Who should have priority for a knee joint replacement?

G. M. Woolhead, J. L. Donovan¹, J. A. Chard and P. A. Dieppe

Medical Research Council Health Services Research Collaboration and
¹Department of Social Medicine, Canynge Hall, University of Bristol,
Bristol BS8 2PR, UK

Abstract

Objectives. To explore patients' views on who should have priority for total knee replacement (TKR).

Methods. In-depth, semistructured interviews were conducted with 25 patients on the waiting list for a TKR.

Results. All participants were willing to comment on waiting lists and prioritization for TKR. Two major themes emerged: what they thought should happen, and what they thought did happen. They thought that priority should be based on length and degree of suffering, pain severity, immobility, paid employment, payment of National Insurance contributions, and caring for dependants. In contrast, they thought that what actually happened depended on age and weight, excessive complaining and access to private practice.

Conclusions. The participants agreed with health professionals that pain and disability should be key criteria on which to prioritize people for a TKR. However, they also argued for a fair decision-making process that also included additional factors specific to the patient's circumstances. Criteria to aid prioritization for joint surgery need to accommodate the views of patients as well as professionals.

KEY WORDS: Osteoarthritis, Priorities, Total knee replacement, Qualitative research.

Total knee replacement (TKR) is a commonly used, effective intervention for severe arthritis [1–3]. About 30 000 such procedures are carried out in England and Wales each year, some 80% of which are done within the National Health Service (NHS) and about 20% in private practice [4, 5]. The annual rate of TKR in the UK has been rising, although there is still concern about unmet need [6–8].

Within the NHS, long waiting times for joint replacements have been an issue for years. Most patients still have to wait for many months for an initial appointment to see an orthopaedic surgeon, and a further 6–18 months before they are put on the list for the joint replacement. Some people wait for shorter times than others, and in general there are far shorter waiting times in private practice than in the NHS. Furthermore, a proportion of those referred to NHS surgeons for consideration of joint replacement are not put on the waiting list, being told that surgery is not appropriate for them. This implies that choices are being made within the NHS as to who should have an operation and which cases should be prioritized [9, 10].

Waiting lists and rationing applied to joint replacement are not peculiar to the UK; similar problems have been described in Canada, New Zealand and other countries [11, 12]. In response to this, a variety of attempts have been made to develop criteria for deciding who should have a joint replacement and which patients should have priority [9–15]. The criteria that have been developed are consensus-based, being derived from groups of professionals, and the patients' voice has had little or no direct input.

As part of a programme of research into the provision of total joint replacement surgery in the UK, we sought the views of patients about who should receive a knee joint replacement and why, and compared these views with the published consensus criteria produced by the research community.

Participants and methods

Once ethics committee (South and West Local Research Ethics Committee) approval had been obtained, in-depth interviews were conducted with 25 patients on the waiting list for a TKR to explore their views about the operation. Patients were sampled from three orthopaedic surgeons' waiting lists to obtain information about a broad range of demographic characteristics, including age and gender. Information about previous TKRs and other comorbidities were not available from the waiting list cards. Selected patients were contacted...
by post with a letter signed by their respective consultant and an information sheet, with a reply slip requesting consent. Of the 40 patients approached, 25 gave their consent. Of the remaining 15 patients, 10 did not reply to the letter and five refused to participate. GMW conducted semistructured interviews with the consenting participants in their own homes approximately 3 months before their TKR. A checklist of topics was used to ensure that the same issues were covered with each participant [16]. Topics included the onset or aetiology and experience of joint problems, the effects of arthritis on everyday life, referral and listing for TKR, views and expectations of the TKR, and views on patient selection and prioritization.

Analysis was conducted according to the method of constant comparison [17]. This means that the processes of sampling, data collection and analysis were continuous and iterative. For example, a small number of interviews were carried out and analysed. Analysis of subsequent interviews was then compared with analysis of the first interviews, so that similarities and differences between cases could be examined. This in turn shaped further sampling, data collection and analysis. Interviews, which lasted from 1 to 2.5 h, were recorded on audio tape and fully transcribed. These transcripts, together with field notes and reflective comments made at the time of the interviews, formed the raw data for further analysis. Data were analysed by detailed scrutiny of the transcripts to identify common themes, which were then coded, using the computer software package Atlas.ti. [18]. Several transcripts were coded independently by GMW, PAD and JAD, the resulting codings compared, and any differences discussed and resolved. Once coding had been completed, all the information was transferred back to a word-processing package for further in-depth analysis. Data were examined for similarities and differences within themes, retaining the context of the discussion and the characteristics of the participants. The themes were refined as new transcripts were analysed. Sampling continued with the aim of achieving data saturation, i.e. when new themes no longer emerged from the data. Descriptive accounts were produced and discussed by the authors to check the credibility (internal validity), plausibility (reliability) and clinical relevance of the findings.

This paper focuses on data relating to prioritization for TKR. The themes that emerged from the data are presented below, together with illustrative quotations. All names have been replaced by letters to protect confidentiality.

Results

Twenty-five patients (14 women and 11 men) were interviewed. Participants were aged between 40 and 84 yr (mean 65 yr) The age range was different for the two sexes, with more older females (55–84 yr; median 68 yr) and more younger males (40–80 yr; median 66 yr). This reflects the general profile of those operated on in the UK [4, 28]. The age of the participants was reflected in their occupational status. At the time of preoperation interview, 21 were retired, three on disability allowance and one in full-time employment. Occupations varied from domestic cleaner to manager: 19 participants had a manual occupation and six had a non-manual occupation. Sixteen were married, five were widowed, two were divorced and two were single. All but one of the participants (who lived in a residential home) lived in their own home. Sixteen had had previous operations on their knee or hip and one informant had rheumatoid arthritis and systemic lupus erythematosus, the remainder having osteoarthritis.

All 25 participants admitted to some pain, which varied from a ‘slight niggle’ (three) or ‘dull ache’ (nine) to ‘agonizing’ or ‘excruciating’ (six), and two said that they had very little pain. Nearly half admitted to experiencing night pain, but one-third indicated that they had no pain at night. Similarly, all stated that they had some disability, although this also varied from relatively mild (able to continue with daily life, 17) to severe (housebound, eight).

All were willing to comment on the issue of waiting lists and priority for surgery, and most indicated that they realized that choices were being made. Their views were divided into two major themes: what they thought should happen and what they thought happened in practice.

What should happen

About half the participants accepted that there has to be a waiting list system as resources are limited and there is a high level of demand:

Mr Q: ‘I know we all have to wait, there is a list’.

These participants suggested a number of different factors they thought should be taken into account when deciding who should be operated on and when. A major factor was pain, specified by nearly half of the participants, with ‘crippling’ or severe pain identified as particularly significant by five:

Mrs I: ‘Well, there is a lot of pain . . . someone else who is weeping with the pain every morning, obviously this takes precedence’.

Mrs K: ‘I am in lots of pain, and I want to be done and have a better quality of life, but if there is someone out there that has been in such agonizing pain, although they may not have been in it for as long as I have, then my sympathies would go to them’.

Mrs K exhibits considerable altruism (above). This was also apparent in five other interviewees who thought that people worse off than themselves should have greater priority:

Miss D: ‘There’s so many people wanting it and I’ve had to accept there are probably people worse off than I was, and maybe they need it first. And if there are people worse off who need it, then you can’t really argue about that’.
Mr U: ‘Well obviously if someone is in desperate need ... I am certainly happy to let God knows how many people go ahead. If people are worse off ... I certainly don’t want to have it done’.

The idea that people with limited mobility should be given priority was indicated by five participants, with two specifically mentioning better quality of life:

Mrs E: ‘well I don’t know because I have got a certain mobility and I should imagine there are some that are completely incapacitated’.

Just over one-third thought that the surgeon should decide on the basis of medical evidence (such as X-ray changes):

Mrs H: ‘The X-rays told it all ... it was obvious ... he said it had just wore out’.

Mrs N: ‘I suppose they should look into their records and see exactly how much they have suffered’.

Mr X: ‘It depends on the specialist ... he has got to decide and sort it out’.

A smaller number of participants cited other factors that they thought should be taken into account, e.g. that priority should be given to younger people (four participants), those in paid employment (six), those paying National Insurance contributions (four), those caring for others (two) and those needing bilateral replacements (one). Although there was evidence of altruism, several participants indicated that it was difficult for them not to show self-interest when thinking about who should be prioritized:

Mrs I: ‘As it is my knee, I want it done quick ... I don’t particularly want to wait another 6 to 8 months ... it’s difficult to go through your self-interest and your awareness that there are other people who may need it more’.

*What they perceived happens in practice*

The participants drew on their own experience to identify several other factors that they believed played a role in who gets a TKR, particularly weight and age. Six said that they had been told that their excess weight was a problem; many of them felt that this was unfair and that the doctors did not appreciate that arthritis led to reduced mobility and therefore to weight gain:

Mr P: ‘All I was told was to lose a bit of weight and come back again which, like I said, just annoys me a little bit, well a lot really, because I have had all the problems before I put the weight on ... since then I’ve given up the sport and I’ve been doing less and less physical exercise, I have put the weight on ... They tend to look at you as thought it is your own fault ... the problems I have got have not been caused by being overweight ... I’m overweight because of the problems that I’ve got’.

Ten thought that age was used as a criterion. Nine reported having been told that they were too young and, again, many felt that this was inappropriate and that they should have been offered their surgery earlier:

Mrs K: ‘I said, “well can I have something done about it, can I have an operation?” And they said, “No, you are too young” ... I think there should be some way, irrespective of age. I would rather go in and have a check-up every 10 years than endure the pain ... so if this could be done earlier, you are not like this ... I should be out now enjoying myself because I have worked hard all my life’.

One felt that ageism operated in the NHS so as to exclude older people:

Mr T: ‘I don’t like this ageism that’s creeping in. I am over 65 and I am expecting all that crap and put down the bottom of the list and I do believe that’s what’s happening ‘cos I know two people have gone in before me ... its ageism when they muck you about on that list’.

A small, but perhaps important group felt that the system was unfair in other ways. Three, for example, were sure that knowing or bothering the surgeon (and excessive complaining) could result in earlier treatment:

Mrs M: ‘some people they keep worrying them, don’t they?’.

Another three were concerned that private care meant that some received unfair earlier treatment, two of them believing that ‘foreigners’ were also seen too early.

**Discussion**

This study has shown that people on the waiting list for a TKR have clear views as to who should be prioritized for surgery, often exhibiting considerable altruism in terms of believing that others with more severe pain or disability should be prioritized.

Through separate work searching the literature on the treatment of knee disease [19, 20], we have identified seven articles on the subject of criteria for the prioritization of joint replacements [8–15], two of which were confined to the hip [14, 15]. These criteria are consensus-based rather than evidence-based, and have come from health-care professionals without input from patients with joint problems. Manusco *et al.* [9] surveyed orthopaedic surgeons and found that severe pain (particularly rest pain) with X-ray changes was thought to be the main criterion for a TKR. A group in Ontario have published consensus-based criteria for who should be considered for large joint replacements (knee or hip), from which the severity of pain and physical disability emerge as the main issues, along with problems with care-giving [11]. The New Zealand priorities group has published a numerical scoring system for the prioritization of patients for joint replacement [12]. Of the possible 100 points, 40 are based on pain, 20 on physical disability, 20 on joint damage and 20 on other features, such as work, social issues and involvement of other
joints. Other publications indicate that orthopaedic surgeons regard pain severity as the main criterion for operating [10] and the mantra ‘cannot walk, cannot work or cannot sleep’ is often used to express the three main reasons for considering joint replacement [21]. This is also reflected by the main patient-related outcome measures in use in orthopaedic surgery, such as the American Knee Society Score [22], which emphasizes pain, physical functioning and joint damage.

Our interviews with a sample of patients waiting to have a TKR showed that they were well aware that decisions have to be made about who should be prioritized for TKR. They had strong views on what they thought should happen in the decision-making process and distinguished this from what they thought actually happened in practice, drawing on their own experience. In general, agreement between consensus criteria and what patients thought should happen was demonstrated: the participants agreed with professionals that pain and disability should be key criteria on which to prioritize people for a TKR. However, the patients also argued for a fair decision-making process that should include factors specific to the patient’s circumstances, e.g. the length and degree of suffering, whether there is a chance of getting back to work, whether you have dependants, and whether you have paid your National Insurance contributions. Although two of the consensus-based criteria do specify issues such as work/age, social and carer issues, the participants believed that these are not given enough importance and are not used in practice. In contrast, they thought that decisions for TKR were being made according to age, weight, how loudly you shout, and how much money there is in the system. There is some evidence to support these claims. TKRs are, in general, not often performed on those below 50 yr or over about 80 yr, and patients are often turned away on the basis of obesity. The main concern about operating on young people is the risk of early loosening of the prosthesis [23], and concerns about older people revolve around the risk of complications [24]. The participants interviewed in this study argue that if you have bad pain you should have the operation early, even if it does not last. Weight was also a major issue for them. The surgeons told the patients to lose weight and that the obesity causes the arthritis. However, the participants believe that it is the other way round and that they need a joint replacement in order to be more active and to lose weight. There is no evidence to suggest that operating on obese or older patients leads to more failures or complications [20, 24–27].

Other recent data suggest that the degree of improvement in patients with the most severe disease at the time of TKR is similar to that in those operated on earlier, meaning that they never ‘caught up’ with those who were less disabled at the time of TKR [28]. These data also show that the oldest people having an operation usually benefit a great deal, but not as much as younger people. Such findings are in accord with the views of our patients who argued for earlier surgery and no upper age limit. This paper reports only what the patients think happens rather than evidence of what actually happens. Future work aims to confirm or refute whether there is evidence for the biases mentioned by our informants (such as age and obesity) that affect who is actually operated on.

The small sample is obviously not representative of all those who undergo a TKR, although their demographic fits well with the general profile of those operated on in the UK [4, 28]. Analysis of the severity of pain and disability at the time of surgery shows huge variation [28], suggesting that the absence of clear criteria for prioritization leads to some people being operated on much sooner in the course of their arthritis than others. In this context, it is interesting to note that some of these patients, although put on the waiting list for a TKR, had relatively little pain or disability and might not have fitted the clinical criteria reviewed above.

An agreed measurable threshold of the severity of pain and physical disability could probably be agreed upon by both patients and professionals as an essential entry criterion for joint replacement. Patients would then argue that age, weight, ability to pay, race and sex should not be taken into account, whereas ability to return to work and the need to care for others should. However, the views of the patients also stress the need for an individualistic approach rather than a purely formulaic one. Many people mentioned specific factors of importance to them as individuals which they thought should have been taken into account. It is difficult to know how to harmonize an individualistic approach with demands for explicit criteria for decision-making and health-care delivery. However, open sharing of information and the concerns of both parties at consultation might bridge the gap.

There is evidence for unmet need for TKRs in the UK [6, 7] and great regional variations and inequities in use [4, 5]. We need to develop prioritization criteria to help solve these problems, and to aid routine decision-making in rheumatology and orthopaedic clinics. This research suggests that it is possible to develop criteria to prioritize access to joint replacement that encompass the views of both patients and surgeons. Accommodating the views of patients will, however, require that physicians and surgeons suspend some of their current practice criteria and take greater account of social factors. An important issue that this paper raises is the origin of the bias that results in a patient being referred or put on the waiting list or not. Future work will address these issues and will aim to explore the nature of the decision-making processes used by patients, general practitioners and consultants.

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