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Title

An exploration of the experiences of people living with painful ankle osteoarthritis and the non-surgical management of this condition

Abstract

Objectives

Osteoarthritis (OA) of the ankle joint is associated with life-long joint pain and disability if not appropriately managed. There is a dearth of research concerning ankle OA and the impact on those living with the condition.

Aim: To explore the experiences of people living with painful OA ankle and their views about the non-surgical management of this condition.

Design

Qualitative design, using semi-structured interviews.

Participants

Nine participants, recruited from an orthopaedic clinic at a UK hospital and the general population. All had a clinical and radiographic diagnosis of OA ankle.

Interviews were digitally recorded and transcribed verbatim. Thematic analysis was undertaken to identify emerging themes. Ethical approval was obtained.

Results:

Nine semi-structured interviews were undertaken. Eight participants were male, median age = 55 years (IQR = 42.5 - 64.5). Mechanism of onset was due to trauma (falls, repeated inversion injuries or road traffic collisions) (n = 7), or the effects of haemophilia (n = 2). The median duration of symptoms was 2 years (IQR = 1.5 - 10). Data saturation was achieved. Four themes were identified:

- Signs and symptoms

- Impact on participation
- Impact on self-identity & mental wellbeing
- Views on non-surgical management

Conclusions

This is the first study to explore the experiences of people with symptomatic OA ankle. Our findings suggest that those with OA ankle suffer with severe pain, which has a substantial negative impact on a person's physical and mental wellbeing. The findings of this study may be used to inform future research.

Contribution of the Paper

- It is not known the issues people with OA ankle experience or the impact it has on their physical and mental wellbeing. This is the first study to explore the experiences of people living with this condition.
- Our findings suggest that OA ankle has a substantial negative impact on a person's physical and mental wellbeing.
- Participants indicated a mixed experience of non-surgical management of their OA ankle. This may be attributed to a lack of guidance on treatment best practice.
- The findings of this study may be used to inform future research.

Keywords

Ankle osteoarthritis; pain, physical functioning, mental wellbeing, quality of life, non-surgical management

Background

Osteoarthritis (OA) of the tibiotalar (ankle) joint is known to be painful and disabling resulting in substantial functional impairment^{1,2}. Information on this condition is scarce¹. Recent studies have identified the overall UK population prevalence of symptomatic ankle OA as 3.4% (95% CI – 2.4, 4.3)³. Post traumatic (PT) OA is the predominant form of OA in the ankle, accounting for 70% to 78% of cases, followed by secondary arthritis (12% to 13%) and primary/idiopathic OA (7% to 9%)². In 2005, treatment for lower extremity PTOA in the United States cost over \$11 billion, with annual direct costs exceeding \$3 billion⁴. As injury rates rise and PTOA becomes more prevalent, the financial burden on the health care system will likely increase⁵.

Non-surgical treatment of ankle OA includes medication, exercise, bracing, taping, shoe-wear modifications, and selective joint injections^{6,7}. For patients who fail to respond to non-surgical modalities, the two primary surgical treatment options for ankle OA are arthroplasty and arthrodesis. There are inherent risks linked with each surgical treatment option, but those of greatest concern are early implant loosening following arthroplasty and the acceleration of painful arthritic degeneration in other joints following arthrodesis⁸. There is also a sizable minority of patients who wish not to or who cannot undergo surgery and have to endure chronic pain. There is an unmet need for this group.

Pain is a complex physiological, psychological and socio-cultural phenomenon⁹. Each aspect of which may impact on how pain is perceived and experienced. Pain can impact on quality of life, function, mental and physical wellbeing, and is the leading cause of disability for people with arthritis¹⁰⁻¹². Furthermore, it has been

argued that reducing pain in people with arthritis would have the greatest positive impact on their quality of life⁹. Recent OARSI reviews of the year¹³⁻¹⁵ have emphasised the dearth of research in the treatment of painful ankle OA compared to knee and hip OA.

Therefore, the aim of this study was to explore the experiences of people living with painful OA ankle and their views about the non-surgical management of this condition. Gaining an understanding of the experiences of people with OA ankle and the impact it has on their lives will help inform future research into the management of this condition to ensure it meets patients' needs.

Methods

An exploratory qualitative research design was employed, using Gadamerian hermeneutic phenomenology¹⁶ to explore the lived experiences of people living with painful ankle OA. This approach was undertaken as it is best suited to understanding meaning as it is lived¹⁶ and thus, to explore the study aim. This involved interpretative in-depth one to one semi-structured interviews with the participant and the interviewer (XX), which explored participants' pain experience, the impact on their physical and mental wellbeing and their experiences of the non-surgical management of this condition. This research was undertaken according to the Consolidated Criteria for Reporting Qualitative Research (COREQ)¹⁷.

Nine participants were purposively recruited via their orthopaedic or physiotherapy consultant during their attendance at a National Health Service (NHS) orthopaedic clinic in North West England and via snowball sampling from the general

population¹⁸. Participants were included if they had a clinical and radiographic diagnosis of painful OA ankle and had either received non-surgical treatments or were on a waiting list to receive surgical treatment. Participants were excluded if they had other forms of arthritis, such as rheumatoid arthritis, and if the ankle had been surgically managed. Recruitment continued until data saturation was achieved.

Interviews were undertaken by a researcher trained and experienced in qualitative interviewing (XX), in a setting of the participants' choosing. Interviews lasted between 40 - 60 minutes and were digitally audio-recorded. An interview guide was developed from a review of the literature and was refined following piloting and critical discussion with the research team (see supplementary file). The interview guide was used to direct the interview by providing *a priori* topics to be explored in relation to the aim of the study. Further discussion was guided by the participant's response to these questions to ensure sufficient flexibility to allow the exploration of new and unanticipated issues. Due to the depth and richness of the data generated, repeat interviews were not required. Emerging findings from each interview iteratively fed into subsequent data generation and analysis.

Interview data were transcribed verbatim by a professional transcriber to ensure the accuracy of the transcription. Transcriptions were read independently by the research team (XX, XX) and reflexive, iterative and inductive thematic analysis was undertaken manually to transform the data^{16,19}. This involved initial open coding of data followed by coding of sections of the data that identify salient points. Patterns across the dataset were then iteratively explored to identify sub-themes. Conceptually similar sub-themes were grouped together into overarching themes.

Reflexive field notes of the interviewer's role and how this may have impacted on the data generated were made and fed into the analysis of the findings. For example, the interviewer was a female physiotherapist, which may have impacted on the information that participants wanted to share due to differences in gender and the participants' previous experience of physiotherapy. Critical discussions took place amongst the researchers to verify, modify and refine the themes. The preliminary analysis of the data were shared with the participants, who confirmed that it accurately reflected their experiences.

To ensure the quality of the research and therefore its trustworthiness, due consideration was given to the following. Credibility was ensured by describing and understanding the phenomena of interest from the participant's perspective.

Respondent validation was used to ensure the participants recognised the validity of their accounts. Transferability was enhanced by describing the research participants, the setting and context of the research. Reflexivity of how the research process may have influenced the data generated along with critical discussions of the analysis ensured confirmability and dependability.

Results

All participants who were invited, consented to take part in the study. Nine semi-structured interviews were undertaken. Eight of the participants were male, with a mean age of 54 years (range 30-70). Mechanism of onset was from trauma (falls, repeated inversion injuries or road traffic collisions) ($n = 7$), or due to the effects of haemophilia ($n = 2$). The median duration of symptoms was 2 years (range 1 – 20 years). All participants had received non-surgical treatments. Seven were on a NHS

orthopaedic waiting list to receive surgical treatment, two were recruited via snowball sampling at preliminary dissemination events.

Analysis of the data confirmed data saturation had been achieved as no new themes were emerging^{18,19}. Four themes were identified: 'Signs and symptoms'; 'Impact on participation'; 'Impact on self-identity & mental wellbeing'; 'Views on non-surgical management'. Each theme is presented with anonymized participant data to illuminate the findings.

Theme 1: Signs and symptoms

Participants complained of two main symptoms and one physical sign in relation to their ankle OA: pain, instability and swelling. However, pain was the central issue for all participants in terms of the type, intensity and persistence of the pain:

The pain is horrific. It's just terrible, I wish someone could ... you know what, I would have it cut off and a false one there if they could. It's horrendous pain, it's terrible. It's driving me round the bend. I'd go for anything to get rid of this pain, I'd try anything now.

For those that had OA in other joints, they perceived the pain in the ankle as having a more substantial impact:

I can live with the [OA] hip - but I'm not living well with this right ankle. It's just stopping the living of life, I can't live my life with it, it's crazy.

Participants also highlighted the unrelenting nature of the pain.

It's just always there and it just hurts. If it was just one or two blasts of tooth ache then you'd be ok; "ooh that's not nice", but when it's there every time you walk, it just gets you down.

All participants described fearing the pain they might experience if they took part in any physical activity and how this fear was preventing them from engaging in this. This impacted on them taking part in social activities, which had a negative impact on their quality of life.

I can get away with doing it, it's afterwards, when I stop, it doesn't, it's endless ... but wow the pain I felt over the following days. It's like we'd go to the park and I don't want to risk it. I don't want to risk it and then it affect me; not moving tomorrow.

All participants reported symptoms of swelling and most felt their ankle was always swollen to some degree:

It's so swollen, it's disfigured; it looks quite horrendous.

The degree of swelling was affected by the by the duration of weight bearing and type of weight bearing activity:

If I want to play golf I just go out in a buggy [golf buggy to avoid walking], but you do a lot of twisting. And I can see it, even though I've got my socks on, I can see it is all swollen and it's throbbing.

Participants felt that uneven surfaces were particularly problematic in terms of a perceived lack of stability in the ankle:

My ankle just doesn't feel strong. I don't like walking on cobbles or uneven surfaces as it feels I will go over on my ankle.

Anything that's got rough terrain I don't want it, I won't go on it. I might be walking and I hit uneven ground and it gives way.

Theme 2: Impact on participation

The symptoms the participants experienced impacted on their function and social life:

We tend to go the climbing centre and I'm very limited to where I can go. My friend was into his hiking and we went on loads of walks and I just can't go.

I get no enjoyment out of it [dancing] like I used to ... and that means I've stopped doing that, because I'm not sufficiently 'macho' that I will force myself to do it if it hurts.

Ultimately this impacted on their perceived quality of life.

I'm sat in the house, I can't do nothing. I have no social life. My friends, they all say come and have a pint, but what's the good in going for a pint when I'm sat there, I can't move, I can't go to the bar, I can't get to the toilet.

Theme 3: Impact on self-identity & mental wellbeing

Several participants talked about how living with OA ankle impacted on their self-identity. They felt that they had experienced a change in their self-identity and perceived this as a loss of self-worth:

I was like the leader, and then the handbrakes because they were slower than me; now I'm the handbrake.

I'm just useless, just because of a daft ankle. It's unbelievable that isn't it. It makes me feel as if I'm good for nothing, I might as well just turn it in, you know, just go for a couple of tablets and I'll call it a day. Just a waste of time. I'm good for nothing at the minute. I feel like crying. It's horrible. Every day of my life; it gets a bit upsetting. You just wanna give in, in the end, you get sick of it.

As illuminated above and by others, this led to feelings of depression and adversely affected their mental wellbeing. For most participants, this related to the impact and consequences of the pain experienced from OA ankle:

I got quite depressed with it all. I didn't realise that there was such an adverse effect that the pain grinds you down and gives you that low self-esteem and no self-confidence. You can see other people your age doing things but you're not able to. It wears you down mentally and makes you very depressed at times. What you don't realise is it's not just physical, it very much affects you mentally.

Theme 4: Views on non-surgical management

All participants had received various non-surgical interventions including heat, exercise, external ankle supports, orthoses, medication and corticosteroid injections. The response to these inventions were mixed with some finding them helpful, for others this was of limited, or short-lived benefit.

The physio gave me some exercises which, quite frankly, didn't really help ... it was just movement exercises and strengthening - the idea being to strengthen the joint.

It was gentle exercises, which helped the stiffness in the joint. Doing any kind of mild exercise was unbelievable and the manipulation stuff helped because it kept the joints from freezing up. So, they definitely helped.

Participants who used external ankle supports and orthoses found these to be beneficial. However, some participants highlighted the difficulty of donning the

support due to swelling in the ankle, and for many there were issues of tolerance and acceptability which impacted their benefit.

I have an ankle brace, it's really good ... of course in the summer time they're not great - That's because it's hot, and your feet start sweating more. You get sores on your feet with them, so I take them off.

Due to this, several male participants talked about wearing high boots to provide ankle support, however, there was also an acceptability issue with this:

And I wear boots just pass the ankle and I strap them up around me ankle. So it looks stupid when you wear shorts.

Additionally, wearing high boots was not considered to be an acceptable option aesthetically for the one female participant.

Furthermore, there was a feeling amongst participants that in the earlier stages of the condition, where the radiological changes were not substantial, their condition was not taken seriously and few treatment options were offered. Ultimately, this impacted their mental and physical wellbeing and quality of life:

They x-rayed it, and they said it's not too bad. They said you can see it, but it's not bad ... but I can barely walk on it [in the mornings] until it wakes itself up a bit.

In some sense, it seems that it's not being treated seriously, and if I physically couldn't walk, I'd be referred to people. Actually, it matters. Long before people are physically incapacitated, because it's affecting my mental health, it's affecting my physical health, but it's not extreme enough with the level of funding the NHS has at the moment for it to be treated seriously. With ankle pain, the pain doesn't have to be that bad to have a massive impact on your quality of life.

Discussion

Pain is widely reported as the main symptom of OA^{6,20}. In common with other studies on OA^{7,21,22}, pain was a central issue for participants with OA ankle in this study and affected all aspects of the participants' lives. This is commonly the symptom that makes individuals seek medical attention and contributes to participation restrictions and reduced quality of life^{7,21,23}. Despite this, little is known about the quality and effects of OA ankle pain. The findings from this study indicate that OA ankle pain had a substantial negative impact on a person's physical and mental wellbeing, with many participants describing their pain in emotive terms such as 'terrible' and 'horrendous'.

Participants who also had painful hip or knee OA, felt that the greatest impact on their quality of life was due to their ankle pain. Although the radiological severity of the OA in the hip or knee was unknown in our participants, another study found health-related quality of life in patients with end-stage ankle OA was at least as severe as end-stage hip OA¹.

Participants highlighted that in addition to the severe nature of their ankle pain, the relatively long lasting nature of the pain resulted in them not participating in activities to avoid having to cope with their ankle pain over subsequent days. This impacted on their function and resulted in many not taking part in social activities with friends and family, which adversely affected their social relationships²³. In common with studies on OA affecting other joints^{20-22,24}, those we interviewed had previously been active but the ankle pain had changed how they lived their lives and affected their ability to do the things they wanted to do. This appeared to affect their mental wellbeing, with several participants reporting feelings of anxiety and depression related to their pain and the impact on their function and social life. It is known that chronic pain can cause or worsen anxiety and depression²⁵ and has been reported in those with OA in other joints^{20, 26}. This can adversely impact quality of life and patient outcomes²⁶. Identifying effective management strategies for OA ankle pain may positively impact their mental wellbeing and in turn, their quality of life.

Participants in this study, who were told by their specialists that their radiological changes were not substantial, felt that their condition was not taken seriously and that few treatment options were offered. However, it is widely reported that there is discordance between radiological findings and patient symptoms²⁷⁻²⁹. Thomas et al.²⁴ in their study exploring the experiences of patients with symptomatic foot OA found similar findings of patients feeling that they were not being taken seriously by their GP and that their concerns were invalid. Therefore, to meet patient need, due consideration to the management of symptoms for people presenting with painful OA ankle and minimal radiological changes is recommended.

The participants' mixed experience of the non-surgical management of their OA ankle may be attributed to a lack of guidance on treatment best practice²⁴. Whilst guidelines exist for the care and management of OA in general, there are no recommendations for specific joints¹⁵. All guidelines on the management of OA include education and exercise as core elements of treatment^{6,30-32}. However, due to the dearth of evidence in relation to the conservative management of OA ankle, these guidelines are informed by knee and hip osteoarthritis research; no guidelines exist for the management of OA ankle^{6,30-32}. Therefore, it is not known if exercise is beneficial for OA ankle or what type or prescription of exercise is recommended. Current practice includes mobilising, strengthening or proprioceptive exercises and refer to the exercise frequency, intensity and timing^{6,7,30-32}. The widely varying exercise programmes for ankle OA may account for the mixed response to exercise reported by our participants. Exercise in combination with education for those with OA in other joints results in clinically important improvements in pain, physical function and quality of life¹⁵; the impact of this on OA ankle is unknown. It has been found that patient characteristics can have a significantly greater negative impact on health-related quality of life domain scores among people with with OA ankle compared to those with OA knee³³. This suggests that that a one-size-fits-all approach to patient education for OA will limit its effectiveness, and joint specific education may be of benefit to people with OA ankle to optimize health-related quality of life outcomes.

It is known that symptomatic lower-limb OA is made more painful by weight-bearing through an affected joint^{6,7}. This reflects our participants' experiences who found their ankle pain was aggravated by walking, especially on uneven surfaces.

However, which biomechanical interventions, such as footwear, insoles, and splints are most beneficial in OA ankle is unknown⁶. Witteveen et al.⁷ investigated the difference of opinion between the patient and orthopaedic surgeon on the impact of ankle arthritis, and found that patients considered wearing a brace was the most effective non-pharmacological conservative treatment. However, whilst external supports to stabilize the ankle did seem to be of benefit to some of the participants in this current study, there were issues of acceptability and comfort which negatively impacted their use in the management of this condition. Further research is recommended to investigate the mechanism and the participants' experience of these devices.

The strengths of this study were the robustness of the methodology to explore the phenomenon of interest including its reflexivity, participant data verification and independent data analysis with critical discussions to identify the themes. The limitation was small sample size of nine participants. However, this is considered appropriate in a qualitative study¹⁸. Further studies on specific populations such as those with non-traumatic OA, female participants, different duration of symptoms and specific age groups, might add further insight to these findings.

Conclusions

This is the first study to explore the experiences of people with symptomatic OA ankle. Our findings suggest that those with OA ankle suffer with severe pain, which has a substantial negative impact on a person's physical and mental wellbeing. Although there is a wide range of conservative non surgical interventions available,

there is little evidence of their clinical effectiveness for this condition. The findings of this study may be used to inform future research.

Abbreviations

Osteoarthritis (OA)

Post traumatic (PT)

United Kingdom (UK)

Osteoarthritis Research Society International (OARSI)

Consolidated Criteria for Reporting Qualitative Research (COREQ)

National Health Service (NHS)

Quality of Life (QoL)

Ethical approval

NHS Health Research Authority approval was obtained from Newcastle and Tyneside 1 Research Ethics Committee: Ref 17/NE/0129; and XX University ethics committee: Ref 1515.

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Conflict of Interest

There are no conflicts of interest

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