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How do patients make decisions about which surgical treatment to undergo? A Qualitative Study

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Conflict of Interest

We have read and understood the BMJ Group policy on declaration of interests and have no relevant interests to declare.

Authorship

All of the four authors listed were involved in conception, design, analysis and interpretation of generated data. Additionally all were involved in drafting, revising and final approval of the version to be published.

Abstract

Objective To examine how patients decide between different surgical options for their condition.

Design Purposive patient selection, qualitative design based on in-depth interviews.

Setting Royal National Orthopaedic Hospital, Stanmore, UK.

Participants 14 patients diagnosed with end-stage ankle osteoarthritis.

Results We interviewed 6 male and 8 female with a mean age of 58 years (range 41 to 83). All had opted for surgery after failure of at least 6 months of conservative management, sequentially trading-off daily activities to limit 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 media. The treating surgeon was viewed as the most reliable and influential source of information. Information gleaned from other patients was also important but carries risks as does information gleaned from the Internet and grey media, both of which invariably required validation by the surgeon and in some cases the GP. The quality of the doctor-patient relationship dictated the validity patients ascribed to their clinical interaction.

Conclusions Patients seek knowledge from a wealth of sources including the Internet, web forums, and other patients. Whilst they leverage family and friends 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 process between patient and clinician.[1] This ideal is the foundation of high-quality healthcare and is especially important in the context of long-term conditions and chronic illness,[2] such as osteoarthritis.

End stage osteoarthritis of the ankle is a major cause of disability with an impact on quality of life similar to end-stage heart failure[3] and hip arthritis.[4] Its demand incidence has been recently estimated to be 47.7 per 100,000 in the UK.[5] The majority of cases of ankle osteoarthritis are secondary to trauma or other diseases such as inflammatory arthritis.[5]

Its treatment includes a wealth of non-operative measures, such as activity modification, analgesia, bracing and physiotherapy. After these measures have failed, there are two established surgical treatments, ankle fusion, and ankle replacement, both of which have been shown to be valid and cost effective treatments[6] with a degree of clinical equipoise between them.[7] End-stage ankle osteoarthritis therefore serves as a good model to assess how patients decide on surgery and between surgical treatments. The aim of this paper is to carry out a qualitative study that explores how patients make decisions regarding their surgical treatment options.

Methods and Materials

This study took a qualitative, interview-based approach to explore and analyse how patients' with end-stage ankle osteoarthritis decide between two different surgical treatments, ankle fusion and total ankle replacement (TAR).

Sample

The study was based at the Royal National Orthopaedic Hospital NHS Trust, Stanmore, UK, a specialist hospital which offers both TAR and ankle fusion as standard treatment options. Patients

diagnosed with end-stage ankle osteoarthritis were purposively recruited prior to their outpatient visit to discuss their surgical treatment. Recruitment continued until data saturation became noticeable during the last three interviews. The interviews took place prior to the appointment with their surgeon to discuss their decision on treatment, but after at least 6 months of unsuccessful non-operative measures had been tried and all treatment options had been discussed with them.

Data collection and analysis

Having given informed consent all participants underwent semi-structured interviews, face-to-face (n=14). An interview guide was used for each interview. It focused on their experience of the condition, the information sources they had used, the treatment options and preferences. The interviews lasted between 30 and 60 minutes; they were audio-recorded and transcribed verbatim. The data was analysed inductively by RZ and MP, using manual thematic analysis[8] to identify, validate and report any themes arising from the data. These were organised, described in rich detail, interpreted and interlinked within a comprehensive categorisation system. Finally, in order to validate our results a process of peer-debriefing[9] was also employed. This meant that the remaining authors questioned the analytical results requiring their justification based on the original data.

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 no formal ethical approval was required. Nevertheless, ethical procedures were strictly adhered to including the provision of full participant information enabling informed consent and assuring that strict participant anonymity was maintained, for example by allocating numeric codes to all participant contributions.

Results

A total of 14 patients (6 male and 8 female), with a mean age of 58 years (range 41 to 83), each with a diagnosis of ankle osteoarthritis were purposively recruited. All participants had suffered with ankle arthritis for between 10-40 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. 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. Hence persistent pain and failure of non-operative measures seemed to be 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 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 post-surgery.

"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)

The ability to work was a key factor and appeared to both induce and resist the need for surgical intervention. Loss of earnings during the post-operative rest period was raised as a major reason for putting off surgery in those previously offered intervention (n=5). This represents a 'worker's paradox'. Surgery is required to continue in employment, but the temporary loss of earnings during the recovery period is seen as being prohibitive.

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)

Indeed, several patients felt that other joints were painful as a result of their ankle (n=6) and this contributed to their decision to proceed with surgery in a hope they could prevent or ease these symptoms.

Theme 2: Information sources for decision making

Three major source of information emerged from our study; healthcare professionals; peer influence; and the media.

The patients in our sample reported good relationships with their current surgeons and rated the information provided by them as the highest influence in deciding between operations because of its perceived reliability (n=14).

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

The role of the general practitioner differed depending on the relationship between patient and 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 patient and GP was strong, GP's were frequently used as sounding boards, but where the relationship was poor, demonstrated the role of the GP as merely 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, rapport between patient and surgeon was also 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 its 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 to 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 different procedure to fuse a different joint in the foot. This formed the incorrect perception in his mind that he would have a good range of motion in his ankle following fusion, which sets out to stiffen the joint by definition.

The third major source of information in terms of influence was the Internet. All patients (n=14) used the Internet to search for information on the procedures, and on other patient 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 appear to represent a widening of the peer-influence on the patient. Using this part of the Internet allowed the participants 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 (n=10). The strength attributed to the surgeon's advice was demonstrated when it overruled 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 (n=14), while the treating surgeon was the most influential (n=14). 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, and the practicalities of their home and work situation.

One key confounding factor seems to relate to a patient's adversity to risk. Patients with an inherent risk aversion, find it difficult to accept anything new and select their treatment based on the lowest risk and the most predictable outcome.

> *"If had 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% per year[10] and in patients who want certainty this was seen as a significant barrier. In contrast patients willing to accept risk, found that certainty was in some cases unpalatable. For example, ankle fusion was viewed as a "*final*" (patient 2 and 4) option, after which there were no other alternatives.

Patients seemed to realise that short term both surgical options would provide them with good pain relief, which in most cases is a correct assumption.[11] Often patients did not mind the 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)*

Discussion

More than 5 million elective admissions for surgery take place in the UK each year[12]. 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.

Whilst there have been previous studies exploring the factors that influence patient decision making in medical situations[13] and when to opt for surgery[14,15], we believe that our study is the first to assess not just why patients elect to undergo an intervention, but at how they decide between two interventions that have a degree of clinical equipoise.

Three main sources of information emerged of which the surgeon was the most influential factor, followed by peer influence, and finally the media. The command of the surgeon has been described previously,[16,17] and even information gathered from other sources, invariably is proffered to the surgeon as final key validator.

In the wake of "The Bristol Case" British medicine has changed for the better[18] and increased scrutiny exists both from within the profession and from outside. As clinicians we have a duty to protect and promote the health of our patients[19]. The profession has acted by introducing revalidation[20] and in orthopaedics, the UK has been proactive in creating the world's largest National Joint Registry, that records every hip, knee, ankle and shoulder replacement implanted in England and Wales, containing in excess of 1.5m records.[21] In the future, surgeon-level reported outcome data is a possibility.[22]

Aside from publicly available information, public scrutiny often manifests in patients seeking second opinions[15] as took place with several patients interviewed in this study.

The Internet is fast becoming a key driver of healthcare[23] and although is well described in young populations,[16] clearly also affects the more mature patients including 83 years olds in this study. Importantly, however, this study also identifies that patients are aware of the limitations and risks associated with information from the Internet[16,17,24] and invariably turned to their surgeon for validation. Peer influence from other patients remains important, but the divide between peer influence and the Internet is blurring with the use of web forums[25] where accounts of patients who have undergone surgery seem highly persuasive and empowering,[26] but has the potential to deliver an unbalanced and sometimes inaccurate and hence dangerous view.

Qualitative research employs smaller samples than randomised-controlled trials. In this study the sample size (n=14) was determined firstly, by purposively selecting participants who each could provide exhaustive data, and secondly by continuing to interview until data saturation' was achieved.[8] 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 was carried out in a specialist centre offering both treatments and where clinical equipoise exists so that patients had been appropriately counselled by surgeons who have a clear understanding of both treatment options. Whilst it could be argued that a sample from a specialist centre is not representative of patients seen in the community or at a district general hospital, it also means that all patients interviewed had been given a complete set of validated information to guide their decision. Indeed, given that a third of surgeons in the UK do not carry out ankle replacement[27] it is likely that patients from other centres, might not be offered complete and impartial information, which undoubtedly would influence the patient's decisions.

This study used end stage ankle arthritis as its model, however, we believe that our results are applicable to a much wider range of chronic conditions requiring surgery and that patients' decision-making and its associated needs remain the same whatever the condition and wherever the patient is treated.

Conclusion

Patients seek knowledge from a wealth of sources including the Internet, web forums, and other patients. Whilst they leverage family and friends to guide decision making, the most important and influential factor in governing how patients decide on any particular surgical intervention is their surgeon, hence a surgeon's personal preferences and inclinations can dominate the patient's decision. Therefore clear and balanced, evidence-based information is crucial to allow patients to make informed choice. Good communication by the surgeon assists in the development of a high quality doctor-patient relationship and will enable shared decision-making to become a reality.

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How do patients with end-stage ankle arthritis make decisions between two different surgical treatments? A Qualitative Study

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Authorship

All of the four authors listed were involved in conception, design, analysis and interpretation of generated data. Additionally all were involved in drafting, revising and final approval of the version to be published.

Abstract

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

Design Purposive patient selection, semi-structured interviews, thematic analysis.

Setting Royal National Orthopaedic Hospital, Stanmore, UK.

Participants 14 patients diagnosed with end-stage ankle osteoarthritis.

Results We interviewed 6 male and 8 female with a mean age of 58 years (range 41 to 83). All had opted for surgery after failure of at least 6 months of conservative management, sequentially trading-off daily activities to limit 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 media. The treating surgeon was viewed as the most reliable and influential source of information. Information gleaned from other patients was also important but carries risks as does information gleaned from the Internet and grey media, both of which invariably required validation by the surgeon and in some cases the GP.

Conclusions Patients seek knowledge from a wealth of sources including the Internet, web forums, and other patients. Whilst 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.

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 patient's use to aid their decision-making.

Key Message

- The surgeon, the Internet and peers influence patients in their decision making but 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.

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 process between patient and clinician.[1] This ideal is the foundation of high-quality healthcare and is especially important in the context of long-term conditions and chronic illness, such as osteoarthritis.

Patient and doctor interactions are underpinned by three main decision making models,[2] these being paternalistic, informed and shared.

The paternalistic model assumes 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 even be counter to the patient's wishes, as long as the patient is perceived to benefit.[3] 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 consciousness 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 is to deliver to the patient information on all relevant treatment options including their benefits and risks. Communication in this model is one way.[2]

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

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.[6,7] We chose to look at 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.

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 of which have been shown to be valid and cost effective treatments[8] with a degree of clinical equipoise between them.[9] Osteoarthritis of the ankle is a major cause of disability with an impact on quality of life similar to end-stage heart

failure[10] and hip arthritis.[11] Its demand incidence has been recently estimated to be 47.7 per 100,000 in the UK.[12] The majority of cases of ankle osteoarthritis are secondary to trauma or other diseases such as inflammatory arthritis.[12] The aim of this paper is to carry out a qualitative study that explores how patients who have decided that they want to undergo surgery, make decisions between these two treatments.

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, 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, and whom were suitable for either a TAR or fusion and had opted for operative intervention but were undecided between the two treatment options. The patients were given verbal and written information pertaining survivorship, function, complications and post-operative rehabilitation relating to both treatments. Skeletal models and pictures were used during the consultation to support verbal information conveyed, and all patients were provided with a written patient information sheet, as aides to decision making. Interviews took place prior to the second appointment, which served as a platform for them 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 clinic and the purpose of the study was explained to each

patient. Following a 'cooling-down' period of 72 hours 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, semi-structured 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 and was based on the research objective and 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 minutes; they were audio-recorded and transcribed verbatim.

The data was analysed inductively by RZ and MP, using thematic analysis[13]. This is a highly flexible analytical method capable of producing the detailed and systematic account of the issues and opinions contained within in the data that was required for this study.[14] 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 interlinked within a comprehensive categorisation system. Finally, in order to validate our results a process of peer-debriefing[15] was also employed. This meant that the remaining authors (AG, AM) questioned the analytical results requiring their justification based on the original data.

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 no formal ethical approval was required. Nevertheless, ethical procedures were strictly adhered to including the provision of full written participant information enabling informed consent and by assuring that strict participant anonymity 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 male and 8 female), each with a diagnosis of ankle osteoarthritis were purposively recruited. All participants had suffered with ankle arthritis for between 10-40 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 following trauma such as severe sprains[16] or fractures of the ankle.[17] 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. Hence 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 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 post-surgery.

"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, it could also result in patients initially declining surgery. In these cases loss of earnings during the post-operative rest period was raised as the reason for putting off surgery. This represents a 'worker's paradox' as 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 source of information emerged from our study; healthcare professionals; peer influence; and the media. The patients in our sample reported good relationships with their current surgeons and rated the information provided by them as the highest influence in deciding between operations because of its perceived reliability.

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

The role of the general practitioner differed depending on the relationship between patient and 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 patient and GP was strong, GPs were frequently used as sounding boards, but where the relationship was poor, the role of the GP as merely 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, rapport between patient and surgeon was also 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 its 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 to 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 different procedure to fuse a different joint in the foot. This formed the incorrect perception in his mind that he would have a good range of motion in his ankle following fusion, which sets out to stiffen the joint by definition. None the less there are 26 joints in the foot and ankle, and even if the ankle joint itself is stiffened, the adjacent joints remain mobile giving the impression of good motion in the ankle after fusion.

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 patient 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 appear to represent a widening of the peer-influence on the patient. Using this part of the Internet allowed the participants 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 it overruled 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.[18] However, one key factor influencing patient choice 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 had 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% per year[19] and in patients who want certainty this was seen as a significant barrier. In contrast patients willing to accept risk, found that certainty was in some cases unpalatable. Instead, they did not mind the 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 patient groups viewed ankle fusion as a "*final*" (patients 2 and 4) option, after which there were no other alternatives. Although there are surgeons that have performed ankle replacement after fusion, [20,21] in the main, most surgeons would not recommend it, as results are generally poor.

Discussion

More than 5 million elective admissions for surgery take place in the UK each year[22]. 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. Whilst there have been previous studies exploring the factors that influence patient decision making in medical situations[23] and when to opt for surgery[6,24], our study is 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 was the most influential factor, followed by peer influence, and finally the media. The command of the surgeon has been described previously, [25,26] and even information gathered from other sources, invariably is proffered to the surgeon as final key validator. Although decision aides have been shown to be off great value,[27] and most patients in our group had utilised such aides, during our interviews no patients elected to mention such aides as being an influencer on their decision making.

During this study surgeons had no treatment preference. None the less the participating patients made it clear that the surgeons' views had profound effects on their decision-making. Previous work has shown preferences can be asserted in other non-verbal ways.[28,29] For example the surgeons' cognizance of their patients' needs and expectations will tailor the delivery of information. This serves to establish rapport as a more patient-centred approach, but it can makes the communication of a balanced view problematic.[29] Hudak has shown that surgeons orient to their professional identity,

which in our study maybe a proponent of ankle fusion or ankle replacement.[28] Further, Hudak 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.[28] 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 within the scope of this paper.

The expression of treatment preference by the surgeon and patient are key tenets of shared decision making (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 in an informed type.[2] Decision making is distributed over time and involves many sources of information (human and non-human),[30] a finding echoed by our patient group. However, despite the other sources weighing in, the surgeon continued 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 were simply used additional reference points. Our work adds further weight to the idea of decisions being "distributed" over time and people.

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.[31] As clinicians we have a duty to protect and promote the health of our patients[32]. The profession has acted by introducing revalidation[33] 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 in excess of 1.5m records.[34] In the future, surgeon-level reported outcome data is a possibility.[35] Aside from publicly available information, public scrutiny often manifests in patients seeking second opinions[6] as took place with several patients interviewed in this study. The Internet is also fast becoming a key driver of healthcare[36] and although this is well described in young populations,[25] it also affects the more mature patients, including octogenarians in

this study. 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,[25,26,37] and invariably turned to their surgeon for validation. Peer-influence from other patients remains important, but the divide between peer-influence and the Internet is blurring with the use of web forums[38] where accounts of patients who have undergone surgery seem highly persuasive and empowering,[39] despite the potential to deliver an unbalanced, inaccurate and hence dangerous view**.** Peer-influence was also described by McKinley in 1973[40] 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.[40] 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 procedures in question.

Qualitative research employs smaller samples than randomised-controlled trials. In this study the sample size (n=14) was determined firstly, by purposively selecting participants who each could provide exhaustive data, and secondly by continuing to interview until 'data saturation' was achieved.[13] 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. RCT's offer generalisability of their results, qualitative research does not. Nevertheless, the findings in this study raise 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. None the less in this centre all patients had been appropriately counselled by surgeons who have a clear understanding of both treatment options and provided in their opinion, a complete set of

unbiased information to guide their patient's decision making. Since one third of orthopaedic foot and ankle surgeons in the UK do not carry out ankle replacement[41], 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 feedback from patients who had sought a second opinion because they did not feel 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. Whilst they leverage family and friends to guide decision making, 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. Therefore clear and balanced, evidence-based information is crucial to allow patients to make an informed choice. Good communication by the surgeon assists in the development of a high quality doctor-patient relationship and will enable shared decision-making to become a reality.

Tables

Table 1: The 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?	Acquiring information
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?	Knowledge of treatment options
7	How did you find out about these treatment options?	Acquiring information
8	What do you think about the treatment options you have? What are their advantages and disadvantages?	Personal treatment preferences

Table 1

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How do patients **with end-stage ankle arthritis make decisions between two different surgical treatments?** A Qualitative Study

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Conflict of Interest

We have read and understood the BMJ Group policy on declaration of interests and have no relevant interests to declare.

Authorship

All of the four authors listed were involved in conception, design, analysis and interpretation of generated data. Additionally all were involved in drafting, revising and final approval of the version to be published.

Abstract

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

Design Purposive patient selection, **semi-structured interviews, thematic analysis.**

Setting Royal National Orthopaedic Hospital, Stanmore, UK.

Participants 14 patients diagnosed with end-stage ankle osteoarthritis.

Results We interviewed 6 male and 8 female with a mean age of 58 years (range 41 to 83). All had opted for surgery after failure of at least 6 months of conservative management, sequentially trading-off daily activities to limit 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 media. The treating surgeon was viewed as the most reliable and influential source of information. Information gleaned from other patients was also important but carries risks as does information gleaned from the Internet and grey media, both of which invariably required validation by the surgeon and in some cases the GP.

Conclusions Patients seek knowledge from a wealth of sources including the Internet, web forums, and other patients. Whilst 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.

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 patient's use to aid their decision-making.

Key Message

- The surgeon, the Internet and peers influence patients in their decision making but 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.

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 process between patient and clinician.[1] This ideal is the foundation of high-quality healthcare and is especially important in the context of long-term conditions and chronic illness, such as osteoarthritis.

Patient and doctor interactions are underpinned by three main decision making models,[2] these being paternalistic, informed and shared.

The paternalistic model assumes 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 even be counter to the patient's wishes, as long as the patient is perceived to benefit.[3] 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 consciousness 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 is to deliver to the patient information on all relevant treatment options including their benefits and risks. Communication in this model is one way.[2]

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

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.[6,7] We chose to look at 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.

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 of which have been shown to be valid and cost effective treatments[8] with a degree of clinical equipoise between

them.[9] Osteoarthritis of the ankle is a major cause of disability with an impact on quality of life similar to end-stage heart failure[10] and hip arthritis.[11] Its demand incidence has been recently estimated to be 47.7 per 100,000 in the UK.[12] The majority of cases of ankle osteoarthritis are secondary to trauma or other diseases such as inflammatory arthritis.[12] **The aim of this paper is to carry out a qualitative study that explores how patients who have decided that they want to undergo surgery, make decisions between these two treatments.**

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, 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, and whom were suitable for either a TAR or fusion and had opted for operative intervention but were undecided between the two treatment options. The patients were given verbal and written information pertaining survivorship, function, complications and post-operative rehabilitation relating to both treatments. Skeletal models and pictures were used during the consultation to support verbal information conveyed, and all patients were provided with a written patient information sheet, as aides to decision making. Interviews took place prior to the second appointment, which served as a platform for them 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 clinic and the purpose of the study was explained to each patient. Following a 'cooling-down' period of 72 hours 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, semi-structured 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 and was based on the research objective and 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 minutes; they were audio-recorded and transcribed verbatim.

The data was analysed inductively by RZ and MP, using thematic analysis[13]. This is a highly flexible analytical method capable of producing the detailed and systematic account of the issues and opinions contained within in the data that was required for this study.[14] 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 interlinked within a comprehensive categorisation system. Finally, in order to validate our results a process of peer-debriefing[15] was also employed. This meant that the remaining authors (AG, AM) questioned the analytical results requiring their justification based on the original data.

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 no formal ethical approval was required. Nevertheless, ethical procedures were strictly adhered to including the provision of full written participant information enabling informed consent and by assuring that strict participant anonymity 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 male and 8 female), each with a diagnosis of ankle osteoarthritis were purposively recruited. All participants had suffered with ankle arthritis for between 10-40 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 following trauma such as severe sprains[16] or fractures of the ankle.[17] 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. Hence 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 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 post-surgery.

"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, it could also result in patients initially declining surgery. In these cases loss of earnings during the post-operative rest period was raised as the reason for putting off surgery. This represents a 'worker's paradox' as 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 source of information emerged from our study; healthcare professionals; peer influence; and the media. The patients in our sample reported good relationships with their current surgeons and rated the information provided by them as the highest influence in deciding between operations because of its perceived reliability.

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

The role of the general practitioner differed depending on the relationship between patient and 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 patient and GP was strong, GPs were frequently used as sounding boards, but where the relationship was poor, the role of the GP as merely 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, rapport between patient and surgeon was also 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 its 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 to 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 different procedure to fuse a different joint in the foot. This formed the incorrect perception in his mind that he would have a good range of motion in his ankle following fusion, which sets out to stiffen the joint by definition. **None the less there are 26 joints in the foot and ankle, and even if the ankle joint itself is stiffened, the adjacent joints remain mobile giving the impression of good motion in the ankle after fusion.**

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 patient 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 appear to represent a widening of the peer-influence on the patient. Using this part of the Internet allowed the participants 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 it overruled 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.[18] However, one key factor influencing patient choice 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 had 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% per year[19] and in patients who want certainty this was seen as a significant barrier. In contrast patients willing to accept risk, found that certainty was in some cases unpalatable. Instead, they did not mind the 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 patient groups viewed ankle fusion as a "*final*" (patients 2 and 4) option, after which there were no other alternatives. Although there are surgeons that have performed ankle replacement after fusion, [20,21] in the main, most surgeons would not recommend it, as results are generally poor.

Discussion

More than 5 million elective admissions for surgery take place in the UK each year[22]. 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. Whilst there have been previous studies exploring the factors that influence patient decision making in medical situations[23] and when to opt for surgery[6,24], our study is 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 was the most influential factor, followed by peer influence, and finally the media. The command of the surgeon has been described previously, [25,26] and even information gathered from other sources, invariably is proffered to the surgeon as final key validator. **Although decision aides have been shown to be off great value,[27] and most patients in our group had utilised such aides, during our interviews no patients elected to mention such aides as being an influencer on their decision making.**

During this study surgeons had no treatment preference. None the less the participating patients made it clear that the surgeons' views had profound effects on their decision-making. Previous work has shown preferences can be asserted in other non-verbal ways.[28,29] For example the surgeons' cognizance of their patients' needs and expectations will tailor the delivery of information. This serves to establish rapport as a more patient-centred approach, but it can makes the communication of a balanced view problematic.[29] Hudak has shown that surgeons

orient to their professional identity, which in our study maybe a proponent of ankle fusion or ankle replacement.[28] Further, Hudak 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.[28] 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 within the scope of this paper.

The expression of treatment preference by the surgeon and patient are key tenets of shared decision making (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 in an informed type.[2] Decision making is distributed over time and involves many sources of information (human and non-human),[30] a finding echoed by our patient group. However, despite the other sources weighing in, the surgeon continued 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 were simply used additional reference points. Our work adds further weight to the idea of decisions being "distributed" over time and people.

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.[31] As clinicians we have a duty to protect and promote the health of our patients[32]. The profession has acted by introducing revalidation[33] 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 in excess of 1.5m records.[34] In the future, surgeon-level reported outcome data is a possibility.[35] Aside from publicly available information, public scrutiny often manifests in patients seeking second opinions[6] as took place with several patients interviewed

in this study. The Internet is also fast becoming a key driver of healthcare[36] and although this is well described in young populations,[25] it also affects the more mature patients, including octogenarians in this study. 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,[25,26,37] and invariably turned to their surgeon for validation. Peer-influence from other patients remains important, but the divide between peer-influence and the Internet is blurring with the use of web forums[38] where accounts of patients who have undergone surgery seem highly persuasive and empowering,[39] despite the potential to deliver an unbalanced, inaccurate and hence dangerous view**. Peer-influence was also described by McKinley in 1973[40] 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.[40] 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 procedures in question.**

Qualitative research employs smaller samples than randomised-controlled trials. In this study the sample size (n=14) was determined firstly, by purposively selecting participants who each could provide exhaustive data, and secondly by continuing to interview until 'data saturation' was achieved.[13] 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. **RCT's offer generalisability of their results, qualitative research does not. Nevertheless, the findings in this study raise 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. None the less in this centre all patients had been appropriately counselled by surgeons who have a clear understanding of both treatment options and provided in their opinion, a complete set of unbiased information to guide their patient's decision making. Since one third of orthopaedic foot and ankle surgeons in the UK do not carry out ankle replacement[41], 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 feedback from patients who had sought a second opinion because they did not feel 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. Whilst they leverage family and friends to guide decision making, 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. Therefore clear and balanced, evidence-based information is crucial to allow patients to make an informed choice. Good communication by the surgeon assists in the development of a high quality doctor-patient relationship and will enable shared decision-making to become a reality.

Tables

Table 1: The 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?	Acquiring information
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?	Knowledge of treatment options
7	How did you find out about these treatment options?	Acquiring information
8	What do you think about the treatment options you have? What are their advantages and disadvantages?	Personal treatment preferences

Table 1

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

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YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	1
3. Occupation	What was their occupation at the time of the study?	1
4. Gender	Was the researcher male or female?	1
5. Experience and training	What experience or training did the researcher have?	n/a
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	1 and 7
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	6
12. Sample size	How many participants were in the study?	8

13. Non-participation	How many people refused to participate or dropped out? Reasons?	7, none
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	n/a
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	8
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	17
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	n/a
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	8 -audio
20. Field notes	Were field notes made during and/or after the inter view or focus group?	n/a
21. Duration	What was the duration of the inter views or focus group?	8
22. Data saturation	Was data saturation discussed?	7
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	no
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	8
25. Description of the coding tree	Did authors provide a description of the coding tree?	no
26. Derivation of themes	Were themes identified in advance or derived from the data?	no
27. Software	What software, if applicable, was used to manage the data?	none
28. Participant checking	Did participants provide feedback on the findings?	no
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Please see results
30. Data and findings consistent	Was there consistency between the data presented and the findings?	See results
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	n/a

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

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

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Conflict of Interest

We have read and understood the BMJ Group policy on declaration of interests and have no relevant interests to declare.

Authorship

All of the four authors listed were involved in conception, design, analysis and interpretation of generated data. Additionally all were involved in drafting, revising and final approval of the version to be published.

Abstract

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

Design Purposive patient selection, semi-structured interviews, thematic analysis.

Setting Royal National Orthopaedic Hospital, Stanmore, UK.

Participants 14 patients diagnosed with end-stage ankle osteoarthritis.

Results We interviewed 6 male and 8 female with a mean age of 58 years (range 41 to 83). All had opted for surgery after failure of at least 6 months of conservative management, sequentially trading-off daily activities to limit 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 GP.

Conclusions Patients seek knowledge from a wealth of sources including the Internet, web forums, and other patients. Whilst 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.

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 patient's use to aid their decision-making.

Key Message

- The treating surgeon, Internet and peers are the three main influences on patient 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.

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 process between patient and clinician.[1] This ideal is the foundation of high-quality healthcare and is especially important in the context of long-term conditions and chronic illness, such as osteoarthritis.

Patient and doctor interactions are underpinned by three main decision making models,[2] these being paternalistic, informed and shared.

The paternalistic model assumes 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.[3] 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 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.[2]

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

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.[6,7] 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[10] and hip arthritis.[11] Its demand incidence in the UK has recently been estimated to be 47.7 per 100,000.[12] The majority of cases are secondary to trauma or other diseases such as inflammatory arthritis.[12] 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[8] with a degree of clinical equipoise between them.[9]

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 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 clinic and the purpose of the study was explained to each patient. Following a 'cooling-down' period of 72 hours, 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, semi-structured 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 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 minutes; they were audio-recorded and transcribed verbatim.

The data was analysed inductively (by RZ and MP) using thematic analysis.[13] This is a highly flexible method capable of producing a detailed and systematic account of the issues and opinions contained within in the data.[14] 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 interlinked within a comprehensive categorisation system. Finally, in order to validate our results peer-debriefing was employed.[15] This process required the remaining authors (AG, 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 no formal ethical approval was required. Nevertheless, ethical procedures were strictly adhered to including the provision of full 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 male and 8 female), each with a diagnosis of ankle osteoarthritis were purposively recruited. All participants had suffered with ankle arthritis for between 10-40 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 following trauma such as severe sprains[16] or fractures of the ankle.[17] 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 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 post-surgery.

> *"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 could also result in patients delaying the timing of surgery. In these cases loss of earnings during the post-operative 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 source 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 journey they will interact with not 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 differed and seemed to depend on the relationship between patient and 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 patient and 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, rapport between patient and surgeon was also 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 its 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 to 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 patient 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 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 overruled 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.[18] However, one key factor influencing patient choice 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% per year[19] 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 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,[20,21] most surgeons would not recommend it, as results are poor with limited range of motion due to stiff soft tissues.

Discussion

More than 5 million elective admissions for surgery take place in the UK each year.[22] 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. Whilst there have been previous studies exploring the factors that influence patient decision making in medical situations[23] and when to opt for surgery,[6,24] 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, [25,26] 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,[27] 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, none the less, the participating patients made it clear that the surgeons' views had profound effects on their decision-making. Previous work has shown preferences can be asserted in other non-verbal ways.[28,29] For example the surgeons' cognizance 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.[29] Hudak has shown that surgeons orient to their professional identity, which in our study may be a proponent of ankle fusion or ankle replacement.[28] Further, Hudak 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.[28] 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 how these decisions are made.

The expression of treatment preference by the surgeon and patient are key tenets of shared decision making (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.[2] Decision making is distributed over time and

involves many sources of information (human and non-human),[30] 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 were simply used additional reference points. Some of these, for example GP's, 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.[31] As clinicians we have a duty to protect and promote the health of our patients.[32] The profession has acted by introducing revalidation[33] 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 in excess of 1.5m records.[34] In the future, surgeon-level reported outcome data is a possibility.[35] Aside from publicly available information, public scrutiny often manifests in patients seeking second opinions[6] as took place with several patients interviewed in this study. The Internet is also fast becoming a key driver of healthcare[36] and although this is well described in young populations,[25] we identified that it also affects patients in their eighties. 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, [25,26,37] and invariably turn to their surgeon for validation. Peer-influence, for example by other patients remains important, but the divide between peer-influence and the Internet is blurring with the use of web

forums[38] where accounts of patients who have undergone surgery seem highly persuasive and empowering,[39] despite the potential to deliver an unbalanced, inaccurate and hence dangerous views**.** Peer-influence was also described by McKinley in 1973,[40] 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.[40] 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 firstly, by purposively selecting participants who each could provide exhaustive data, and secondly by continuing to interview until 'data saturation' was achieved.[13] 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. None the less 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,[41] 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 feedback from patients who had sought a second opinion because they did not feel 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. Whilst 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 by the surgeon assists in the development of a high quality doctor-patient relationship and will enable shared decision-making to become a reality.

Tables

Table 1: The 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?	Acquiring information
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?	Knowledge of treatment options
7	How did you find out about these treatment options?	Acquiring information
8	What do you think about the treatment options you have? What are their advantages and disadvantages?	Personal treatment preferences

Table 1

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

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Conflict of Interest

We have read and understood the BMJ Group policy on declaration of interests and have no relevant interests to declare.

Authorship

All of the four authors listed were involved in conception, design, analysis and interpretation of generated data. Additionally all were involved in drafting, revising and final approval of the version to be published.

Abstract

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

Design Purposive patient selection, semi-structured interviews, thematic analysis.

Setting Royal National Orthopaedic Hospital, Stanmore, UK.

Participants 14 patients diagnosed with end-stage ankle osteoarthritis.

Results We interviewed 6 male and 8 female with a mean age of 58 years (range 41 to 83). All had opted for surgery after failure of at least 6 months of conservative management, sequentially trading-off daily activities to limit 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 GP.

Conclusions Patients seek knowledge from a wealth of sources including the Internet, web forums, and other patients. Whilst 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.

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 patient's use to aid their decision-making.

Key Message

- The treating surgeon, Internet and peers are the three main influences on patient 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.

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 process between patient and clinician.[1] This ideal is the foundation of high-quality healthcare and is especially important in the context of long-term conditions and chronic illness, such as osteoarthritis.

Patient and doctor interactions are underpinned by three main decision making models,[2] these being paternalistic, informed and shared.

The paternalistic model assumes 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.[3] 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 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.[2]

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

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.[6,7] 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[10] and hip arthritis.[11] Its demand incidence in the UK has recently been estimated to be 47.7 per 100,000.[12] The majority of cases are secondary to trauma or other diseases such as inflammatory arthritis.[12] 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[8] with a degree of clinical equipoise between them.[9]

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 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 clinic and the purpose of the study was explained to each patient. Following a 'cooling-down' period of 72 hours, 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, semi-structured 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 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 minutes; they were audio-recorded and transcribed verbatim.

The data was analysed inductively (by RZ and MP) using thematic analysis.[13] This is a highly flexible method capable of producing a detailed and systematic account of the issues and opinions contained within in the data.[14] 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 interlinked within a comprehensive categorisation system. Finally, in order to validate our results peer-debriefing was employed.[15] This process required the remaining authors (AG, 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 no formal ethical approval was required. Nevertheless, ethical procedures were strictly adhered to including the provision of full 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 male and 8 female), each with a diagnosis of ankle osteoarthritis were purposively recruited. All participants had suffered with ankle arthritis for between 10-40 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 following trauma such as severe sprains[16] or fractures of the ankle.[17] 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 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 post-surgery.

> *"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 could also result in patients delaying the timing of surgery. In these cases loss of earnings during the post-operative 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 source 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 journey they will interact with not 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 differed and seemed to depend on the relationship between patient and 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 patient and 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, rapport between patient and surgeon was also 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 its 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 to 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 patient 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 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 overruled 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.[18] However, one key factor influencing patient choice 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% per year[19] 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 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,[20,21] most surgeons would not recommend it, as results are poor with limited range of motion due to stiff soft tissues.

Discussion

More than 5 million elective admissions for surgery take place in the UK each year.[22] 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. Whilst there have been previous studies exploring the factors that influence patient decision making in medical situations[23] and when to opt for surgery,[6,24] 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, [25,26] 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,[27] **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, none the less, the participating patients made it clear that the surgeons' views had profound effects on their decision-making. Previous work has shown preferences can be asserted in other non-verbal ways.[28,29] For example the surgeons' cognizance 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.[29] Hudak has shown that surgeons orient to their professional identity, which in our study may be a proponent of ankle fusion or ankle replacement.[28] Further, Hudak 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.[28] 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 how these decisions are made.**

The expression of treatment preference by the surgeon and patient are key tenets of shared decision making (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.[2] Decision making is distributed over time and

involves many sources of information (human and non-human),[30] 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 were simply used additional reference points. Some of these, for example GP's, 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.[31] As clinicians we have a duty to protect and promote the health of our patients.[32] The profession has acted by introducing revalidation[33] 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 in excess of 1.5m records.[34] In the future, surgeon-level reported outcome data is a possibility.[35] Aside from publicly available information, public scrutiny often manifests in patients seeking second opinions[6] as took place with several patients interviewed in this study. The Internet is also fast becoming a key driver of healthcare[36] and although this is well described in young populations,[25] we identified that it also affects patients in their eighties. 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, [25,26,37] and invariably turn to their surgeon for validation. Peer-influence, for example by other patients remains

important, but the divide between peer-influence and the Internet is blurring with the use of web forums[38] where accounts of patients who have undergone surgery seem highly persuasive and empowering,[39] despite the potential to deliver an unbalanced, inaccurate and hence dangerous views**.** Peer-influence was also described by McKinley in 1973,[40] 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.[40] 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 firstly, by purposively selecting participants who each could provide exhaustive data, and secondly by continuing to interview until 'data saturation' was achieved.[13] 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. None the less 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,[41] 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 feedback from patients who had sought a second opinion because they did not feel 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. Whilst 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 by the surgeon assists in the development of a high quality doctor-patient relationship and will enable shared decision-making to become a reality.

Tables

Table 1: The 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?	Acquiring information
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?	Knowledge of treatment options
7	How did you find out about these treatment options?	Acquiring information
8	What do you think about the treatment options you have? What are their advantages and disadvantages?	Personal treatment preferences

Table 1

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	1
3. Occupation	What was their occupation at the time of the study?	1
4. Gender	Was the researcher male or female?	1
5. Experience and training	What experience or training did the researcher have?	n/a
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	1 and 7
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	6
12. Sample size	How many participants were in the study?	8

13. Non-participation	How many people refused to participate or dropped out? Reasons?	7, none
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	n/a
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	8
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	17
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	n/a
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	8 -audio
20. Field notes	Were field notes made during and/or after the inter view or focus group?	n/a
21. Duration	What was the duration of the inter views or focus group?	8
22. Data saturation	Was data saturation discussed?	7
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	no
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	8
25. Description of the coding tree	Did authors provide a description of the coding tree?	no
26. Derivation of themes	Were themes identified in advance or derived from the data?	no
27. Software	What software, if applicable, was used to manage the data?	none
28. Participant checking	Did participants provide feedback on the findings?	no
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Please see results
30. Data and findings consistent	Was there consistency between the data presented and the findings?	See results
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	n/a

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process, please select the file type: *Checklist*. You will NOT be able to proceed with

submission unless the checklist has been uploaded. Please DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.