Unmet need for joint replacement: a qualitative investigation of barriers to treatment among individuals with severe pain and disability of the hip and knee

C. Sanders, J. L. Donovan1 and P. A. Dieppe2

Objective. To explore barriers to health-care utilization in respondents with moderate to severe hip/knee symptoms of pain and disability.

Methods. In-depth interviews were carried out with 27 participants who had high levels of hip/knee pain and disability (according to New Zealand scores). There were 10 men and 17 women; median age 76 yr (range 51–91). The data were analysed thematically using the constant comparison technique.

Results. Three types of barrier were identified: (i) people’s own perceptions of need and reluctance to seek treatment, (ii) perceptions and experiences of primary care and (iii) experiences of treatment in secondary care. Pessimism about availability of treatments, and concerns about effectiveness and risks of surgery, made older people reluctant to seek medical help. Such views were often confirmed by GPs. Some of those referred to a hospital specialist were told that they were too young or too mobile for surgery.

Conclusion. Barriers to treatment and unmet need for joint replacement exist in the UK, particularly amongst older people.

Key words: Total joint replacement, Osteoarthritis, Unmet need, Qualitative research.

Severe arthritis of hips and knees is common in older people and a major cause of pain and disability [1–7]. Total joint replacement (TJR) is an effective treatment [3, 8], and about 70 000 hip or knee replacements are performed in English hospitals each year [9]. High demand is reflected in large waiting lists for surgery [9]. However, recent reviews have highlighted variations in surgical activity at both national [9] and international levels [8], with the USA, for example, having much higher rates of total knee replacement (TKR) than the UK. Rates of TJR also vary by age, gender, ethnicity and socio-economic status, despite there being no evidence that such factors affect outcome [10–13]. These findings have raised concerns that there may be unmet need for treatment for severe arthritis in the UK and underprovision of total knee joint replacements [14–16]. However, there is little empirical evidence for unmet need or possible reasons for it. One recent study identified potentially eligible surgical candidates in the community, but many indicated that they would not accept surgery if it were offered [17]. These findings are consistent with the results of this study.

The sample for the interviews in this study was drawn from the Somerset and Avon Survey of Health (SASH), a community-based survey of around 27 000 people which took place between 1992 and 1994. Approximately 2000 respondents reported hip and knee symptoms, and many had a clinical examination and radiograph [17]. Information collected in the survey was used to provide New Zealand scores, which are designed to indicate the level of need for hip and knee replacement surgery [18]. The score allocates points up to 100 based on questions about pain and ability to carry out daily activities (walking, washing, dressing etc), and clinical examination (including radiography). In the second survey, a 25% random sample of this group was followed up between 1998 and 1999, and asked identical questions to those in the original survey, plus some additional questions about service utilization (contact with GPs and specialists, and provision of surgery for joint problems). New Zealand scores were once again calculated (out of a maximum score of 80 because 20 points are allocated for the clinical component which was unavailable at follow-up).

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The sample for the interviews in this study was drawn from the follow-up survey described above and comprised people with moderate to severe self-reported symptoms of pain and disability. They were considered eligible for the study if they responded positively to a survey question that they had been told by a doctor that they had either ‘osteoarthrosis’ or ‘arthritis’ of the hip or knee. Candidates were excluded if they had reportedly been diagnosed with some other form of arthritis (e.g. rheumatoid or lupus). Sampling for the interviews was purposive and theoretically driven—such non-probability sampling is common and appropriate for qualitative research [19, 20], where the aim is to sample in

Participants and methods

Qualitative interviews were conducted with respondents who had moderate to severe pain and disability of the hip and/or knee. Available data from two questionnaire surveys were used to identify individuals and inform the sampling for these interviews.

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Results

Altogether, 27 (59%) out of the 46 sampled were interviewed. Of those who were not interviewed, 10 refused without giving a reason. Six people who did not respond initially, later declined to take part, one because of an acute illness. One member of the sample had moved on to an unknown address. Twenty-nine gave written consent to be interviewed and all except two consented for the interview to be audio-taped. Recorded interviews were transcribed and detailed notes made for the two cases not transcribed.

Perceptions of need and reluctance to seek treatment

Most had experienced the pain and disability of arthritis for one or more decades and tended to perceive their symptoms as being inevitable and associated with normal ageing [23]. The predominance of this view of arthritis as a natural degenerative condition of older age made respondents pessimistic about formal care and this was a major factor in making them reluctant to seek care:

‘...to my mind nothing ever seems to happen where arthritis is concerned...All right, you go on a list, perhaps they think you have to have a replacement knee or something like that. I mean that’s years, so I think to myself well, I’m 73 now, there’s not much point really and truly.’ (int. 24, female, age 72).

Table 1. Table to show profile of New Zealand scores for worse joint at baseline and at follow-up for the same joint

<table>
<thead>
<tr>
<th>Interview no.</th>
<th>Worse joint (Hip [H] or knee [K])</th>
<th>Score at baseline (% of total NZ score out of 80)</th>
<th>Score at follow-up (% of total NZ score out of 80)</th>
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<tbody>
<tr>
<td>1</td>
<td>K</td>
<td>34 (42.5)</td>
<td>59 (73.7)</td>
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<td>2</td>
<td>K</td>
<td>56 (70)</td>
<td>36 (45)</td>
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<td>3</td>
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<td>54 (67.5)</td>
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<td>16 (20)</td>
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<td>14 (17.5)</td>
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These interviewees had received TJR between baseline and follow-up on the joint scored here. Interviewee numbers 8 and 16 were less than 6 months post-operation.

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‘...to my mind nothing ever seems to happen where arthritis is concerned...All right, you go on a list, perhaps they think you have to have a replacement knee or something like that. I mean that’s years, so I think to myself well, I’m 73 now, there’s not much point really and truly.’ (int. 24, female, age 72).
Most informants relied on ‘over-the-counter’ medications, health food supplements, exercise and application of heat or cold to treat their symptoms, although most conceded that, at best, these brought limited relief. Respondents were often reluctant to seek care for joint problems, even when their symptoms caused severe disruption to their lives. Several assumed that they would not be considered as appropriate candidates for surgery because of their age and so had not even discussed the possibility of treatment with a doctor:

‘Well I think, I do think to myself I shall be 90 next year. Perhaps all that money they might spend on me could be done perhaps for a younger person. That’s the way I’m looking at it. Also, I’m wondering if they put me on a list, it would be so long a wait, it probably wouldn’t be worth it. I don’t know if they do you when you get so old…this morning when I got out of bed it was so painful. I thought to myself, girl you’re gonna have to think about something for your leg. I don’t want to be kept in with my leg you know, I couldn’t even go (on holiday) if this collapsed properly. You know that it may have to come to it. I would like some treatment on it if I could have it.’ (int. 23, female, age 89).

Four different respondents also mentioned how old age had been discussed as a reason for not undertaking surgery for some other condition and, consequently, they assumed doctors would consider them to be too old for TJR.

Some reluctance to seek treatment stemmed from perceptions of the risks and personal costs of surgery. Twelve respondents told stories about people they knew who had had joint replacements, but because many reported poor outcomes, particularly from knee surgery, they were fearful, or at least uncertain, about whether or not they should submit to having surgery themselves:

‘…to be quite honest, so many of my friends that I know have had, they haven’t been satisfactory. I mean one after 3 years her knee completely went again, and another one had never been free of pain since after going through with the surgery. So, I thought, well if I can manage without it, you know, I would.’ (int. 21, female, age 83).

A number of personal factors leading to reluctance to have surgery were also identified, such as weight (2 respondents), comorbidity (5 respondents) or caring commitments (3 respondents):

‘My neighbour next door had a knee replacement. Well, that was no good for her because she was too heavy, and that’s what I feel now, I’m a bit heavy for anything like that.’ (int. 5, female, age 91).

One man was caring for his wife who had Alzheimer’s disease:

‘…if they’re going to do something like that, my wife, where is she going to be like, do you know what I mean?…I wouldn’t put her away or anything like, no.’ (int. 19, male, age 74).

These views were expressed by older respondents; the four youngest people were much more determined to get treatment. They were all of working age and three were in paid employment. Three had found it necessary to pay for a private referral to a specialist:

‘I went back and I said I’m just not happy with it…He gave me some tablets to take and said that should sort it out… Because I am covered by BUPA at work. I said to my GP that I wasn’t happy and he said well I think we’ll put you through to a [private] specialist.’ (int. 25, female, age 55).

Perceptions and experiences of primary care

Respondents stated clearly that they did not want to ‘bother’ GPs with symptoms for which they considered there was no appropriate/acceptable treatment:

‘Well, I don’t see her [GP] about the joints because there’s nothing she can do other than give me tablets, but I do see her because I’ve got to keep going for blood tests, so I do see her regularly but not about the joints. Well I’d just think why go to the doctor? She can’t do no more you know, she might be able to change the tablets. No, I don’t go because I don’t think she can do anything herself you know.’ (int. 13, female, age 70).

For some, GPs seemed to reinforce the perception that nothing could be done:

‘I’ve told him the doctor (about joint problems) and he said “well there’s nothing really we can do about it”, and well I just say it’s something I’ve just got to put up with and get on with.’ (int. 5, female, age 91).

And then the results would come back, and this is what I thought was pretty demoralizing at the time…[GP said] “Oh yeah, you have a slight arthritis condition you know in your hips but it shouldn’t cause the pain you’re complaining about.” More or less saying that you’re pulling the wool over somebody’s eyes or trying to.’ (int. 4, male, age 67).

Two had been referred for an arthroscopy, but neither experienced improvement or received any follow-up, and it would appear that they expected the GP to take the initiative:

‘Yes, I went back to the GP, and then he sent me for an x-ray “cause they thought then I would have been able to have had a hip replacement. But when I went and had the x-ray, they had the results back like, and I went back to the doctor, and he said that I had it in me knees and me hips and that they wouldn’t touch me, well his exact words were they wouldn’t touch me with a barge pole.’ (int. 3, female, age 82).

‘I was in agonesie and um, I said to him [doctor] “what about my knees being done?”’, and he said “look Mrs X, if it was your hips I would send you in, but they don’t do the knees much good, they’re not perfect with it.” He said “you’re wasting your money to have a specialist”…Anyway, I couldn’t go on any longer, and my son and I went over to see him, and he said “look mother has got so bad with her knees…don’t you think she should try the operation?” And he said [doctor] “She might not even come round from the anaesthetic because she’s getting on in years”.’ (int. 8, female, age 82).

Experiences of secondary care

The majority of the group had been referred to a specialist at some stage. Fourteen had been seen by a rheumatologist or orthopaedic surgeon since the baseline study, but less than half had been offered surgery—four had received a TJR, one was on the waiting list, and one had refused it. Two had been told that TJR would be inappropriate because they had additional problems with their spine. Two had been seen and then discharged from a specialist clinic several years earlier. Four were under periodic review. A further four had been seen by a hospital doctor more than 5 yr prior to interview.

Some respondents talked about initial difficulties in getting a referral. As indicated above, four paid for a private referral. Others experienced problems with long waiting lists:

‘I said could you put me on the waiting list you know. And he said it’s a long waiting list…He said it’ll be a 12 month when he’ll do them…So, I put up with the pain… I knew something was being done.’ (int. 8, female, age 82).

Once respondents had actually seen a specialist, the majority seemed satisfied with their treatment. However, there were two who clearly felt that they needed TJR, but believed that they had been stalled from having the surgery because the surgeon considered them to be ‘too young’ or ‘too mobile':
‘He [surgeon] said I was too young to have it done . . . but he said that was what I needed because it had gone too far. He said did I think I could manage and go on with it until I got older? So I said well yeah . . . That was when I was 65 and I’m nearly 70 . . . I’m sort of waiting for him to say I’ll do it like you know. . . He probably thinks that by the time it’s time for me to have it done I’ll be dead, and that’ll save them the money (laughs) . . . They don’t seem to bother with the old people these days do they?’ (int. 13, female, age 69).

‘I actually got as far as the pre-op assessment appointment which was two weeks before the operation, and on the day I saw a different consultant. Um, he was quite sharp with me and it seemed to me, I felt as if I had pushed myself to the front of the queue and he decided I had no right to be there . . . he said I was still too mobile and too young, and I should go away and just wait . . . I came away feeling very upset about that, and thought well ok I’ll struggle on.’ (int. 16, female, age 56).

These informants had no clear indication of how they might be reconsidered for surgery.

Discussion

Unmet need was clearly identified in this study. The majority of informants had moderate or severe symptoms, but only four had received a TJR between baseline and follow-up (a period of 5 or 6 yr). The accounts given by the informants indicated that they perceived barriers at three stages: first, some were reluctant to put themselves forward for treatment because of their perceptions that arthritis was part of normal ageing and that there was little that could be offered to them; second, while many had consulted GPs, their experiences were mostly negative, with GPs appearing to confirm the lack of effective treatment and rarely offering referral to secondary care; and third, waiting lists and rationing were perceived to be a barrier to getting treatment in secondary care and sometimes TJR appeared to be denied because they were considered ‘too young’ or not sufficiently disabled.

There is considerable evidence that older people tend to perceive pain and disability as a normal part of ageing [24–28] and this is perhaps unsurprising owing to the high prevalence of arthritic symptoms in older age and some of the cultural connotations of ageing as symbolizing a period of decay [29, 30]. The common perception that symptoms were related to ageing contributed to the informants feeling pessimistic about treatment and reluctant to seek help. This confirms findings of previous studies about seeking treatment in older age [31, 32]. More specifically, the findings are closely aligned to a recent Canadian study reporting that older people with severe arthritis were reluctant to consider TJR and assumed that their physician would advise them if they were appropriate candidates for surgery [11]. In our study respondents commonly made assumptions that they would not be considered appropriate candidates for surgery owing to their age, weight or the presence of other chronic conditions. This was the case even when they had not discussed these factors with a doctor, and highlights the communication gap between patients and doctors. Younger informants were, however, much more determined to get the treatment they felt necessary. This was demonstrated in requests for private referrals.

In previous work done on the subject of illness behaviour, Tuckett [33] refers to a three-stage process involved in the process of becoming a patient which comprises recognition (that there is a problem), definition (that it requires attention) and action (that they should consult a doctor). Similarly, Mechanic [34] and Zola [35] have highlighted the importance of recognizing symptoms and interference with daily life in ‘triggering’ help-seeking. Although these informants tended to minimize the significance of their symptoms in the context of their older age, all had consulted a GP at some point—indicating that they had recognized that their symptoms were significant enough to seek formal care. However, in many cases their experiences of consulting a GP made them even more pessimistic. GPs often seemed to confirm that their symptoms were inevitable and untreatable and that they were not suitable for referral. Of course, we cannot be sure what actually occurred in these consultations. It may have been that the informants had milder symptoms when they consulted the GP many years previously, or that they presented their difficulties as relatively unimportant.

Age emerged as a consistently important theme, albeit in different ways in different circumstances. Most informants thought that it would be better to have surgery when they were younger and thus could recover more easily and gain more years of benefit. For the younger informants, this was also driven by the impact of their joint problems on their lives. Older informants tended to suggest that they felt too old for surgery and that younger people should have priority. GPs appeared to provide a barrier to both groups—they did not refer older people because of comorbidity or younger people because they were not sufficiently disabled. Indeed, three out of the four youngest respondents paid for a private consultation with a specialist. For those who managed to obtain an orthopaedic consultation, several felt they had been refused surgery because they were too young or too mobile. The question about appropriate age for surgery is important because recent research has suggested that those who have early surgery have better outcomes than those who have later surgery when they are older with more severe symptoms [36]. However, surgeons have to offset this against the risk of prosthesis failure in younger patients.

The data also demonstrated that there was considerable concern about the outcome of TJR, particularly knee replacement. This was evident both from informants, based on their knowledge of previous recipients of surgery, and also GPs, who appeared to confirm that knee surgery was experimental or had poor outcomes. This is counter to recent evidence that TKR has become a very effective procedure [3, 37–39].

This study shows that meeting unmet need may require several approaches. Information about TKR as an effective procedure needs to be disseminated among GPs and the public. There is also a need for information to counter prevalent lay beliefs that pain and disability are an untreatable and inevitable part of ageing, even when there are profound effects for people’s lives. Amongst practitioners (in primary and secondary care), there needs to be a debate about appropriate indications for TJR, and particularly the importance (or otherwise) of factors such as age and obesity. Finally, this study demonstrates the need for an urgent review of referral practices for joint disease. The majority of these informants were ambivalent about surgical treatment, and it was clear that most had not had their potential need for surgery adequately assessed, nor the opportunity to discuss the risks and benefits. Many appeared to be waiting for GPs or specialists to initiate treatment if and when required—something that is unlikely to happen. TJR rates, particularly TKR rates, are lower in the UK than in many other countries. This study provides clear evidence of perceived barriers to treatment at three levels. Thus, a concerted multidisciplinary approach is required to tackle unmet need for TJR.

Acknowledgements

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The authors have declared no conflicts of interest.
key messages

Rheumatology

Barriers to treatment and unmet need for joint replacement exist in the UK.

Older people are often reluctant to seek help for joint problems.

Improved communication is needed between clinicians and potential candidates for surgery.

References


