

# How do patients with end-stage ankle arthritis decide between two surgical treatments? A qualitative study

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## ABSTRACT

**Objective:** To examine how patients decide between ankle fusion and ankle replacement in end-stage ankle arthritis.

**Design:** Purposive patient selection, semistructured interviews, thematic analysis.

**Setting:** Royal National Orthopaedic Hospital, Stanmore, UK.

**Participants:** 14 patients diagnosed with end-stage ankle osteoarthritis.

**Results:** We interviewed 6 men and 8 women with a mean age of 58 years (range 41–83). All had opted for surgery after failure of at least 6 months of conservative management, sequentially trading-off daily activities to limit the evolving pain. To decide between two offered treatments of ankle fusion and total ankle replacement (TAR), three major sources informed the patients' decision-making process: their surgeon, peers and the internet. The treating surgeon was viewed as the most reliable and influential source of information. Information gleaned from other patients was also important, but with questionable reliability, as was information from the internet, both of which invariably required validation by the surgeon and in some cases the general practitioner.

**Conclusions:** Patients seek knowledge from a wealth of sources including the internet, web forums and other patients. While they leverage each of these sources to guide decision-making, the most important and influential factor in governing how patients decide on any particular surgical intervention is their surgeon. A high quality doctor–patient relationship, coupled with clear, balanced and complete information is essential to enable shared decision-making to become a standard model of care.

## INTRODUCTION

The UK National Health Service (NHS) has adopted a philosophy of “no decision about me, without me,” moving away from a paternalistic model of decision-making towards a shared decision-making (SDM) process between the patient and the clinician.<sup>1</sup> This ideal is the foundation of high-quality health-care and is especially important in the

## ARTICLE SUMMARY

### Article focus

- Qualitative assessment of how patients with end-stage osteoarthritis of the ankle decide between surgical interventions offered to them.
- Discuss the sources of information the patient's use to aid their decision-making.

### Key messages

- The treating surgeon, the internet and the peers are the three main influences on a patient's decision-making.
- The surgeon appeared to be the most valued source of information.

### Strengths and limitations of this study

- The strengths include this being the first study to take a qualitative look at how patients decide between ankle fusion and ankle replacement to treat end-stage ankle osteoarthritis.
- The limitations include sampling from a single specialist centre and the relatively small sample size although data saturation was reached.

context of long-term conditions and chronic illness, such as osteoarthritis.

The patient and doctor interactions are underpinned by three main decision-making models,<sup>2</sup> these being paternalistic, informed and shared.

The paternalistic model assumes that the doctor knows best. It is characterised by the passive compliance of the patient to the authority of the surgeon, who is the custodian of the patient's best interest. As a result, decisions may not take account of a patient's values and preferences, as long as the patient is perceived to benefit.<sup>3</sup> This approach is less desirable in the setting of elective surgery, but still has its applications in trauma and life-threatening situations, where patients may present acutely with altered conscious or mental state.

At the other end of the spectrum is the informed model, where all decisions are made by the patient. The role of the doctor

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is to deliver to the patient information on all relevant treatment options including their benefits and risks. Communication in this model is largely one way.<sup>2</sup>

SDM is a two-way interaction where the doctor and the patient share all stages of the decision-making process simultaneously and reach a decision together.<sup>4</sup> This is the ideal held by the NHS and affords many advantages in the orthopaedic setting. SDM increases the patient's knowledge and understanding, and creates more accurate expectations. It allows for better tailoring of treatment to the patient's values and has been shown to result in higher satisfaction.<sup>5</sup>

Decision-making has been examined in orthopaedic surgery mainly in the context of hip and knee joint replacement. The majority of the work has centred on the decision of whether to undergo surgery or not.<sup>6 7</sup> Our aim was to address a different question namely as to how patients that have decided to undergo surgery decide between different treatment options. The model we have used pertains to patients with end-stage ankle osteoarthritis.

Osteoarthritis of the ankle is a major cause of disability with an impact on quality of life similar to end-stage heart failure<sup>8</sup> and hip arthritis.<sup>9</sup> Its demand incidence in the UK has recently been estimated to be 47.7/100 000.<sup>10</sup> The majority of cases are secondary to trauma or other diseases such as inflammatory arthritis.<sup>10</sup> We believe that ankle osteoarthritis is a good model to study because there are two accepted surgical treatments, ankle fusion and total ankle replacement (TAR). Both have been shown to be valid and cost-effective treatments<sup>11</sup> with a degree of clinical equipoise between them.<sup>12</sup>

**METHODS AND MATERIALS**

This study took a qualitative, interview-based approach to explore and analyse how patients with severe-ankle osteoarthritis decide between two different surgical treatments, ankle fusion and TAR.

**Sample**

The study was based at the Royal National Orthopaedic Hospital NHS Trust, Stanmore, UK. This is a specialist

hospital, which offers both ankle fusion and TAR as standard treatment options. Patients diagnosed with end-stage ankle osteoarthritis were purposively recruited prior to their outpatient visit to discuss their surgical treatment. Our inclusion criteria were patients of all ages with ankle osteoarthritis (diagnosed by clinical history and plain radiography), who had tried at least 6 months of non-operative treatment, that were suitable for either a fusion or a TAR, and had opted for operative intervention, but were yet undecided between the two treatment options. The patients were given verbal and written information, including a letter from the consultant, explaining the two treatment options in their case. Skeletal models and pictures were used during the consultation to support verbal information conveyed, and all patients were provided with a written departmental information leaflet on treatment options for ankle osteoarthritis as a further adjunct to decision-making. Interviews took place prior to the second appointment, which served as a platform for the patient to declare their treatment choice. We excluded patients who were only suitable for one of the interventions, or had declined surgery. Patients were approached directly (by RZ and AG) in the clinic and the purpose of the study was explained to each patient. Following a 'cooling-down' period of 72 h, patients were asked if they remained happy to participate in the study. Recruitment continued until data saturation became noticeable during the last three interviews.

**Data collection and analysis**

Following informed consent, all participants underwent face-to-face, semistructured interviews (n=14). The interviews were conducted by one of the authors (RZ) in the outpatient department. An interview guide was used. It consisted of open-ended questions that were based on the research objective and the existing literature (table 1). The schedule focused on the patients' experience of the condition, the information sources they had used, the treatment options open to them and their preferences. The interviews lasted between 45 and 60 min; they were audio-recorded and transcribed verbatim.

**Table 1** Interview schedule

Question	Focus
1 Could you please explain your ankle problem to me?	Knowledge of ankle arthritis
2 How did you find information about your ankle condition?	
3 Where did the information come from?	
4 How did you find that information?	
5 What did you find out about it?	Knowledge of ankle arthritis
6 What can you tell me about the treatment options you have?	
7 How did you find out about these treatment options?	Knowledge of treatment options
8 What do you think about the treatment options you have? What are their advantages and disadvantages?	Acquiring information Personal treatment preferences

The data were analysed inductively (by RZ and MP) using thematic analysis.<sup>13</sup> This is a highly flexible method capable of producing a detailed and systematic account of the issues and opinions contained within in the data.<sup>14</sup> The first analytical step involved repeatedly reading the interview transcripts and becoming familiar with the content. This allowed initial patterns and codes to emerge from the text. During the subsequent line-by-line analysis, these codes were refined and grouped into themes. Each theme was described in rich detail and interpreted. Themes were eventually inter-linked within a comprehensive categorisation system. Finally, in order to validate our results peer-debriefing was employed.<sup>15</sup> This process required the remaining authors (AG and AM) to scrutinise the data to justify the findings.

### Ethical issues

This work was approved locally through the R&D Institutional Review Board at the Royal National Orthopaedic Hospital NHS Trust, who confirmed that as these interviews were carried out as part of a wider service evaluation and no formal ethical approval was required. Nevertheless, ethical procedures were strictly adhered to including the provision of fully written participant information enabling informed consent and by assuring that strict participant confidentiality was maintained, for example, by allocating numeric codes to all participant contributions. All participants were aware that they could stop taking part at any time.

## RESULTS

A total of 14 patients (6 men and 8 women), each with a diagnosis of ankle osteoarthritis, were purposively recruited. All participants had suffered with ankle arthritis for between 10 and 40 years and all had tried at least 6 months of non-operative measures prior to being referred. All patients had developed a good understanding of their condition and current state over many years using a wide variety of information sources.

I have osteoarthritis in the ankle possibly due to a fracture of the tibia and fibula I had many years ago. This had led to the wearing away of cartilage in the joint, which creates pain. (Patient 6)

Indeed the commonest cause of osteoarthritis of the ankle is trauma such as severe sprains<sup>16</sup> or fractures of the ankle.<sup>17</sup> We have divided our findings into three broad themes:

### Theme 1: why patients opt for surgery

All patients in our sample had unsuccessfully tried non-operative treatment. Persistent pain and failure of non-operative measures were the dominant reason for surgery, frequently described as 'horrendous' (Patient 2) or 'unbearable' (Patient 1). All patients described a

sequential process of activity reduction as a result of worsening pain.

You live with the pain and restrict your lifestyle to cope with it, until you can't cope. So I now need an operation. (Patient 1)

This trade-off process eventually concluded with one of the two events that preceded the decision to undergo surgery. The first arose when the participants had become so restricted by the pain that they were unable to function or work and had no further activities to trade-off, and the second when they were forced to give up a specific activity that was very important to them. One participant was particularly keen to return to dancing and asserted that this was her main impetus for surgical intervention. Overall recreational activities were an important theme and participants anticipated some return to them postsurgery.

Squash, golf, I can't do any of them now; the only activity I can do is swimming. I have put a lot of weight on as a result of not being able to do what I used to; I just hope to get back to doing something. (Patient 9)

In some cases, the worry of spreading pain was an impetus to proceed with surgery.

It's affecting my other joints, my knee and my back, so I just want to get the ankle sorted to take the pressure off the rest. (Patient 11)

Several patients felt that other joints were painful as a result of their ankle and this appeared to contribute to their decision to proceed with surgery in a hope they could prevent or ease these symptoms.

The ability to work was a key factor that not only induced a perceived need for surgical intervention but also resulted in patients delaying the timing of surgery. In these cases, loss of earnings during the postoperative rest period was the reason for putting off surgery. This represents a 'worker's paradox' since surgery is required to continue in employment, but the temporary loss of earnings during the recovery period is seen as being prohibitive.

### Theme 2: information sources for decision-making

Three major sources of information emerged from our study: healthcare professionals; peer influence; and the internet.

Speaking to the consultant and team has had the most impact on my decision making. (Patient 7)

Our Unit has a multidisciplinary approach, and during the patient's journey they will interact with not only just surgeons but also physician's assistants, clinical nurse specialists, orthotists and physiotherapists, as well as other modalities, as required. Although a few patients (n=4) mentioned a role for other allied health

professionals, every patient mentioned the importance of the surgeon as being the highest influence in deciding between the two surgical treatment options because of its perceived reliability.

The role of the general practitioner (GP) differed and seemed to depend on the relationship between the patient and the GP.

I go to my GP with the letter from the surgeon and find it helpful to talk through the letter with someone I am close to. (Patient 13)

Where the relationship between the patient and the GP was strong, the GPs seemed to have a valuable role as a sounding board, but where the relationship was poor, the role of the GP seemed to be more simply that of a gate keeper.

I don't ever see the same GP twice. I don't see any role for my GP other than to refer me. (Patient 14)

Indeed, a rapport between the patient and the surgeon was also a key. This distinction became clear in cases where patients had been referred on for second opinions.

I didn't have confidence in the first surgeon, so I sought a second opinion. (Patient 1)

Similarly, the lack of treatment options by a centre would influence some patients.

The surgeon I initially saw only offered fusion and I didn't feel I had all the information I needed, so I sought a second opinion. (Patient 4)

Peer influence was the second most significant factor that shaped decision-making.

I had [famous sportsman] in my cab and he told me he had an ankle fusion, with a great result, so I decided if it's good enough for him, then it's good enough for me. (Patient 7)

Equally, reports of substandard outcomes could result in the formation of negative perceptions.

I asked a friend of mine who had the operation; she said it extremely painful so that made me reconsider. (Patient 3)

Peer influence also has the potential to mislead when patients mistakenly compare themselves with others who have undergone a different operation. In our sample, one patient undergoing ankle fusion took peer advice from a friend who had undergone a procedure to fuse a different joint in the foot and was therefore using inappropriate information to guide their decision-making.

The third major source of information in terms of influence was the internet. All patients used the internet

to search for information on the procedures, and on other patients' experiences.

You have to make sure the information you find is reliable but I was largely reading stuff from medical journals and websites from institutions that specialise in ankle replacement. (Patient 6)

The effectiveness of the internet to find information could at times be overwhelming and some participants found it hard to limit their searches.

The Internet is big and too scary because you don't know enough, anyone can say anything. (Patient 5)

Internet forums were often accessed and function as an extension of peer influence. Forums allowed the participants to direct contact with other patients, who had undergone the same operation.

I went onto a forum to try and gather other people's experiences, I found it very useful. (Patient 1)

A common theme was a difficulty in knowing how to ensure credibility of the information source. The strength attributed to the surgeon's advice was demonstrated when 10 of our 14 participants asserted that it over-ruled other, conflicting information sources.

I always check any new information with my surgeon. I trust what he tells me over anyone else, he sees this all the time and knows best. (Patient 12)

Overall, the internet was rated by patients as having the least influence on deciding what operation to have, while the treating surgeon was the most influential. The influence of friends and family appears to feature more in the final theme.

### Theme 3: how patients decide the best option for them

Patients make decisions based on their own summary of all the information available to them coupled with the sounding and guidance from their immediate friends and family, as well as the practicalities of their home and work situation. Patients realised that in the short term both surgical options would provide them with good pain relief, which in most cases is a correct assumption.<sup>18</sup> However, one key factor influencing the patient's choice is related to the individual's adversity to risk. Patients with an inherent risk aversion found it difficult to accept anything new and selected their treatment based on the lowest risk and the most predictable outcome.

If I had a replacement I would be looking at another operation ten years down the line. With a fusion I can have one operation and still have a good quality of life and get back to work. (Patient 8)

Indeed the cumulative annual failure rate for ankle replacements is 1.9%/year<sup>19</sup> and in patients who want certainty this was seen as a significant barrier. Some patients were willing to accept risk of further surgery providing their choice offered them greater immediate benefits.

I think a replacement would be best for me as I want to be active, even though I understand that I might need further surgery at a later date. (Patient 10)

Both risk-sensitive and risk-tolerant patients viewed ankle fusion as a 'final' (patients 2 and 4) option, after which there were no other alternatives. Although there are surgeons that have revised fused ankles to an ankle replacement,<sup>20 21</sup> most surgeons would not recommend it, as results are poor with limited range of motion due to stiff soft tissues.

## DISCUSSION

More than five million elective admissions for surgery take place in the UK each year.<sup>22</sup> In most cases, more than one surgical treatment is available and it is therefore crucial to better understand how patients decide between different surgical treatments. While there have been previous studies exploring the factors that influence the patient's decision-making in medical situations<sup>23</sup> and when to opt for surgery,<sup>6 24</sup> our study appears to be the first to assess not just why patients elect to undergo an intervention, but at how they decide between two orthopaedic types of surgery in the face of surgeon equipoise.

Three main sources of information emerged, of which the surgeon appeared to be the most influential, followed by peer influence, and finally the internet. The command of the surgeon has been described previously,<sup>25 26</sup> and even information gathered from other sources, is invariably proffered to the surgeon as final key validator. Although formally developed decision aids to supplement a consultation can be of great value,<sup>27</sup> no such formal decision aids are available in relation to ankle osteoarthritis. Our unit uses bespoke information leaflets to assist the patient to better understand their options, although such information leaflets are very different to decision aids, nonetheless in the absence of any formal decision aids we felt this was a useful adjunct in the information available to patients. All patients in our study had utilised our written information, although none elected to mention these as being an influencer on their decision-making.

From our knowledge of the treating surgeons in our unit, we believe that the surgeons expressed no overt treatment preference, nonetheless, the participating patients made it clear that the surgeons' views had profound effects on their decision-making. Previous work has shown that preferences can be asserted in other non-verbal ways.<sup>28 29</sup> For example, the surgeons' cognisance of their patients' needs and expectations might

tailor the delivery of information. This serves to establish rapport as a more patient-centred approach, but it can make the communication of a balanced view problematic.<sup>29</sup> Hudak *et al*<sup>28</sup> has shown that surgeons orient to their professional identity, which in our study may be a proponent of ankle fusion or ankle replacement. Further, Hudak *et al*<sup>28</sup> showed that when surgeons talked about surgery versus no-surgery, surgery was portrayed as having a special, privileged status relative to other options; this resulted in asymmetry in the delivery of information. The concept of subtle hierarchical delivery of information may be applicable to ankle replacement and fusion, but we would only be able to confirm this through conversational analysis, which was not within the scope of this paper, although would form a useful component of future research to contribute to better understanding of how these decisions are made.

The expression of treatment preference by the surgeon and the patient are key tenets of SDM. In reality, the complex and evolving nature of the patient–surgeon relationship results in a hybrid-type consultation, for example, as knowledge is gained by the patient the process may start as SDM and evolve to become an informed type.<sup>2</sup> Decision-making is distributed over time and involves many sources of information (human and non-human),<sup>30</sup> a finding echoed by our patient cohort. However, despite the other sources weighing in, the surgeon continued to appear to be the final validator of any other information gleaned outside the consultation room. This idea also extended to other members of his team who simply used additional reference points. Some of these, for example, GPs, may have valuable input as was asserted by one patient in the sample. Other key individuals include allied professionals to health such as nurse specialists and physiotherapists. Our work adds further weight to the idea of decisions being 'distributed' over time and people.

Our study shows that the surgeon was both a validator of information and a key influencer in the decision-making process, whereas family members seem to be key influencers in the decision to undergo surgery or not. We did not find any evidence that family and friends played any role in being validators of information.

Health policy in the UK has been influenced by high-profile incidents such as the "The Bristol Case." This has resulted in increased scrutiny from within the profession and from outside.<sup>31</sup> As clinicians, we have a duty to protect and promote the health of our patients.<sup>32</sup> The profession has acted by introducing revalidation<sup>33</sup> and in orthopaedics, the UK has been proactive in creating the world's largest National Joint Registry, recording every hip, knee, ankle and shoulder replacement implanted in England and Wales and containing an excess of 1.5 m records.<sup>34</sup> In the future, surgeon-level reported outcome data are a possibility.<sup>35</sup> Aside from publicly available information, public scrutiny often manifests in patients seeking second opinions<sup>6</sup> as took place with several patients interviewed in this study. The

internet is also fast becoming a key driver of health-care<sup>36</sup>; although this is well described in young populations,<sup>25</sup> we identified that it also affects patients in their 80s. Importantly, however, this study also identifies that patients are aware of the limitations and risks associated with information from the internet, a finding which is in line with other groups,<sup>25 26 37</sup> and invariably turn to their surgeon for validation. Peer influence, for example, by other patients remains important, but the division between peer influence and the internet is blurring with the use of web forums,<sup>38</sup> where accounts of patients who have undergone surgery seem highly persuasive and empowering,<sup>39</sup> despite the potential to deliver an unbalanced, inaccurate and hence dangerous views. Peer influence was also described by McKinley in 1973,<sup>40</sup> who also highlighted concerns as different 'lay consultants' perceive problems differently and consequently, give differing advice, and that the context in which advice was given influenced its weighting.<sup>40</sup> For example, information given in a hospital forum, web group or in a social gathering might have different meanings. We found the most influential of peers were patients who had undergone the same procedures.

In this study, the sample size (n=14) was determined first, by purposively selecting participants who each could provide exhaustive data, and second, by continuing to interview until 'data saturation' was achieved.<sup>13</sup> This became noticeable when during the last three interviews no new themes emerged, and so data collection ceased. It is therefore unlikely that a larger sample would have provided a bigger picture or different result. This study raises issues that are of great importance to this specific patient group. The role of the surgeon, peer influence and the internet might have wider implications in other chronic conditions beyond ankle arthritis, but further research would be needed to confirm this.

A further limitation of this study was that it was carried out in a single specialist centre, which could be argued as not being representative of patients seen in the community or at a district general hospital. Nonetheless, in this centre, all patients had been appropriately counselled by surgeons who have a clear understanding of both treatment options and provided, in our opinion, a complete set of unbiased information to guide patient decision-making. Since one-third of orthopaedic foot and ankle surgeons in the UK do not carry out ankle replacement,<sup>41</sup> it is possible that patients from other centres might not be offered such unbiased information, and this would undoubtedly influence their decision. This was evidenced in our study by the feedback from patients who had sought a second opinion because they did not feel that they had been provided with all of the information they needed at the initial hospital.

## CONCLUSION

Patients seek knowledge from a wealth of sources including the internet, web forums and other patients. While

they leverage all these sources, the most important and influential factor in governing how patients decide on a particular surgical intervention is their surgeon. Other groups have shown how a surgeon's personal preferences and inclinations can dominate the patient's decision, and therefore clear and balanced, evidence-based information is crucial to allow patients to make an informed choice. Good communication of the surgeon assists in the development of a high-quality doctor-patient relationship and will enable SDM to become a reality.

**Contributors** The study idea was conceived by RZ and AG with all the authors involved in its design. RZ and AG were responsible for recruiting patients and RZ conducted the interviews. RZ and MP conducted the initial data analysis with AG and AJM involved in validation, critique and further analysis. All members of the team were involved in the interpretation of the results. The initial draft of the manuscript was prepared by RZ and circulated repeatedly among all authors for critical revision. All authors read and approved the final manuscript.

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