

# Quality of care for people with osteoarthritis: a qualitative study

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## Quality of care for people with osteoarthritis: a qualitative study

**Aim.** The overall aim of this qualitative study was to explore within primary care the experiences of management and care of individuals with end-stage lower limb osteoarthritis who are on the waiting list for joint replacement.

**Background.** Osteoarthritis, one of the most common chronic diseases, causes loss of physical function and severe pain among sufferers. Improving quality of care and service provision for individuals with chronic diseases is high on the UK's NHS agenda.

**Methods.** Data were collected by semi-structured qualitative interviews with 21 individuals with osteoarthritis who were waiting for a hip or knee replacement operation. Interviews were analysed using framework analysis.

**Results.** Participants had been suffering with osteoarthritis for between seven months and 38 years. The management by health professionals for people on the waiting list for joint replacement was minimal. However, participants spoke of 'hiding' their symptoms from health professionals and were trying to 'self-manage' their symptoms. Families became more involved in helping individuals with osteoarthritis to manage with everyday life.

**Conclusion.** Management of individuals' osteoarthritis while on the waiting list needs to be given consideration by health professionals in primary and secondary care. Health professionals need to be working with each other to provide more comprehensive care across the primary and secondary care interface.

**Relevance to clinical practice.** Case managers or community matrons could be identified as the co-ordinator and assessor of the needs of patients with osteoarthritis so as to try and improve pain management and service provision for these individuals especially while on the waiting list.

**Key words:** interviews, joint replacement, management, nurses, nursing, osteoarthritis

## Introduction

Osteoarthritis (OA) is a chronic disease which causes long-term problems for individuals, such as loss of physical function and severe pain among sufferers. Few patients with chronic arthritis, such as OA, ever reach the state of being entirely pain free (Bellamy 1993). Osteoarthritis of the knee and hip is the most common cause of musculoskeletal disability in older people (Martin *et al.* 1988, Walker-Bone *et al.* 2000).

Pain is one of the main symptoms which causes difficulty in OA, therefore, effective management is important. Managing individuals at the end-stages of OA is more complex and a particular challenge for health professionals. The symptoms associated with OA cause much distress and interfere greatly with everyday life. A reduced quality of life has been found among OA sufferers (Hopman-Rock *et al.* 1997, Hirvonen *et al.* 2006) and an impact on their social life (Croft *et al.* 2002). A national survey by Arthritis Care highlighted that there is often poor management of individuals with OA and these individuals are suffering from high levels of pain and experience difficulty carrying out daily household tasks (TNS Health Care & Arthritis Care 2003, Arthritis Care 2004).

At the later stages of OA, surgery of the hip and knee are often recommended to restore function and relieve pain. Studies examining the effects on pain, physical function and quality of life on individuals while on the waiting list for joint replacement have shown conflicting results. Several studies have found that there was no association between pain and physical function and time on the waiting list (Brownlow *et al.* 2001, Kelly *et al.* 2001, 2002). However, other studies have found that the longer patients waited for their operation the worse pain and disability they had (Mahon *et al.* 2002, Fitzpatrick *et al.* 2004). However, once a decision is reached to have a joint replacement procedure, even with the UK government's drive to reduce the waiting times for joint replacement, waiting for this procedure can be over a year. Some individuals with OA may never be fit enough to have joint replacement surgery due to other health problems, hence the need to ensure appropriate management of their symptoms.

Strategies for improving chronic disease management, such as OA have been highlighted by the DoH (2004) as: identifying patients with chronic disease; stratifying patients by risk; involving patients in their own care and coordinating care. National guidance has also highlighted the evidence-based approach to the clinical management of OA and provides health professionals with a summary of the strength of evidence for its effective management (Scott *et al.* 1998). This guidance says that:

- OA should be mainly treated in primary care by a multi-disciplinary team.
- Patient education is an effective therapy for OA.
- When referral to secondary care is required, a long term management plan should be initiated in consultation with GP and patient.

It is known that many individuals with OA are managed in the community and may not get referred for specialist service provision, such as chronic pain management, rheumatology, or surgery. Other individuals when their condition deteriorates may be referred to specialists for different treatment and management options as recommended by national guidelines (BSR & RCP 1993).

The focus of the UK NHS modernization agenda is on improving service provision and quality of care for patients, emphasizing the need to provide more streamlined care for patients in both primary and secondary care (DoH 2000). Chronic disease management is a focus for the NHS Plan (DoH 2000) and the care of people with long-term conditions is one of the priorities for the NHS (DoH 2004, 2005a,b). Community matrons are being seen as having a key role in managing the care for individuals with long-term conditions (DoH 2005a, 2006).

The NHS policy developments and debates around service provision and patient involvement are a key driver of this research. It is not known what care and management individuals with OA receive while on the waiting list for joint replacement. One study has found an increase in referral rates to health professionals of individuals with OA when compared with other conditions (Linsell *et al.* 2005). If improvements in quality of care and service provision in the NHS are to be achieved, than an understanding of the care and management individuals with end-stage lower limb OA who are on the waiting list for joint replacement is necessary.

## Aim

The overall aim of this qualitative study was to explore within primary care the experiences of management and care of individuals with end-stage lower limb OA who are on the waiting list for joint replacement.

## Methods

### Participants

The sample were patients ( $n = 21$ ) with a confirmed diagnosis of OA who were on the waiting list for hip or knee joint replacement from a regional orthopaedic centre in the UK. Purposive sampling was used to identify 21 patients

from 105 randomly selected patients who were part of a longitudinal study. Purposive sampling is an appropriate form of sampling in qualitative research and allows for the non-random selection of individuals with particular characteristics (Bowling 1997). It enables participants to be selected to meet predetermined criterion of importance (Patton 2002). The participants selected for this study were: women and men of different ages who suffered from either hip or knee OA; and had experienced chronic pain for different lengths of time. As this study was exploring health service provision, it also was important that participants resided in different geographical locations. The local research ethics committee and the University Senate Ethics Committee approved the study and research governance arrangements were followed.

### Interviews

To allow for individual's own views and accounts to be elicited, data were collected by semi-structured interviews and were conducted by one researcher in the participant's own home. These interviews provided an opportunity to obtain more details about experiences. The interviews uncovered issues which were not identified from the longitudinal study. They are found to be useful for exploring experiences of care (Pope *et al.* 2002). An interview guide was developed (Box 1) based on the literature (BSR & RCP 1993, Campbell *et al.* 2000, CSAG 2000) and previous research (McHugh & Thoms 2001).

Information about the study and consent forms were signed by participants, including consent to tape-record the interviews. Study participants were assured that they would not be identifiable and tapes would be destroyed at the end of the study. The interviews lasted on average 45 minutes. Participants had already been interviewed at home as part of the longitudinal study, so were known to the interviewer. Respondents felt confident to open up. If there is unwillingness by respondents to provide the required information, the validity of the data may be reduced (Haralambos 1992). The interviews once tape-recorded were transcribed and anonymized. To ensure that tapes had been accurately transcribed,

#### Box 1 Questioning route

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- What made you decide to have your hip/knee done?
  - What services and treatments have you tried to help manage your pain (use of complementary therapy; other treatments and services used)?
  - What management of your OA and symptoms has occurred while on the waiting list (by health professionals)?
  - How have you managed the symptoms while on the waiting list?
  - How has living with osteoarthritis and the pain affected you?
- 

tapes were listened to again checked against the transcripts. The interviews were undertaken between February and July 2004.

### Analysis

The interviews continued until data saturation was reached (Miles & Huberman 1994, Bowling 1997). This occurs when no new themes emerge from the interviews and analysis. The interviews were analysed as soon as they were carried out using framework analysis (Ritchie & Spencer 1996). Framework consists of five stages: familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation. It provides a systematic approach to sifting, charting and sorting material using the key issues and themes (Ritchie & Spencer 1996). Microsoft® Excel 2002 was used to manage and sort the data. Excel with framework analysis has been recommended as it allows for greater transparency and facilitates charting and colour coding. The use of review toolbars, a feature in Excel enables additional comments and memos to be inserted (Swallow *et al.* 2003).

It is important in qualitative data analysis that the narrative and textual structure of the qualitative data are not lost (Ritchie & Spencer 1996). Therefore, verbatim quotes are used to support the findings. Including quotes from the patients supporting the themes that have been identified enhances the credibility of the study (Sandelowski 1986). The importance of rigour with the data analysis reduces misinterpretation of the data (Mays & Pope 1996). This was ensured by a sample of the tapes being listened to by another researcher, experienced in qualitative research. Independent analysis was undertaken by two researchers and emerging themes discussed with academic peers.

### Results

All twenty-one participants who were approached for the study consented and were subsequently interviewed in their own homes. The average age of the participants was 65 years, ranging from 48–86 years. Sixteen were women and five were men. The study participants were on the waiting list for either a total hip replacement (THR) ( $n = 14$ ) or for a total knee replacement (TKR) ( $n = 7$ ). Participants were representative of 11 geographical locations in the North West of England. More details on the characteristics of these individuals are shown in Table 1.

The majority of study participants were retired, but six participants interviewed were employed. One participant with OA of the hip had recently become medically disabled as he was unable to continue his job as a plasterer. Another

**Table 1** Study participants' demographics

Demographics	Number
Marital status	
Married	11
Widowed	7
Divorced	3
Employment Status	
Retired	14
Employed	6
Medically disabled	1
Length of time diagnosed with OA	
Mean (months)	144
Range (months)	7–456
Length of time diagnosed with chronic pain	
Mean (months)	44
Range (months)	6–240

participant had recently taken early retirement due to OA. The length of time diagnosed with OA and suffering with chronic pain was variable. Some participants were recently diagnosed and had suffered with pain for six months; other had been diagnosed over 30 years with pain becoming chronic years later. All participants reported the main reason for having a THR or a TKR was the high level of pain which was interfering in their daily life.

The major issue which we identified from the analysis was the management of OA while on the waiting list which fell into four categories: (1) use of services and treatments; (2) involvement of health professionals; (3) self-management; and (4) reliance on family members (Table 2).

### Use of services and treatments

The use of services and treatments was very dependent on participants' previous experiences and attitude. Previously participants had tried and used a wide range of treatments to

**Table 2** Categories on the management of osteoarthritis (OA)

1 Use of services and treatments
Experience
Attitude to services and treatments
Concerns of side-effects of medication
2 Involvement of health professionals
Care transferred to secondary care
Lack of assessment by health professionals
Hiding the symptoms
3 Self-management
Changing lifestyle
Taking responsibility
Trial and error
4 Reliance on family members
Role reversal
Effects on family

relieve their pain but while on the waiting list there was little use of both health services and treatments. Most participants perceived that some of the treatments had had little effect on relieving their pain. Around half of the participants reported to be apprehensive about side-effects when taking analgesics. Participants perceived that there was nothing else that could be done but sit and wait to be called for their operation:

At one time I used to go for exercises, you went about six times and then you had to learn to manage it yourself. They (physiotherapists) can only go so far and give you so much treatment. (P8, female 73 years, TKR)

I have had cortisone injections in knee. The first injection was okay. I was told when I had the second one, the arthritis could go worse, and it went worse after the second one. I then saw a physiotherapist, but was told nothing else could be done. I have used knee support and gels. The gels haven't been much good, but the knee support did help and enabled me to walk better and further. (P37, female 60 years, TKR)

Only two of the 21 participants interviewed were not taking analgesics for their pain. The perception among participants concerning the fear of side-effects and addiction was evidenced by participants not taking or reducing their medication:

I don't want to take them (the tablets) he's been giving me. I don't want to take them all the time, because I don't want to get addicted to them. (P43, male 56 years, THR)

I got the prescription but then I read all the side effects that they can make you lightheaded and dizzy and I thought I already am, so I didn't take them. (P7, female 53 years, THR)

### Involvement of health professionals

Participants reported little active management by health professionals in both primary and secondary care while on the waiting list and there was no re-assessment of their symptoms. There was a perception that care had been transferred from primary care to secondary care and that they just had to wait for their joint replacement. This was evidenced by the extracts below:

They (the GPs) just really treat what I go to see them about. They have said you are under treatment at the specialist hospital so they don't get involved, other than this blood pressure check. (P84, female 65 years, TKR)

I've got absolutely nothing really, in fact they (GPs) didn't particularly like prescribing me the medication because it was expensive and they had a bit of a moan about that because the consultant gave it to me. (P105, female 52 years, THR)

Last time I went to the hospital, the consultant was more or less saying to me – go home and keep taking painkillers, we can't do an operation till you've turned 70. (P73, female 63 years, TKR)

Only one out of the 21 participants interviewed reported to have received an assessment by their GP. This had been in regard to their medication while on the waiting list:

I find now if I take medication at different times, later in the day – the GP advised that – I took some very early morning and some later and I felt better for this. (P41, female 85 years, THR)

All 21 participants reported having difficulty with aspects of physical functioning such as climbing stairs, getting in or out of a chair or bath. None of the participants interviewed had the services of community nurses (district nurses, health visitors). Only one participant had received an assessment from an occupational therapist but this was because of a mild stroke and unrelated to her having OA:

You could get a bit more help. I only got the chair raised and the extra banister because of the stroke, when I saw the occupational therapist in hospital; she was really kind and helpful and could see I had high stress levels. She could see how upsetting this was – she said could she come out and see how she could help. (P76, female 48 years, THR)

The lack of involvement by health professionals may have not been helped by the participants 'hiding their symptoms'. Study participants spoke of 'not letting on to health professionals' regarding the pain they were in. Individuals reported that they 'masked the pain' and did not discuss their OA with their GP. One participant felt that because she didn't comply with taking the suggested medication her previous doctor had suggested she didn't feel anything could be done, so when she changed GPs, she kept quiet about her OA:

The old doctor I went to said you don't take anything for this arthritis do you. I said no, I don't like taking too many tablets, so he said well if you feel like that. So when I changed doctors I didn't tell her anything about the arthritis, I kept quiet about my arthritis. (P1, female 73 years, THR)

One patient, desperate to have his hip replacement operation, spoke about wanting to withhold information about his medical condition. This condition may have prevented him from being able to have a THR. The hip replacement was seen as the most important thing to this participant and he was willing to risk the aneurysm rupturing to avoid further pain and co morbidity from the hip:

It was up to me whether I divulged the information to the hospital about my aneurysm; it was only me and my GP who knew about it. (P74, male 80 years, THR)

There was also reluctance by participants to rely on walking aids and participants reported trying hard to 'hide' the limp when walking. Using a walking stick, they perceived as admitting that their symptoms had become worse:

I am using the walking stick more often now. This probably shows that I have gone worse since September. (P38, male 53 years, THR)

### Self-management

The vast majority of participants spoke about self-managing their symptoms associated with OA. There was little active management of symptoms by health professionals. Participants 'hid' their symptoms and there was little use of services and treatments while on the waiting list. This resulted in individuals trying to self-manage their condition. This was in terms of taking responsibility for their health and changing and adapting their lifestyle to cope with their pain:

You've got to literally look after yourself in managing OA, not just on the waiting list, but over the last 5 years, it has been a long haul. (P105, female, 52 years THR)

It is very much down to self managing your pain. It has become more of an effort to keep up fitness. I've just tried to keep up what I've done before. It is however becoming an effort to keep on top of it. When I go in for the operation, I want to be in the best possible physical state. (P10, male 56 years, THR)

Management has just been by trial and error. I've tried to keep my weight down. But I am not losing much weight because I am not able to stand or get out for very long. (P43, male 56 years, male)

The individuals also spoke of adjusting their medication themselves:

Every now and again, I drop off everything (medication), for about a couple of days. I don't last a couple of days, because the pain is so bad. (P73, female 63 years, TKR)

I have tried a few (analgesics). I don't think they help a lot. I sit down to manage the pain. (P20, female 81 years THR)

One participant had attended a six week 'expert patient programme' organized by her local community centre which focused on self-management. She reported it had been of value and made her set little goals each day to try and achieve.

### Reliance and involvement of family members

Participants reported a reduction in their physical functioning. They were not able to do much around the house. This resulted in a greater reliance on family members for help. All

participants spoke of the effect of their OA on their family and how they were involved in helping participants manage their symptoms. It was apparent that there was often a role change within families. An interesting case was a woman who had an eight year old child and she was losing the ability to care for herself, so the child began caring for her:

He (son of 8 years) is aware, I don't ask him. He just does it. He'll say pass me your socks and he puts them on. I used to dress him, now he is dressing me. We laugh about it now. But it upsets me. I am only 48, I feel like 98. (P76, female 48 years, THR)

For the study participants still in employment ( $n = 6$ ), it was apparent that there was a need to keep on working and bringing in money to support their families:

The biggest worry is whether I can carry on working – I've gone to work to be able to afford retirement. (P87, male 56 years, TKR)

The participants who were working also highlighted the fact that having a joint replacement would mean time off work with some not entitled to sick time and therefore a reduction in pay and this was of concern to them.

## Discussion

In this study, individuals awaiting THR or TKR have provided us with their personal insights into their experiences of the management and care of their end-stage lower limb OA. This study is important as it shows that despite problems with physical functioning and high levels of pain, there was little use of services and treatments and little management of symptoms for individuals with OA whilst awaiting joint replacement. There is a need to improve health care delivery, in particular pain management for this group of patients. It is suggested that waiting for joint replacement appears to be seen as an end-point by both patients and professionals and a substitute for effective treatment and pain management.

Previous studies have shown the high levels of pain and poor physical functioning in individuals who are on the waiting list for joint replacement (Bellamy *et al.* 1988, Williams *et al.* 1997, Kelly *et al.* 2001, Croft *et al.* 2002). Other studies have found that pain and physical functioning become worse while on the waiting list for joint replacement (Mahon *et al.* 2002, Fitzpatrick *et al.* 2004). However, pain associated with OA is difficult to manage often requiring many different treatments and services for successful management (Clinical Standards Advisory Group 2000). The Arthritis and Musculoskeletal Alliance (ARMA) have developed standards for people with OA (ARMA 2004). These stipulate that people have a right to: access to appropriate services; timely diagnosis and treatment; information; services which are centred on the needs of users;

independence; and self-determination. This research found that while these individuals were on the waiting list, there was little management of their symptoms. There was a perception by patients that treatment had been transferred to secondary care and individuals would just have to wait to be called for their joint replacement.

Many participants reported giving up on treatments and were just waiting for their joint replacement, suggesting a sense of resignation. One explanation could have been that individuals had previously tried treatments and they felt these had provided them with only short term or no relief.

In this study, participants had had no input from community nurses and only one participant spoke of her positive experience of being referred to an occupational therapist. It was evident from the findings that managing activities of daily living such as getting into or out of a bath or chair, were extremely difficult for the majority of study participants to manage. There was little awareness of the kinds of living aids or home adaptations which were available through social services or by assessment from an occupational therapist or a nurse. Individuals with OA could be assisted if offered a home living assessment by a community health professional (i.e. occupational therapist, community nurse or physiotherapist) to assess the requirement for home care equipment (e.g. bath seat, toilet frame etc) and social care needs (meals on wheels, carer for shopping or cleaning etc.).

The lack of involvement by nurses was an interesting finding considering the government's latest strategy for nurses to become more involved in managing and caring for individuals with long-term conditions (DoH 2004, 2005a,b, 2006). A national target for 2008 has been set by the Department of Health to improve health outcomes for people with long-term conditions. This could be achieved via personalized care plans for vulnerable people and through improved care in primary care and community settings (DoH 2004). One way this improved care will be achieved is through case management by community matrons. The matrons would be involved in identifying, assessing and reviewing people with long-term conditions, including the co-ordination of care, and ensuring all needs are being met. Education and provision of information to individuals with the long-term condition and their families are essential components of this case management approach (DoH 2005a, 2006).

The community matron's role is still in development and differs across Primary Care Trusts (PCTs). It is not clear which groups of patients will be cared for by community matrons. However, the focus appears to be on long-term neurological conditions, diabetes and coronary heart disease. It may be that individuals with OA, a major chronic disease, may not be seen as requiring this type of care. Some PCTs

have started to identify patients with complex needs who are considered to be 'high intensity service users'. However, other PCTs have developed community matron roles differently focusing more on management than on advanced nursing care. Whether individuals with OA, where studies have found that they often may not consult their GP about their OA or pain (TNS Health Care & Arthritis Care 2003, Sanders *et al.* 2004) will be identified as being in need of this service is uncertain. In the study reported here, individuals with OA appeared not to be initiating contact with health professionals which could have contributed to the lack of effective pain management.

Campbell *et al.* (2000) discuss quality of care and suggest that the two principal dimensions of quality of care for patients are access and effectiveness. The effectiveness with which health professionals can help often depends upon the knowledge and availability of resources for the patient (AAGBI, RCoA & Pain Society 1993). It is of concern that individuals were hiding their symptoms from health professionals and also were trying to self-manage by adjusting or omitting medication. Surely quality of care is not going to be achieved if a coordinated approach to care including, involving the patient is not put into practice.

Work has been undertaken in developing programmes to enable individuals with chronic diseases to become expert in managing their condition (Hirano *et al.* 1994, Lorig *et al.* 1998). High on the UK government's NHS modernization agenda is a large investment into the 'Expert Patient Programme' which focuses on empowering and educating patients to take a lead in improving and managing their chronic disease (DoH 2001). There is growing evidence that supporting self-care has an impact not only on patients, in terms of improved feeling of well-being and improvement in quality of life but also on care services, with a reduction in visits to GPs and in admissions to hospitals (DoH 2005b). The focus on self-management is high on the UK's government agenda; however, without assessment of an individual's OA needs and little information or guidance, effective self-management may not be achieved. The provision of useful and relevant information to individuals with OA on how to manage OA and pain is essential to develop and sustain self-management of OA in a positive way and to deliver on the NHS strategic plan of supporting individuals with long-term conditions.

The National Institute for Health and Clinical Excellence (NICE) is in the process of preparing a new guideline for the NHS in England and Wales on the appropriate treatment of OA. A remit was developed in June 2004 which provides an overview of the purpose of the guideline under development and its focus is on reviewing the best

evidence for the management of OA. These guidelines, when published, will not only include recommendations on pharmaceutical and non-pharmaceutical treatments to manage the condition, but will include examining the roles of primary and secondary care and social services in the management of OA.

### Limitations of research

As this is a qualitative study, generalisability to the wider population is limited but this study does highlight issues raised by other research in this area. The study population are individuals at the end-stage of OA and may not reflect the views and experiences of less severely affected individuals with OA. As the individuals in this study had little personal experiences of some health services for managing their OA, it was not possible to explore the benefits of these services.

### Conclusion

In conclusion this study has shown that individuals with OA receive limited management from health professionals while on the waiting list for joint replacement. Placing patients on the waiting list and giving little thought to their care while on the waiting list will not achieve quality of care for these individuals. The difficulties patients experienced in managing their pain while waiting for their joint replacement was of concern. Pain management needs to be given a higher priority among health professionals, to prevent unnecessary suffering. Health professionals need to examine and clarify their roles in respect to caring for individuals with OA, including providing information on services and treatments which are available to patients. Perhaps a named health professional, such as a community matron would be one way forward. It appears that the NHS still has a long way to go to achieve a patient-centred approach; to deliver high quality of care; and to enable effective service delivery for this group of individuals.

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## Contributions

Study design: GM, AS, KL; data collection: GM; data analysis: GM and KL; manuscript preparation: GM, AS, KL.

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