the two conditions and found that the dimensions of illness representation merged according to what is relevant to the condition under study. Their results indicated the disease-specific nature of illness beliefs and suggest that structures other than the five-dimensional model of the self-regulatory model may exist.
4.3. The demands of osteoarthritis

Participants presented coherent views about their experience of the demands and impact of OA. The three main areas that arose were the experience of pain, impact of OA on activity including mobility, activities of daily living and social activity, and impact on mood. These three areas are similar to research on the impact of arthritis generally, in terms of the multidimensional experience of arthritis. The Arthritis Impact Measurement Scale (AIMS) (Meenan, Gertman and Mason, 1980) has been developed to assess functioning and well-being in people experiencing arthritic conditions. The three subscales of this questionnaire describe pain, physical disability and psychological disability. Therefore, in the current study, the participants’ experience of the impact of OA is consistent with the research in the development of the AIMS, in that participants talked about the impact of OA on all three aspects of functioning.

Looking at each aspect of functioning in more detail, the participants’ description of their experience of pain indicated thoughts about the intensity and pattern of pain symptoms, and factors related to pain. Pain has been recognised as a subjective experience, with the need to consider phenomenological and contextual factors (Osborn and Smith, 1998). However, there has been little published work on the personal experience and meaning of pain. The experience of pain seemed to be an individual experience for each participant in this study, although there were some common elements. Participants were able to describe their pain in quite vivid detail, often using metaphors such as ‘stabbing’, ‘burning’, or ‘toothache’ as comparison. Some participants described persistent pain with little relief, and some had
experienced this symptom for several months or longer. This history of persistent pain could be compared to the literature on chronic pain. The emotion and behaviour associated with chronic pain has been linked to the appraisal and the meaning of pain stimuli (Williams, 1997). Osborn and Smith (1998) carried out a qualitative study examining the experience of chronic benign lower back pain. One of the main themes they found included searching for a meaning, and inability to explain the persistence of pain. The participants in the current study also held beliefs about the origin of their pain and factors causing or exacerbating pain.

Each participant reported an impact of OA on their daily activities, including mobility, activities of daily living, and social activity. All sixteen participants experienced reduced mobility and flexibility, with related reduction in social activity, especially attendance at formal groups such as sporting or social clubs, and inability to perform tasks independently such as shopping and housework. Weinberger et al. (1990) examined the impact of social support in people with OA. They examined the impact of different forms of social support on functional status and stress. They found that tangible support was associated with enhanced physical functioning (e.g. shopping and transport), and a sense of belonging correlated with psychological functioning. Blixen and Kippes (1999) examined quality of life in fifty older people with OA and found that although few formal social support services were used, participants reported high levels of satisfaction with informal support from friends and family. They found that social support appeared to play an important moderating role in pain, functional limitations, and depression.
The majority of participants also had problems with self-care such as a difficulty or inability to bath independently. The levels of disability reported in this study seem to reflect research examining quality of life and disability in OA which have illustrated significantly lower scores on quality of life related to pain and physical functioning compared to controls (Briggs et al., 1999). Lam and Lauder (2000) also recently examined the impact of OA in comparison to other conditions in the elderly, and found that limitations in daily activities in people with OA was comparable to people who had suffered stroke.

In terms of impact on psychological functioning, thirteen participants felt that their OA had impacted on their mood. Many expressed anger and frustration with the pain and limitations imposed by OA and the impact on their functioning and perceived lack of control over symptoms. Feelings of anger and frustration have been identified as components in adjustment to chronic illness. Barraclough (1994) has summarised stage models of adjustment to illness by identifying various emotional ‘stages’ involved in the adjustment process. This includes shock, numbness or disbelief, followed by acute distress such as anxiety or anger, followed by depression and despair, and lastly gradual adjustment and acceptance. There is little empirical evidence to support the stage theory, as many individuals do not conform to a set pattern, but the stages seem useful as a framework for understanding adjustment. Although the exact nature of adjustment is debatable, there is consensus that adjustment to adverse life events requires some form of processing of the cognitive and emotional impact and significance of events.
Anxiety and fear seemed to be related to perceived vulnerability in relation to risk of injury and possibility of falling, and fears for the future and uncertainty about prognosis. A small number of individuals had ‘catastrophic’ beliefs about the nature of their condition, especially in relation to the perceived outcome of activity. Beliefs were expressed about the fear of damaging bones further, and bones were often perceived as fragile. Links have been made between anxiety, pain and disability, with anxiety increasing a tendency to focus on symptoms, exacerbating the experience of pain (Dekker et al., 1993), and avoiding pain-related behaviours (Dekker et al., 1992).

Just over half of the sample reported experiencing low mood and one quarter expressed features of depression. These numbers are comparable to studies examining the impact of chronic illness and pain on psychological morbidity (Zautra et al., 1995). Low mood and depression seemed to result from a complexity of factors including sense of hopelessness about the future and perceived inability to control symptoms, and impact on sense of self in relation to limited activities and role.

4.4. Perceptions of osteoarthritis

Previous research on beliefs about arthritis has emphasised the shared beliefs about arthritis. The study of personal models of illness also yields information about individual differences in beliefs. Hampson et al. (1994) examined the personal models of OA and identified some of the shared beliefs about OA in older adults. They found that the majority of participants viewed OA as a permanent condition, and most felt that a cure was unlikely. Most people also viewed their OA as moderately or fairly
serious. The current study elicited similar shared beliefs among participants, with the majority expressing the view that their OA is progressive, and has a poor prognosis without surgery. Many also felt that OA was caused by a range of lifestyle factors. All but one respondent considered their OA to be serious. Examination of appraisal of seriousness identified appraisals on a number of levels. In the main, people assessed seriousness in relation to their symptoms such as pain and the impact on their quality of life. However, in addition to this, some used social comparison with others perceived as worse off than them, concurrently with appraisal of personal impact, to come to a balanced view about the seriousness of their condition.

One interesting perception where participants had differing views was their beliefs about the label of OA. This seemed to be a complex perception operating on two levels, firstly the label for the condition as a whole and secondly the understanding of the mechanism of their condition. Only six respondents knew the correct label for their condition, although many used the general term of ‘arthritis’. When looking at the understanding about the mechanism behind their condition, half felt that the joint was wearing away, or degenerating, but others felt that the bones were damaged and used terms such as ‘cracking’ or ‘crumbling’. These views seemed to be constructed from the sensations they experienced, as well as seeing x-rays. In some cases, health professionals had given verbal information about OA, but none of the participants had received or sought any written information about their condition.
4.5. Coping: Strategies to manage osteoarthritis

The participants in the current study reported active attempts to manage their condition using a range of strategies including health care utilisation, but also a range of independent strategies including changes in behaviour and psychological strategies. This suggests that this group were actively trying to problem-solve or find solutions to help manage their difficulties. Many participants with a long history of OA had exhausted a number of strategies during their illness, combining the different modalities of coping.

Many participants were attempting to manage disability by adapting the tasks. Klinger, Spaulding, Palatajko, MacKinnon and Miller (1999) examined chronic pain in older adults with OA of the hip and/or knee and found that occupational adaptation was an important method of coping. They found that participants adopted two approaches to occupational adaptation, either changing the way they performed activities of daily living or stopping vocational activities. The participants in the current study used both of these strategies. Many had also attempted to find the optimum balance between rest and activity, again in response to symptoms such as pain.

In terms of psychological strategies, just under half of the participants reported acceptance of their difficulties. This is a rather complex issue as many described acceptance in relation to sense of lack of control over symptoms, possibly indicating an element of perceived helplessness rather than acceptance as a result of cognitive or emotional processing of their experience. Some drew on experience of past
difficulties or loss to highlight their competencies in coping with difficult life events. This could enhance sense of mastery or self-efficacy with managing their current difficulties. Others used social comparison as a method of creating an alternative perception of their difficulties, by comparing themselves to others worse off than themselves. Osborn and Smith (1998) found in their study of benign chronic back pain that participants compared themselves to others. They reported that in their group of nine women aged twenty-five to fifty-five years, social comparison was not always experienced as helpful. Although women compared themselves to those worse off, this exacerbated their fears about their future. The women also tended to make upwards comparisons with their ‘healthy’ peers and found this unhelpful as a coping strategy. In the current study, participants tended to compare themselves to peers, but those in a worse condition themselves. Many reported this as a helpful strategy for assessing the seriousness of their condition and also as a cognitive strategy for coping with their OA. It may be that the efficacy of social comparison as a coping strategy could be influenced by cohort affects such as age. For example, in the current study participants often had personal experience of peers and friends within their own age group who were experiencing chronic, severe or terminal illness, and had also witnessed the death of peers. Therefore, comparison to others worse off may have been more tangible or ‘real’ to them.

4.6. Appraisal

In the current study, appraisal featured throughout the main themes of Demands of OA, Perceptions of OA, and Strategies to manage OA. The Self Regulatory Model
does not, however, include appraisal throughout the experience of symptoms, but concentrates on appraisal of coping strategies. There is evidence that appraisal of bodily sensations is an important factor in the experience of those symptoms even before any response is made (Pennebaker, 1982). Participants' appraisal of perceptions of OA such as seriousness and prognosis was a complex procedure, involving comparison to past and future self, as well as social comparison with others. There is little published work specifically on the appraisal process in illness. However, research within the field of stress and coping has identified the importance of the appraisal process. The transactional model of stress includes objective and subjective appraisal as mediators in the experience of stress (Lazarus and Folkman, 1984). The current study therefore supports the importance of the appraisal process as mediating the experience of illness, and expands on the Self Regulatory Model of illness.

Appraisals of strategies were often based on personal experience of attempting strategies and assessing effectiveness in relation to personal indices of efficacy such as pain and mobility. Therefore appraisal of strategies was closely linked to participants' personal model and perception of their condition. Participants often had a long history of illness and had built a repertoire of strategies by trial and error. A few obtained evidence of effectiveness from professionals. Participants had particular concerns about the use of and reliance on medication. Accounts indicate that the decision to reduce or stop medication or other interventions had been a considered one, taking into account the benefits and costs of interventions. This suggests a complex process, based on discordance between patients' and professionals' models.
regarding the benefits of interventions, rather than simple non-adherence or non-compliance with instructions.

4.7. The theoretical framework

4.7.1. The link between illness representations and coping.

There is evidence in the literature for relationships between individual illness representations, but the nature of this relationship has been unclear. The results from the current study suggest that relationships between illness representations are reciprocal. The relationship between pain, distress and disability seems to be multidimensional and neither linear nor causal. Most work in this field has indicated that cognitive representations influence affect, but again this seemed reciprocal in the current study, with one exacerbating or influencing the other, rather than a clear causal model.

The self-regulatory model depicts two largely independent processing systems, one concerned with the cognitive representation of a health threat and its coping procedures, and the other the emotional processing system (Leventhal et al., 1992). The interaction between emotion and illness cognition are potentially numerous. Emotional states could influence illness representations by affecting the progress of a disease, altering attention to and interpretation of representations (catastrophic), and affecting behavioural decisions. Schiaffino et al. (1998) examined the impact of illness representations on psychological adjustment to chronic illness and found that
the relationship between illness representations, mood and disease severity was dynamic.

Some studies have identified particular illness perceptions as most strongly related to functioning. For example, Moss-Morris et al. (1996) examined the regulatory role of illness perceptions in chronic fatigue syndrome and found that beliefs regarding lack of control and serious consequence of the illness were strongly related to disability and psychological problems. Hampson et al. (1994) examined the relationship of older people’s personal models of OA and found that beliefs about symptoms and seriousness of the condition were consistently related to levels of self-management, utilisation of health care, and quality of life. They found a correlation between symptoms and seriousness, for example those who reported more pain and more symptoms also viewed their condition as more serious.

In the current study, beliefs about pain as an indicator of damage, or a noxious stimulus to be avoided, seemed related to people’s unwillingness to engage in activity or to adopt activity as a coping strategy. Literature on pain management suggests that people often believe that the sensation of pain indicates damage and therefore the need to rest. In the current study, the majority of participants used pain as an indication of seriousness and tended to respond to pain by resting until the pain subsided. This is similar to the work carried out by Hampson et al. (1994) who found that pain was viewed as an index of disease severity. Waddell, Newton, Henderson, Somerville and Main (1993) have described how the fear-avoidance of pain is related to rest, which is contraindicated in pain management. Therefore, beliefs about pain have a clear link and relationship to the experience of the impact of OA and attempts
4.7.2. Perception of the self

The current study identified perception of the self as an important factor in the experience of illness, in addition to perceptions about the condition, coping and appraisal. This presents an additional component to the Self Regulatory Model, and highlights the importance of the wider context including beliefs about the self and self-schema. This supports the argument presented by Williams (1997) who has identified the exclusion of self-schema as a limitation of the Self Regulatory Model. The model Williams proposes incorporates illness beliefs within a cognitive triad including beliefs about the self, and interaction between illness-beliefs and non-illness-related beliefs.

Horowitz (1986) suggests that any major life event, such as chronic illness, challenges our view of the world and requires an adjustment of our schemas to fit the new information. Moorey (1996) has also identified the importance of examining the role of self-schema in the experience of chronic illness. Participants in the current study assessed their situation by comparing themselves in the past, present and future. This revealed a sense of loss, and both threat and hopes for the future. The impact of OA had imposed changes to participants’ lives on many dimensions such as inability to manage symptoms. Beliefs about pain have been linked to psychological well-being, such as feelings of lack of control and hopelessness, and comparisons have been made between the cognitions of those experiencing chronic pain and those who are clinically depressed (Turk and Rudy, 1992).
perform tasks, reduced social contact, increased dependence, and related change in role. The illness therefore denied them the opportunity to ‘be’ the person they were prior to the illness. Studies on a range of chronic illnesses have identified a need to reconstruct a concept of the self which is positive and worthwhile (Yoshida, 1993). It is possible that basic assumptions about the self could influence the process of coming to terms with physical illness. For example, the belief that it is weak to show strong feelings may prevent emotional processing, or the belief that the self is defined by physical strength may complicate adjustment to reduced mobility and strength.

Perception of age featured in participants’ perception of self. Age, as a contextual factor, featured in a variety of ways and was described as a factor in appraisal of current health status. Some participants felt that their OA made them feel ‘old’, while others compared themselves favourably to their age and their expectations of age-related health. These disparate views of age are reflected in the literature. Jensen et al. (1992) have found that older people tend to be optimistic when comparing themselves to their own beliefs about age, while others have found that older people themselves may hold the belief that age is a time of inevitable decline (Hart, 1997). For some participants, the experience of OA threatened their sense of self in relation to their age and their beliefs about age as a time of decline. For example, some described a mind-body split, with an expression of feeling ‘young’ mentally, and ‘old’ physically. Participants’ experience of concurrent illness also featured in terms of their appraisal of OA in comparison to other health problems in the present and past, and in the adoption of coping strategies such as ability to engage in behavioural strategies, and to draw on experience of coping with illness.
An additional feature of some participants in the current study was the wait for joint replacement surgery. Some participants had suffered from OA for many years, and therefore OA could be described as a chronic condition. However, the anticipation of the outcome of imminent surgery, which was usually one of hope and improvement, complicates the picture of OA in relation to chronicity and adjustment. Although participants expressed loss in relation to comparison with a past self, they also concurrently expressed fears and hopes for the future in relation to possible deterioration and hopes for positive outcome of joint replacement surgery. This uncertainty therefore complicates the picture of chronic illness as a process of adjustment.

4.8. Summary

The findings of this study are most consistent with the Self-Regulatory Model of illness. This model provides an effective framework for the development of more detailed models of adaptation to illness. It is also flexible to the condition being studied and uses common-sense terminology. The relationship between illness representations and physical and psychological functioning seems reciprocal and dynamic, as does the relationship between cognition and affect. The addition of perception of the self and self-schema provides a more comprehensive model for understanding the role of cognitions in illness. The inclusion of the wider context such as age, concurrent illness and waiting list factors provides a framework within which to understand the experience of illness such as osteoarthritis.
4.9. Methodological Issues

Personal models of illness are shaped by personal experience, such as information and interaction with health professionals. The generalisability of this study may therefore be limited by the recruitment of participants from only one Consultant’s waiting list, and two GPs. Results may reflect participants’ particular experience with those health care professionals and services, and service provision such as information and interaction may vary within GP practices and Orthopaedic Departments. Similarly, this study focused on patients receiving care within the NHS and did not include those receiving private surgery for whom the waiting time for surgery would be shorter. The issues may be slightly different for those individuals for example in relation to perceptions of prognosis and control of OA. In addition, there may be socio-economic differences that were beyond the scope of this study. For example, socio-economic factors may play a role in the experience of the impact of OA via increased accessibility to mobility aids and home adaptations, or help with activities of daily living.

The participants in this study ranged in age from sixty-five to seventy-nine, and did not include older people aged eighty or over. Seven people aged eighty or over were invited to participate in the study, but declined. Six of these were from the GP source, which tended to include individuals in the older age group. The reason why older people may have chosen not to be involved is unclear. Proportionately more individuals volunteered to participate from the surgical waiting list source (ten participants) than the GP source (six participants) although the same number from each source was invited to participate. Although the qualitative methodology did not
involve group comparison or participant matching, placement on the waiting list was used as a crude indicator of illness severity. Participants recruited from the GP source did not appear to be obviously less severe, but the larger number of participants in the waiting list group may have resulted in the sample being skewed towards the more severe end.

The results of this study suggest that the relationships between perceptions, coping, disability and emotional distress are reciprocal and complex. However, the cross sectional nature of the design means that these conclusions are tentative and that nature of causal relationships remain open to question. Disability and emotional distress could determine illness beliefs and coping responses, or vice versa. Alternatively, the relationship could be reciprocal. The nature and relationship of these factors may change over the course of the illness, and therefore these results present a ‘snap shot’ account of the experience of illness.

Although the researcher presented herself as independent from the medical profession, the collaboration with GPs and Orthopaedic Department was made explicit. It is therefore possible that participants may have viewed the researcher as allied to the medical profession and this may have affected their responses. For example, although it was made clear that individual information would not be fed back to the Consultant and GP, there is a possibility that participants felt their responses may influence their relationship with the Consultant or GP. This could have resulted in emphasising the severity of OA to illustrate the need for surgery, or minimising feelings of frustration and anger regarding the amount of time spent on the waiting list. Emotional components such as anger related to the context of the
waiting list, could have exacerbated the experience of the emotional impact of OA. Therefore the contextual factors particular to these participants again limits the generalisability of results.

The aim of the validity and reliability checks was to assess whether the analysis and interpretation was warranted from the data. The results of the respondent validity study indicated that participants felt the account was applicable to their experience, suggesting that the results represented their views. The results of the inter-rater reliability study were also acceptable, indicating transparency and rigour of the coding process and analysis.

4.10. Clinical Implications

Osteoarthritis is a prevalent condition in older people and has a multidimensional impact on functioning and quality of life. Given the prevalence of osteoarthritis and limitations of medical therapies, there is a clear need to explore alternative approaches to management. The results of this study have implications for clinical psychology on a number of levels, including individual work and work with other health professionals.

Firstly, it is useful to consider the broad clinical implications for working with people experiencing chronic conditions. Clinical work of this nature most often arises within models of working such as liaison psychology or primary care. However, there is a strong case for the role of clinical psychology with people who are adjusting to
chronic illness in the absence of a formal mental health diagnosis, across care groups. This work requires liaison with medical colleagues, and may consist of focused pieces of clinical work with individuals who are experiencing difficulty adjusting to chronic illness. There is some evidence for the efficacy of the application of solution-focused approaches or cognitive behavioural principles to this field. For example, Moorey (1996) has written an interesting chapter entitled, 'When Bad Things Happen to Rational People', which describes the application of cognitive-behavioural principles to working with people with chronic or terminal physical health problems. The Self-Regulatory Model could inform this work by providing a comprehensive but common-sense approach to the assessment of the personal meaning of illness. Using this framework, an individual's beliefs about their condition can be elicited and explored. This approach is not limited to osteoarthritis, but could also be applied as a framework to a range of physical health problems and also to beliefs about mental health problems.

The results of this study indicated that a number of respondents were experiencing severe pain at times, and for some individuals pain was a chronic and continuous experience which did not respond to medical intervention. A very small number of participants had attended a specialist pain clinic, where they had usually received an epidural. Psychological approaches to pain management could complement existing approaches to pain management, and prove helpful in providing new coping strategies to manage pain and related symptoms. Cognitive behavioural approaches to pain management have been well-established and there is some evidence to support the efficacy of such approaches for people with OA. For example, Keefe et al. (1990) carried out a random study comparing pain coping skills, arthritis education, or
standard care in older adults with osteoarthritis of the knee. The pain coping skills training involved recognition and reduction of irrational cognitions, attention diversion and changes in activity. Patients in this group had significantly lower pain and psychological distress post-treatment than patients receiving education or standard care.

The results of the current study also highlighted the psychological impact of physical illness. Only a small proportion of participants seemed to be experiencing clinical levels of depression, but none of these were engaged with any mental health support, other than antidepressant medication. Although chronic physical conditions can result in psychological morbidity, clinical levels of anxiety or depression should not be accepted as 'normal' or 'understandable' responses to a situation which does not warrant intervention. Moorey (1996) suggests that cognitive techniques could be useful when excessive distorted thinking may result in unnecessary distress (such as inappropriate guilt) or maladaptive beliefs may prevent the adjustment process from proceeding.

The results also have clinical implications for consultancy with health professionals. There are implications for working with medical colleagues, providing training on the importance and role of information and support, assessing the patient's perception of their condition, and identifying mental health problems requiring referral to specialist services. Dissemination of the application and role of psychological models to the understanding of health could also be an important function of consultancy in this area.
Participants seemed to be receiving little or no information or support while on the waiting list for joint replacement surgery. Participants had little or no information regarding self-management strategies such as levels of exercise and rest. They tended to use strategies by trial and error, basing their judgements on their beliefs, such as pain as an indicator of damage. In this study, participants often viewed pain as an index of severity. However, pain does not correlate with the extent of OA measured radiographically (Dekker et al., 1992). Therefore patients and health care professionals may have different understandings of the assessment of ‘seriousness’ of the condition. The assessment of personal models therefore has implications for patient-provider interactions, and provides an opportunity for the doctor to ‘check out’ the patient’s understanding of their condition. Knowledge of individual patient beliefs could thus provide information about the concordance between patient and professional views, which could ultimately lead to improvements in patient self-management and quality of life.

4.11. Implications for future research

There has been little investigation of how and why personal beliefs such as illness representations are formed, developed and maintained. Therefore, future research could develop further our understanding of personal models by the investigation of the development and stability of personal models of illness. Two main methodologies exist in the literature for assessing personal models of illness. These include structured assessment via standardised measures such as the Illness Perceptions Questionnaire (Weinman et al., 1996) or via structured interviews (Hampson and
Glasgow, 1996). Future research could assess the effectiveness and clinical utility of different methods of assessing illness perceptions.

There has been little research examining the development and effectiveness of clinical interventions based on the assessment of illness representations. Such work could include interventions targeted at individuals, such as cognitive-behavioural models as described above, and could also include evaluation of interventions aimed at improving communication between patients and health professionals.

Most work in this field has concentrated on the application of social cognition models to the experience of physical illness. However, frameworks such as the Self-Regulatory Model could be applied to personal models of other life experiences. In particular, future research could examine the applicability of the model to the personal experience of mental illness.

4.12. Conclusion

The experience of OA in older adults is a complex and multidimensional experience. OA has impact on quality of life via the symptoms of pain and immobility, which result in reduced activity and impact on psychological functioning. Assessment of personal models of OA, using the Self Regulatory Model as a framework, can identify illness-related beliefs. These beliefs seem to have a reciprocal relationship with coping and functioning. Older people in the current study were actively adopting a number of strategies to manage OA and had built a repertoire of strategies, including
using health services, making behavioural changes, and using psychological strategies. Evidence to appraise these strategies included reduction in symptoms, prevention of deterioration, and absence of negative side-effects.

An expansion of the model to include contextual factors, such as age and co-morbidity, and wider beliefs such as self-schema, provides a comprehensive model of the experience of chronic illness. This model provides a framework to guide clinical interventions with individuals, such as adjustment to chronic illness, pain management, and identification of psychological co-morbidity. It also highlights opportunities for consultancy and liaison with health professionals regarding the role of illness perceptions, psychological components of physical illness, and the importance of patient-provider communication.
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Re: Research Project –

Coping and Self Management in Older Adults with Osteoarthritis.

Dear Mr,

I am writing to you regarding my Clinical Psychology Doctorate dissertation which is a qualitative study focusing on the experience of osteoarthritis. My Supervisors are Professor John Weinman at Guys Medical School, and Dr. Sue Holttum at Salomons Centre, Christ Church Canterbury.

I am planning to access patients through an Orthopaedic Department and a GP practice in order to capture a range of disease severity, and I wondered if you would be willing for your department to be involved in this research. This would involve access to non-hospitalised patients through the waiting list system. Patients would be invited to participate and would be included in the study on a purely voluntary basis and I would be responsible for coordinating this and conducting all of the interviews. I would of course report back the results of the study to your department, and the department would be acknowledged in any future reports/publications.

I am currently applying for ethical approval through the Local Ethics Committee. I have enclosed a copy of my proposal for your information, but please do not hesitate to contact me if you have any queries about the study. Otherwise, I will contact your secretary in due course to arrange a meeting with you to discuss this further.

Yours sincerely,

Claire Alwan  BSc (Hons) MSc.
Clinical Psychologist in Training
APPENDIX 2

Practice Manager

Dear

Re: Research Project –

Coping and Self-Management in Older Adults with Osteoarthritis.

I am writing to you regarding my Clinical Psychology Doctorate dissertation which is a qualitative study focusing on the experience of older adults with osteoarthritis. My Supervisors are Professor John Weinman at Guys Medical School, and Dr Sue Holtum at Salomons Centre, Christ Church Canterbury.

The Orthopaedic Department at Hospital are collaborating in this study by providing access to patients. However, I would also like to access some patients through a GP practice and I wondered if you and the partners would be willing for your practice to be involved in this study. I would appreciate it if you would kindly discuss this with the partners.

Patients would be invited to participate and would be included in the study on a purely voluntary basis. I would be responsible for coordinating the study and conducting all of the interviews. I would of course report back the results of the study to your practice, and the practice would be acknowledged in any future reports/publications.

The study has been granted ethical approval from the Local Research Ethics Committee. I have enclosed a copy of my proposal for your information.

Please do not hesitate to contact me if you have any questions about the study.

I look forward to hearing from you.

Yours sincerely,

Claire Alwan  BSc (Hons) MSc.
Psychologist in Clinical Training

cc. Dr , Dr
    Dr , Dr
Dear

I am working with Mr in the Orthopaedic Department at Hospital and GPs on a study looking at people with joint or bone problems. We are very interested in getting people’s views about what it is like to live with these problems. We also want to learn about the different ways people try to manage. We hope that this study will uncover new information that will help us develop services in the future.

Please read the enclosed Information Sheet and take your time to decide whether you would like to be involved.

If you would like to be involved in the study, please complete the tear off slip below and return it in the freepost addressed envelope provided. I will then contact you to discuss the study further. Thank you.

Yours sincerely,

Claire Alwan
Psychologist in Clinical Training

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TEAR OFF SLIP

I am interested in being involved in the Joint/Bone Study. I agree for the Researcher Claire Alwan to contact me to discuss the study further.

My name is:

My telephone number (or address) is:

Please complete and return in the freepost addressed envelope provided. Thank you.
APPENDIX 4

INFORMATION SHEET

What is the study about?
This study is looking at people who have joint or bone problems. We are very interested in getting people's views about what it is like to live with these problems. We also want to learn about the different ways people try to manage. We hope that this study will uncover new information that will help us to develop services in the future.

Do I have to take part?
No. Involvement in the study is entirely voluntary. You can also decide to leave the study at any time whatsoever without having to give a reason. This will not affect your medical care.

What will the study involve?
If you do decide to take part in the study, it will involve an interview with the researcher Claire Alwan. The interview will last for about one hour and can take place in your own home or at a convenient location.

The interview will be quite relaxed and will be looking at your experience of living with osteoarthritis. The interview will be recorded on audiotape and the tape will be destroyed once the study is completed. The interview is confidential. Your name will not be used in any reports and all information will be made anonymous.

Will taking part affect the services I receive?
No. Your GP will be informed of your involvement in the study. However, taking part in the study will not affect the health services you currently receive.

How do I get involved in the study?
Please take your time to decide if you would like to volunteer to be involved in this study. If you would like to be involved or want more information, please complete the tear off slip and return it in the prepaid envelope enclosed. The researcher Claire Alwan will then contact you to discuss the study further.

Thank you.
Claire Alwan, Psychologist in Clinical Training.
APPENDIX 5

Semi-structured interview schedule:
Outline of themes and questions

This schedule outlines the areas of interest to be discussed during the interview but is not prescriptive and acts only as a guide. The aim is to facilitate the participant telling their own story of their experience of osteoarthritis.

Introduction

Thank you for agreeing to take part in this study. As you may remember from the information sheet I sent you, I am a psychologist in clinical training. I am interested in your experience of what it is like to live with joint or bone problems and I am interested in your own personal view. I hope that the information will help us develop services. Once the study is complete I will send a summary of the findings to everyone who took part.

Discuss limits of confidentiality, participant’s choice to stop at anytime, anonymity in reports etc. GP letter. Any questions?
Sign consent form.

Background

(i) Demographic: (Basic demographic information already collected)

- Can you tell me what has been your main occupation? What are the sort of things you usually did? Are you retired? When did you retire?
- Do you live with anyone?

(ii) Health:

- *Open question: How is your health at the moment?*
- *Open question: Please tell me about your joint or bone problems.*

- How long have you had joint or bone problems?
- Where do you have these problems?
- What treatment have you had for your joint or bone problems?

Theme 1: Illness Representations

- *Open question: Can you say a bit about what you understand about your joint/bone problems?*

(i) Identity

- Can you tell me what name you give your joint/bone problems? What is it called?
• What are the mechanisms behind it? What do you think is going wrong?
• What are your symptoms? How often do they occur? How serious are they?

(ii) Cause
• What do you believe caused the osteoarthritis?
• What seems to make it better/worse?

(iii) Timeline
• When you have symptoms, how long do they last?
• Do the symptoms come and go or follow any pattern?
• Has it got better or worse since you first had it? In what way?
• How long do you think you will have osteoarthritis?

(iv) Consequences:
• Open questions: How does your ‘osteoarthritis’ affect you?
• How does it affect your life?

Specific areas to explore/prompt (areas taken from Arthritis Impact Measurement Scale):
(a) Physical functioning
• How has it affected your mobility/physical activities/household activities/activities of daily living e.g. washing, dressing, bathing?
(b) Social activity.
• How has your illness affected your social activity or contact with other people?
(c) Psychological Status (anxiety and depression).
• How does your illness affect your mood?
(d) Pain
• Please describe any pain the osteoarthritis causes. How does it affect you?

(v) Cure/control
• Is your osteoarthritis likely to get better or worse? How?
• Do you think that your osteoarthritis is something that can be cured? How?
• Have you found any medical treatment helpful?
• Have you found anything else (non-medical) helpful?
• How much control do you believe you have over your osteoarthritis?

Theme 2: Coping and self management

a) Coping
• Open question: How do you tend to deal with living with osteoarthritis?

• How do you deal with the symptoms of osteoarthritis e.g. pain? (self management e.g. medication/exercise/diet/other); (coping strategies e.g. cognitive, emotional, social support) How well does this work?
• How do you deal with the emotional aspect? How well does this work?
• What do you tend to do when you have a bad day?
• Is there anything you do which you find doesn’t help?
• Is there anything other people do that helps?
Debriefing

- What was the interview experience like?
- How are you feeling?
- Is there anything else you would like to tell me?
- Is there anything you would like to ask me?

Thank you.

Offer the osteoarthritis leaflet.

I am trying to build up a picture of what it is like to live with bone/joint problems and I would like to check its accuracy once I’ve seen several people. I need to check back to see if I’m getting it right. I wonder whether you would be prepared to give me some comments on a summary of my findings, at some point, maybe over the phone?
27th October 1999

Mrs Claire Alwan
Salomons Centre

Dear Mrs Alwan

Illness Representations, Coping and Self-Management in Older Adults with Osteoarthritis

PROTOCOL NUMBER: 61/99 (Please quote in all correspondence)

At the meeting on Wednesday 20th October 1999 the Local Research Ethics Committee reviewed your application form, together with your protocol, patient information sheet and CV.

The Committee would like to reaffirm the fact that on Page 6 of the protocol under Ethics, The NHS Trust is not the REC. The patient information sheet needs a covering/consent letter stating that the study is useful and that you are hoping to uncover new information. The Committee have also suggested that a tear off slip for consent should be included as part of the covering letter and that the letter should have the orthopaedics department and the researchers institute as headed paper except where the patient has come through a GP and the researchers' institute letterhead would be sufficient.

The Committee would also like to see the fact that the tape recordings will be destroyed included in the patient information sheet.

Please send amended paperwork when available, copied 11 times, to Mrs at the above address.

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed study whose title is given at the head of this letter. I am therefore happy to give you our approval on the understanding that you will follow the protocol as agreed.

The project must be started within 12 months from the date of this letter. It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given.
If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, 11 revised protocols should be submitted to the Committee.

You will no doubt realise that whilst the Committee has given approval for the study on ethical grounds, it is still necessary for you to obtain approval from the relevant Clinical Directors and/or Chief Executive of the Trust in which the work will be done.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of results is sent to the Secretary in due course.

Yours sincerely,

Dr.
Chairman - Local Research Ethics Committee

cc: Chief Executive, Trust.
Dear Claire,

Re: Research Project: Coping & Self Management in Older Adults with Osteoarthritis

Thank you for your letter of 17th November regarding your Clinical Psychology Doctorate dissertation.

I have now had the opportunity to peruse your protocol and confirm that I am happy to grant approval for your qualitative study at to commence.

Yours sincerely,

Chief Executive
Dear Ms Alwan

Thank you for your letter dated 17 11 99 and I am happy for you to undertake the study of Coping and Self-Management in Older Adults with Osteoarthritis. I look forward to seeing the results.

Yours sincerely

Clinical Director for Surgery and Director & Consultant Accident & Emergency Services

cc
Dear

Re: Dissertation – Illness representations, coping and self management in older adults with osteoarthritis.

My final year dissertation for the Clinical Psychology Doctorate is a qualitative study focusing on older adults with osteoarthritis. I am planning to access my participants through the Orthopaedic Department at Hospital and will shortly be applying for ethical approval through the Local Ethics Committee.

Salomons has emphasised the importance of informing relevant Psychology Departments of our research so that you are aware of what is going on in your local area. As my study focuses on older adults I thought it would be best to write to you informing you of the study, and I have enclosed a copy of my proposal for your information.

I am looking forward to meeting with you and later this month. If in the meantime you wish to discuss anything about my research please do not hesitate to contact me via Salomons.

Yours sincerely,

Claire Alwan
Clinical Psychologist in Training
Dr

Research: Coping and Self-Management in Older Adults with Osteoarthritis.

Dear Dr

Re: DOB

I am writing to inform you that your patient, , has volunteered to participate in my doctoral research dissertation. This study is being carried out in collaboration with Mr in the Orthopaedics Department, Hospital. The study has full Ethics Committee approval.

I met with for an interview on . The interview focused on the experience of living with joint/bone problems, including the participants’ beliefs about their illness, the impact of their difficulties, and the ways they attempt to manage their difficulties.

Yours sincerely,

Claire Alwan BSc (Hons) MSc.
Psychologist in Clinical Training
Dear Sir/Madam,

Re: Research Project –
Coping and Self-Management in Older Adults with Osteoarthritis.

I am writing to you regarding my Clinical Psychology Doctorate dissertation which is a qualitative study focusing on the experience of older adults with osteoarthritis. My Supervisors are Professor John Weinman at Guys Medical School, and Dr Sue Holtum at Salomons Centre, Christ Church Canterbury.

I am accessing participants via an Orthopaedic Department and a GP practice and am interviewing a total of 16 older adults who have osteoarthritis. The study has been granted ethical approval from the Local Research Ethics Committee.

During the interview process it is important that I am able to give participants details of where to get further information or support. I have one copy of your Osteoarthritis Information Booklet, and understand that the limit is 3 copies per application. I am writing to make a special request for 16 copies of this booklet for participants in the study.

Please do not hesitate to contact me to let me know the cost involved, or if you have any questions. I would also be happy to send you further information about the research.

I look forward to hearing from you.

Yours sincerely,

Claire Alwan  BSc (Hons) MSc.
Psychologist in Clinical Training
May 1999
I am really interested in exploring how people live with chronic illness, particularly in older adults. I first learnt about social cognition models during my Health Psychology Masters and have used the Self Regulatory Model to inform my clinical work (mental and physical health) on a few occasions, but want to look at its applications further. I am clinically interested in work with older adults, but also feel that they have sometimes been neglected in the area of understanding the impact of illness and health improvement. I’m particularly interested in the interaction between representations of illness and coping to explain individual difference. The problem is that the self-regulatory model is quite structured with its various components and the more I read, the more I find endless possibilities for questions I could be asking participants.

During my clinical work with older adults, I met a lot of people who were experiencing aches and pains in relation to arthritis and it seemed very common among that age group. I have also seen relatives with osteoarthritis, and am married to an orthopaedic surgeon so have been exposed quite a lot to thoughts about bone conditions, and interventions such as joint replacement.

July 1999
I’ve played around with my draft interview schedule so that it reflects the core models I am interested in. I’ve drawn on some of the general and specific measures in the field like the IPQ and the AIMS rather than making every single question up from scratch. But I also don’t want to miss the opportunity to explore further with people their own experience. The IPA approach I’m interested in seems to emphasise the need to facilitate the individual’s story-telling. I think that too much structure and questions could inhibit this.

I’ve come up with a draft interview schedule which I hope will help facilitate story telling, while also exploring some components of the self-regulatory model. I’m sending the draft to my supervisors for comments. I also feel I need to practice the interview so I can hold the schedule in my head and not feel I have to be rigid in the ordering of questions. This reminds me of the seminar Len Rowland gave us about interview design and practising questions— it now feels that his advice really applies to this stage of the research!

August 1999
Positive feedback from supervisors re interview schedule. John Weinman made a valid point about avoiding the word ‘osteoarthritis’ in my communications with participants, and one of the things we are interested in looking at is participants label for their condition. I quickly had to change all of my participant documents, letters, information sheet etc. before they are sent out – decided to call it Bone/Joint Study instead. I’m looking forward to seeing how the pilot interview goes.
September 1999
I have had a lot of support and cooperation from the medical practice and the Orthopaedic Department and the surgical waiting list sample have been invited to participate first. I am going to send the invites out in batches, just in case everyone volunteers to participate and I have too many and feel I have to interview everybody! I am still waiting to hear from GPs, but all is going well so far. I have been really pleasantly surprised by the support I have had from the medical profession. It’s frustrating relying so much on other people to help set up the study but I’ve had good experiences so far.

October 1999
Presented to the Local Research Ethics Committee – was quite daunting, but they asked some interesting questions. We discussed the merits of informing participants’ GPs of their involvement in the study, in case the interview raises issues which they may bring up with their GP. Will include this in the protocol. Very pleased that approval was given, with only minor amendments to be made.

November 1999
Approval from Chief Executive and Clinical Director to access participants from Orthopaedic Waiting list.

January 2000
Carried out my pilot interview this morning with the first participant and raised some issues to consider. Timing seemed fine, just about an hour. I wonder whether it was a bit too structured? Listening to the tape afterwards, I was aware how I tended to move the participant onto the next section of my schedule, without being aware of it. As I become more familiar with my questions I think it will become more fluid. I have decided to include a question on what other people do which is helpful/unhelpful as this lady talked about her husband quite a lot, so broadening to consider the systemic rather than just individual issues.

February 2000
I keep wondering how much reading to do! I have done a lot of reading around the model I am interested in and about Osteoarthritis, but I also want to keep an open mind to a certain extent. Also, bit of a dilemma whether to read methodology, illness models, or older adult stuff. It’s helping me think about writing my introduction but it feels a bit overwhelming.

I keep trying to think about the clinical implications – some people have expressed an interest in how this might apply to clinical psychology via older adult work, which is great. But I keep wondering whether the area of Clinical Health Psychology could be acknowledged as a speciality in its own right – bridging the gap between Clinical and Health Psychology.

March 2000
I am glad I have arranged the next lot of interviews as a block over the next few weeks – it is really tiring but I do feel emerged in the study and the subject, especially as the other demands of coursework and placement can feel really distracting.
I initially thought that people on the waiting list would be experiencing more severe OA, but severity just seems so subjective, and not really related to physical indices of severity. One or two participants who seem quite disabled are from the GP sample and are not being considered for surgery, I’m not sure why.

I am feeling drained because today I interviewed two consecutive participants who were both distressed at points during the interview. This prompted assessment of mood and risk, one of them expressed suicidal ideations and I had to liaise with the GP re a referral to the older adult mental health services. It actually went quite well, and I was pleased that it resulted in a referral. It was really strange to be working without the back-up of a clinical team, as I am currently in-between placements. However, I was pleased that I was able to put my clinical skills into practice to manage the situation. I carried out research before clinical training and it felt quite different – now the roles of researcher/clinician are dual and although I am seeing participants in the role of a researcher, the clinical skills proved really important today.

April 2000
Transcribing is interesting is taking so long, about three hours per tape. I’ve been surprised at how few people know the name of their condition. Some have really vivid images of what is happening in their joints – corroding, crustaceans, snapping etc. No wonder they don’t feel like putting much strain on the joint, with fears of making their condition worse. People really seem quite expert in their experience of different strategies to manage OA: health service, behaviour and psychological e.g. distraction techniques. Many have abandoned strategies based on evidence from self and others: e.g. they have felt that they are of little benefit or the benefits are only short lived.

Participants have been talking a lot about the symptoms and impact of OA. This is emerging as a theme in its own right, rather than within the Perceptions of OA theme. The impact seems so complex and multidimensional, impacting on all areas of life including mobility, ADL, social contact, and mood. I have been looking at the links between the themes and it really seems quite complex and reciprocal, including the context and Perception of the Self. I have been playing with some diagrammatical representations of my analysis, which seems to be the best way to try and map the experience of OA.

It is quite difficult with 16 transcripts to keep everything in mind – I have to keep checking back to the original transcripts to see if the emerging model applies to each person. I have been using the method of analysis suggested for larger sample, looking for commonalities, rather than a detailed case analysis for each person. I am pleased I did 16 interviews because people were still coming up with novel themes to a certain extent, but it has meant that the nature of the analysis is slightly different than IPA with a smaller number of participants. I feel that I am engaged with the material, but need to keep checking.

May 2000
I was pleased to hear from participants in the participant validity study that my initial analysis made sense to them and their experience of OA, and that in addition some mentioned that it had helped them think about their condition. Hopefully this means I have not moved too far away from the original meaning during analysis.
### THEMES, CATEGORIES and CODES

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<td></td>
<td></td>
<td>• duration of improvement</td>
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<td></td>
<td>Evidence against efficacy</td>
<td>• -ve side effects</td>
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<td>• concerns about medication</td>
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<td></td>
<td>Source of appraisal evidence</td>
<td>• self</td>
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<td></td>
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<td>• others (e.g. health professionals)</td>
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</tbody>
</table>
## APPENDIX 14

### EXAMPLE OF CODING: INTERVIEW EXTRACT

<table>
<thead>
<tr>
<th>Themes/Codes</th>
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</thead>
<tbody>
<tr>
<td><strong>Pain</strong>: pattern - <strong>cyclical</strong></td>
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<tr>
<td><strong>Pain</strong>: exacerbating factors - <strong>sitting</strong></td>
</tr>
<tr>
<td><strong>Pain</strong>: cyclical</td>
</tr>
<tr>
<td><strong>Strategies</strong>: behaviour - <strong>activity</strong></td>
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<tr>
<td><strong>Self concept</strong>: <strong>age</strong></td>
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<tr>
<td><strong>Strategies</strong>: behaviour - <strong>rest vs activity</strong></td>
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</table>

<table>
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<tr>
<th>Text</th>
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| 02: No, I mean I don’t . . . I do get pain yes, but I’m not in pain all the time, you know what I mean?
I: Mm.
02: Perhaps when I’m sitting down. I mean I couldn’t really say I’m in pain all the time.
I: Right.
02: I mean I do the garden, I cut the grass, and weed and everything, so I do all them sort of things. But, naturally, your mind is the same, but it’s your body let, when you’re getting older, you know. Er, I just sort of can’t, I have to sit down sort of once I’ve had a little, do a little bit then I can sit down, you know.
I: Mm. Just rest for a little while.
02: Yes.
I: So what are your symptoms, how would you describe them?
02: Well, it’s hard to explain really. I mean . . .
I: You said, not much pain, is it stiffness, or not so mobile or . . .?
02: Well, sometimes when you keep in bed of a night, if I lay in position, then you perhaps want to turn over. That’s when it gets stiff, you know, your knee, it sort of hurts then sort of thing.
I: Mm.
02: To turn over and perhaps sort of if you’ve had your leg out straight, and then you bend it, you know, it’s sort of painful then.
I: Yeah. So if you’ve had your leg in one position for a while?
02: Oh yes, when I get up in the morning I hobble about a bit, you know. But once I sort of get going I’m alright, and usually I come down and my husband tapes all the soaps for me of a night, like Coronation Street (laughs) so, and Emmerdale, so I sit and watch them, I sit down for sort of an hour, before I get cracking and start doing work like, you know.
I: Mm. So you just give yourself a bit of time to come round as it were.
02: Yes, that’s it.
I: And you mentioned about not being able to walk as far as you’d like?
02: No, I can’t, you know. If I walk, we go shopping like yesterday afternoon, and I can walk around the supermarket and that’s enough. I get back here and put my shopping away, I’m glad to sit down then, you know.
I: So what happens after you’ve been walking for a while? What does it feel like?
02: Well, it just sort of, well it does ache then, you know. You sort of feel I’ve got to sit down sort of thing, you know? |
APPENDIX 15

SUMMARY OF RESULTS OF RESPONDENT VALIDITY STUDY

A report of the results of the initial analysis was sent to five participants (three from waiting list source and two from GP source) who were re-interviewed once they had had a chance to read the report. Participants were asked to judge the accuracy of the analysis and its applicability to their experience, and to make comments about the emerging framework.

All five participants agreed with the themes and categories generated from the analysis, providing support for the emerging analysis. They also expressed the view that the results reflected their experience of OA:

'I think you have covered most of the things that people have told you about osteoarthritis.'

'I can agree with most of the comments and I think you have covered all the aspects which have been raised thoroughly.'

'I can say I do identify with your findings from the interviews. Briefly, it is my experience, very true and real for me.'

Participants reiterated points from the analysis to support the emerging themes, but did not suggest any significant changes or additions to the emerging model.