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Patient perspectives on participation in exercise-based rehabilitation for Achilles tendinopathy: a qualitative study

Introduction

Achilles tendon-related pain and its associated functional limitations, termed tendinopathy, is common and contributes to substantial societal burden (Sleeswijk Visser et al., 2021). Achilles tendinopathy (AT) has an estimated incidence rate of 2.35 per 1000 person-years for the general adult population (Albers et al., 2016; de Jonge et al., 2011). Likewise, 52% of top level runners will suffer with AT during their lifetime (Kujala et al., 2005) and may contribute to premature retirement in up to 5% of professional athletes (Lysholm and Wiklander, 1987). AT, however, is not only a problem that impacts sports participation. It effects the sedentary population also, negatively affecting the ability to work (Albers et al., 2016). People affected report impaired quality of life (Albers et al., 2016), potentially leading to significant physical and psychological burden (Mc Auliffe et al., 2017; Turner et al., 2020).

AT can be traumatic or insidious in onset and short-lasting or persistent in nature (Scott et al., 2013). AT is characterised by load-related pain that is localised to the tendon (Cook and Purdam, 2009); for example, during activities such as walking, running and hopping. The aetiology of AT is mixed and uncertain; factors considered to be involved include modifiable ones such as plantarflexor strength, weight and cholesterol levels, and also non-modifiable factors such as age, previous injury and steroid exposure (O'Neill et al., 2016). Pain associated with AT is localised to either the midportion of the tendon (2-7cm proximal to the calcaneal enthesis) (Chen et al., 2009) or the calcaneal insertion (van Dijk et al., 2011). Factors influencing the experience of pain are poorly understood; little is known about mechanisms driving pain and the response (or lack of) to rehabilitation (Mallows, Debenham, Malliaras, Stace, & Littlewood, 2017; O'Neill, Watson, & Barry, 2015; Rio et al., 2015, 2014).

Despite this limited understanding, there is a growing body of evidence supporting the use of exercise to manage AT, (Coombes et al., 2013; Lewis, 2013; Magnussen et al., 2009) and exercise is recommended first-line care in practice and expert consensus (Martin et al., 2018; Scott et al., 2013; Van Der Vlist et al., 2021). Interestingly, variation in exercise approach does not appear to significantly impact outcome, with no single approach demonstrating superiority over another (Beyer et al., 2015; Malliaras et al., 2013; Van Der Vlist et al., 2021). It is therefore paramount that in order to optimise outcomes in AT, the mechanisms underpinning change (or lack of) are explored.

To date, two previous qualitative research studies have explored the experience of people living with AT (Mc Auliffe et al., 2017; Turner et al., 2020). Findings highlight the substantial fears, frustrations and impact on quality of life and daily functioning in individuals with AT, underscoring the need for clinicians to adopt a biopsychosocial approach to rehabilitation. Whilst the experience of rehabilitation features in the previous work, neither specifically set out to explore how rehabilitation is viewed from a patients' perspective. Patients' perceptions of factors related to rehabilitation that may influence outcome could provide a valuable addition to help guide future research and practice. Therefore, the aim of this study is to gain an insight into patients' experiences of participating in an exercise-based rehabilitation programme for AT.

Ethical approval

Ethical approval was sought from the University of X and granted on 02/03/2020 (Ethics ETH1920-0940)

Method

In order to start to understand and explore an under-research phenomenon and generate knew knowledge relevant to a specific clinical context, a qualitative interpretive description design was chosen. This approach allows the exploration of complex clinical phenomena whilst acknowledging the practical experience of the researchers (Hunt, 2009). This research focused on identifying themes within the participants' experience of completing an exercise programme for AT. To develop these themes, data generated from semi-structured interviews were analysed using a qualitative interpretive description design (Thorne et al., 1997). Thematic analysis is the most appropriate method for this type of inquiry, as codes and themes can be created inductively to capture meaning and content without prior preconceptions allowing flexibility to generate a rich and detailed account of the data (Braun and Clarke, 2006). In this study, data were analysed thematically using the guidelines set out by Braun and Clarke (Braun and Clarke, 2006) and will be reported in line with the COnsolidated criteria for REporting Qualitative research checklist (Tong et al., 2007).

Recruitment

A convenience sample of participants were recruited from 4 private physiotherapy practices in the United Kingdom and Australia. All participants had undergone or were undertaking an exercise programme for AT. Upon commencement of treatment, a patient diagnosed with AT was provided with a participant information sheet by their treating physiotherapist and they discussed the study. At the next treatment consultation, the physiotherapist further discussed the study and gained consent from willing patients. It is not known if any potential participants refused to participate; researchers were only made aware of those who agreed to participate. No participants dropped out. A member of the research team (JH) then contacted the participant by telephone or email and invited them for interview. To understand the range of outcomes from the rehabilitative process the participant’s current levels of pain and disability were measured. Disability was measured using the patient reported outcome measure, the Lower Extremity Functional Scale (LEFS) (Binkley et al., 1999). The LEFS is a self-report questionnaire designed to measure physical function of people with lower extremity dysfunctions, such as AT. Twenty items covering a range of lower extremity functional activities are scored on a numerical rating scale from zero (extreme difficulty or unable to perform activity) to four (no difficulty). This provides maximum scale points of eighty, with zero representing maximum dysfunction (Binkley et al., 1999). Self-reported pain was measured using the Numerical Pain Rating Scale (NPRS) (Farrar et al., 2001). During the data collection the interviewer (JH) kept a reflective journal, noting down initial thoughts and ideas after each interview which were used to inform topic guides for later interviews.

Sample size

Ten participants were recruited (3 from site 1, 3 from site 2, 2 from site 3 (all UK-based) and 2 from site 4 (Australia-based). Based upon studies using similar patient groups, we anticipated the need to recruit ten participants to reach data saturation (Mc Auliffe et al., 2017; Smith et al., 2018) and this was agreed a priori.

Inclusion and exclusion criteria

For participants to be included in the study they were required to:

- be a minimum of 18 years old
- to be able to understand spoken English
- be diagnosed with AT by their treating physiotherapist. Diagnosis of AT was based on criteria from expert consensus: local mid-portion Achilles tendon pain reproduced with load-based activity and tenderness on palpation (Martin et al., 2018).
- be undertaking or completed treatment that included exercise (within the last month) by a physiotherapist.

Participants were excluded from the study if they had:

- not provided informed consent
- a diagnosis of Achilles tendon tear/rupture on the affected side
- prior surgery to the affected Achilles tendon
- other diagnoses that could explain their Achilles pain (e.g. referral from the lumbar spine, posterior impingement, etc)

Treatment

The effect of treatment is not under examination; the type, duration and content of treatment for recruited patients was determined by the treating physiotherapist and was not influenced in any way by participation in this interview study.

Data collection

One-on-one interviews were conducted via telephone or online over Zoom. Interviews were directed by a topic guide and were recorded using a digital voice recorder and transcribed verbatim. The topic guide was designed by the researchers with an exploratory approach to knowledge generation with regards to the lived experience of TA rehabilitation. Training in conducting interviews was undertaken prior to data collection and two practice interviews were carried out, one with an experienced clinician and one with a patient, to pilot the topic guide. All interviews were undertaken by a male clinical physiotherapist (JH) with 4 years of experience working in physiotherapy practice after completing an MSc in Physiotherapy. JH had no prior connection with any participants prior to data collection.

Data analysis

All audio files were collected and transcribed verbatim by one of the researchers (JH). During transcription, initial thoughts and ideas were noted in a reflective journal. All data were stored on a password protected laptop computer. Familiarisation of the data began early on by listening to the audio files several times to check for accuracy (JH), with the reviewing of all interviews and notes of the participants' responses during each interview (JH & BES); this allowed for 'data immersion' by the researchers and generation of preliminary ideas. Once all interviews had been transcribed, recurrent topics of interest were identified, and cross referenced against the notes made and topic guides to ensure the list was exhaustive and against the research objectives to confirm their relevance. Data coding then identified and coded pertinent features of the data giving equal priority over the whole dataset. Themes were then sorted and grouped in a hierarchal arrangement of themes and subthemes so that an overall structure can be viewed. The generated structure was then reviewed and refined (JH & BES), ensuring that they explained the data in relation to the coded data, and the whole dataset. Finally, the themes and sub-themes were named and defined to demonstrate a clear narrative, using compelling extracts as illustrations. Data were organised and analysed using QSR International's NVivo V.11. After ten interviews, it was determined by the researchers (BES & JH) that data saturation had occurred as no new thoughts or concepts were generated in the final few interviews. Generated themes and subthemes were then sent to the participants for feedback and checking, although no comments were received.

Results

Participants ranged from 33 to 73 years old (mean age 49.2 years old) with a diagnosis of AT for a mean duration of 12.9 months (range 5 months to 28 months). For participant characteristics please see table 1. The interviews ranged from 13.47 to 35.35 minutes (mean time: 26.51 minutes).

Table 1. Participant Characteristics

Participant	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Mean**	**SD**
Gender	F	M	F	F	M	M	M	M	M	F	-	-
Age (years)	50	40	63	48	43	33	40	73	53	49	49.2	11.8
BMI	27	26.5	24.3	28	23.8	25.8	24.2	24	29	21.0	25.5	2.2
Symptom duration (months)	5	7	13	14	5	5	24	18	10	28	12.9	8.2
Disability (LEFS)	55	80	53	38	73	80	71	50	57	62	61.9	13.8
Average pain levels over last week (NRS)	5	1	4	6	2	1	3	0	2	2	2.6	1.9
Pain site (MP/I)	I	MP	I	I	I	I & MP	MP	MP	MP	MP	-	-
Medication use	NO	NO	NO	NO	YES	NO	NO	NO	NO	NO	-	-
Prior physical activity level (hours/week)*	6	3	6	7	5	3	7	7	10	18	7.6	4.4
Current physical activity level (hours/week)*	7	3	4.5	0	1.15	3	2	2	5	9	4.5	3.4

Previous history of Tendinopathy	NO	NO	NO	NO	YES	NO	YES	YES	NO	YES	-	-

F, female; M, male; MP, mid-portion; I, insertion; SD, standard deviation; LEF. Lower Extremity Functional Scale (score ranges from 0-80, with 0 representing maximum dysfunction); NRS, Numerical Pain Rating Scale (scale ranging between 0 (no pain at all) and 10 (the worst pain ever possible)); BMI, Body Mass Index.
*Physical activity was described as ‘any bodily movement produced by skeletal muscles that requires energy expenditure’ (Bull et al., 2020).

The first theme identified from the data was the *‘understanding the impact’*. A further three themes were identified; *‘expectations’*, *‘what matters’* and finally *‘the burden of exercise’.* Data are presented to demonstrate the range and meaning to each theme.

Theme 1: understanding the impact

A strong theme with our participants was the importance of the therapist understanding the impact AT was having on them, with the need for the therapist to be empathic to the pain and disability:

‘I think being empathetic, the empathy towards your client, I think is really important’ (participant 1).

When discussing the need for understanding, participants provided rich detail about the impact AT was having on them. Subthemes which participants discussed reflected the importance of physical activity to them, their loss of identity, the negative impact of AT on wellbeing and their feelings towards their Achilles tendon.

The loss of the ability to exercise or be physically active caused by AT was a strong feature of discussions with many participants:

‘I didn't like exercising less, or walking less or being less independent, that was my issue’ (participant 10).

With several participants describing the negative impact of AT on their self-identity:

‘It's just, it's just frustration because I can't be the person that I want to be’ (participant 3)*.*

A number of participants identified the negative impact AT had on their wellbeing:

‘*And it does depress you a little bit because obviously I'm used to just doing what I want*(participant 7).

One participant described how the psychological burden of AT pain resulted in further negative feelings towards their Achilles tendon with body perception disturbance being a feature of the discussion:

*‘And I've had times my worst times where I thought if I just could just chop my leg off. I know it sounds extreme but if we just chop my foot off get one of those blades’ (*participant 4*).*

Theme 2: expectations

Expectations were a key topic raised by many participants during the interviews. With dissonant expectations when compared to the reality of their experience; expectations related to 1) the condition; 2) the physiotherapist 3) treatment.

Participants discussed their expectations around AT and how they felt unprepared for the condition to be persistent in nature.

‘I couldn't believe how long it was dragging on for. I assumed it would go fairly quickly’ (participant 9)*.*

The majority of participant discussions around the expectations from the physiotherapist related to hope and frustration. Hope that seeking treatment in a timely manner would be beneficial.

'I was hopeful that because I've gone early they'd be able to intervene and fix it. And that's why I've gone early. I kind of thought, I just need some strengthening exercises or something. And I'll get a program of exercises and couple of months. It'll be sorted' (participant 4).

However, when hope faded, frustration was apparent.

'I was frustrated because that physio didn't have the skills to deal with my condition. So I went away, frustrated because it was more a general health check, and I didn't feel I was getting anywhere' (participant 5).

'And she was like "Oh, I don't know what that is". And I thought to myself well if you don't know what that is, then doesn't really fill me with much confidence' (participant 2).

Expectations of treatment were based on previous experience and the experience of undertaking the treatment, with some participants expressing dissatisfaction at the physiotherapy approach.

'It wasn't physio as such. It's just they were looking at it, checking in a few things and then giving me exercises. I thought it would be proper deep tissue physiotherapy like massage and maybe ultrasound' (participant 7).

Other participant views on physiotherapy were based around exercise prescription:

'I expected him to give me some exercises. I expected the physio to at least feel and tell me what was going on whether I had damaged it, whether I needed an operation' (participant 1).

With another sub-set of participants reported that they had limited understanding of how exercise and treatment from a physiotherapist could help their AT.

'It was such a painful manoeuvre. And I kind of imagined that's what I'm going to be given to do and I thought that didn't make sense to me. And I was very reluctant to go down that kind of path. And also in my ignorance I wasn't sure what physio could achieve' (participant 8).

Theme 3: what matters

The important elements of rehabilitation which the participants felt mattered were a central component to the interviews. The important subthemes identified were taking an individualised approach, the burden of exercise, the level of support, addressing fears and confidence through relationship building — with education being an overarching sub-theme throughout.

Education was perceived by many of the participants as a crucial first step in the rehabilitation process.

'There were visual diagrams at the assessment of which aided what he was saying. It was the clarity and the confidence in what and how he was dealing with it, which I found the most useful' (participant 5).

Understanding pain during exercise and activity was viewed as a key learning. Some valued an objective approach.

'So he told me that some pain isn't necessarily bad. So if I'm going out and I'm perhaps two or three out of 10 I'll find that quite easy to grasp (participant 5).

Whilst others found this unhelpful and confusing.

'It's really hard because pain's so subjective isn't it' (participant 4).

Being seen as an individual and helping to develop a personalised approach to treatment was viewed as a positive by participants:

'The way he approached me it wasn't like another patient with the same Achilles issues. It was completely different' (participant 10).

A consistent theme among the participants was that the level of support provided was seen as an important determinant of success, with an opportunity to discuss and personalise the exercises seen as a positive, whilst sticking to a prescribed number was seen as a negative. A physiotherapist who appears interested and is available to communicate between appointments was seen as a positive.

'He was very keen on trying to understand if it was working. So as busy as he is, he still made sure that I could contact him ' (participant 10).

'For example, when I went on that run and I was in pain I messaged him straight away on Facebook and he gets back to me' (participant 6).

One participant felt it was important to see the physiotherapist regularly in order to make progress but others did not mention this aspect.

'Unless you're seeing the physio regularly, they are not able to judge what you should or shouldn't be doing (participant 3).

Addressing fears about exercising was seen as a positive component in rehabilitation. Participants discussed their fears about being asked to exercise with a painful Achilles tendon.

'And actually, as a result of that assessment because I'm starting to get a bit fearful that doing any exercise is actually making it worse. Whereas the physio reassured me that we need to get back to running don't hold off for another couple of months. And that was quite pleasing to hear that. Before I was probably starting to get a bit fearful' (participant 5).

Confidence in the physiotherapist and the approach they took to build a therapeutic relationship was seen as an important step in the rehabilitation.

'He owned it, he owned that treatment and he owned the fact that he needed to get me better, even though he didn't know me that well. That really stood out to me' (participant 1).

'He is the kind of clinician that I admire in the sense that he would listen carefully to what I was saying' (participant 8).

Theme 4: the burden of exercise

This theme describes the emotional burden and challenge associated with the commitment needed with a rehabilitation and exercise programme. Challenges to commitment centred on time restraints and the demands of the exercise programme.

'So it was it was quite a challenge at times' (participant 8).

'I think at times it sort of wore me down a little bit and it took quite a bit of time in the day and I think I went through periods where I didn't do them daily as he wanted me to. So, I went through some non-compliant periods' (participant 8)

Understanding a person's social circumstances and lifestyle were linked to higher levels of commitment.

I had opportunities to do all the exercises and to take his advice and to do what I need to do to get back. So, there was a conversation and it seemed like it could fit with me (participant 7).

'I think that's perhaps why it's worked as I can fit it into my lifestyle quite comfortably' (participant 5).

The burden of home exercises was a key point of discussion. *'The first physio, she had me be doing like three sets of 15, three times a day. And I was like, when am I* *going to do all that? And then I had to introduce the balance board and then there was some standing on a cushion and then there was some stretching. It was like I need to give up work just to be able to do all of these exercise'* (participant 4).

The main subthemes that emerged in relation to the burden of exercise were schedule constraints, personal circumstances, personalisation and the burden of loss of time.

Discussion

Quantitative research methods dominate the literature for AT. This is the first study to use a qualitative method of inquiry to gain data on the experiences of people undertaking exercise-based rehabilitation for AT. The four major themes that were identified from the data were: (1) *'understanding the impact* (2) *'expectations'* (3) *'what matters'* and (4) *'the burden of exercise'.*

Participants in this study expressed negative impact of AT pain on their well-being, activity levels, and feelings towards their Achilles tendon, with motivation for seeking physiotherapy the hope at a positive outcome on their symptoms. Pain affects quality of life and sense of self. This study is the first to report participants' sense of body perception disturbance in AT, where one participant expressed feelings of the tendon not belonging to them and wanting surgery to excise the painful part or remove the limb. People who have altered body perception behaviour differently towards the affected body parts (Lewis et al., 2007). A greater understanding of how pain and body perception relates to AT may provide novel treatment opportunities (Debenham et al., 2016).

Participants evaluated their treatment in relation to their expected timeframes for recovery. The participants felt their recovery was slower than expected and acknowledged this as surprising and frustrating. The negative emotional toll of AT further compounded their frustration. Frustration at the treatment process is not unique to people with Achilles tendinopathy (Mc Auliffe et al., 2017; Turner et al., 2020), with inconsistent messages from health care practitioners contributing. However, our study draws attention to the value placed on support for managing patient expectations and the importance of support during setbacks during rehabilitation. How best to do this in a healthcare setting is not yet known.

Our participants valued highly the educational component of the rehabilitation process which underpinned shared decision making through a strong therapeutic alliance. Therapeutic alliance is defined as the collaborative and affective bond between a healthcare practitioner and a patient; a positive social interaction collaboratively problem solving and sharing the decision-making process (Babatunde et al., 2017). Components of this alliance include empathy, respect and active communication. A strong therapeutic alliance may result in improved exercise adherence (Babatunde et al., 2017), an important component of successful rehabilitation. Therapeutic alliance is an emerging field of research in tendinopathy, but there are initial data that suggest stronger therapeutic alliance is associated with improved outcomes (Mallows et al., 2020). How therapists can optimise this is currently unknown.

Previous qualitative research has identified the psychological burden of AT on the individual (Mc Auliffe et al., 2017; Turner et al., 2020). Both these qualitative studies share a number of key features with our findings, including the lived experience of fear, frustrations and impact on quality of life; however further phenomena identified in our study was the burden of rehabilitation and exercise prescription on the individual and the value participants placed on shared decision making through the rehabilitation process. Current best practice guidelines include strength training and load-management as key components (Littlewood et al., 2016; Malliaras et al., 2013; Martin et al., 2018). However, the participants found exercise time consuming and difficult to complete, citing busy lifestyles and, uncertainty of levels of pain with the exercise. The participants recognised the benefit of flexibility within the exercise prescription and value was placed on the programme to fit their everyday life. The participants felt that a large part of the expertise of the physiotherapist was in their ability to understand, empathise, and adapt the programme accordingly. This would seem important as trust in the physiotherapist fosters active engagement in therapy

(Bernhardsson et al., 2017). The experience of the participants reported in this study suggest current AT guidelines (Littlewood et al., 2016; Malliaras et al., 2013; Martin et al., 2018) may not sufficiently reflect what matters to patients during rehabilitation.

The themes and phenomenon identified in this study highlight key gaps in the AT literature and future studies are needed to explore biopsychosocial targeted interventions for this population. We propose further research that aims to improve our mechanistic understanding on *how* physiotherapy rehabilitation works, and the development of complex interventions and trials that investigate a rehabilitation framework built around developing a strong therapeutic alliance with educational components addressing the pain-related fear, psychological factors, body perception disturbance, with customisation of the prescription of exercise to optimise commitment.

There are several methodological considerations of this study that should be acknowledged. Firstly, our findings may have been influenced by ‘volunteer bias’, additionally, participants in this study were accessing private health-care and for pragmatic reasons a convenience sampling technique was used. Therefore, we can’t be sure how representative these findings are, particularly when considering how athletic the included participants were compared to sedentary populations, another high-risk group for AT. A targeted recruitment process may have better representation across high-risk groups. Future research should consider exploring patient experiences in public healthcare settings. Secondly, despite two researchers (JH & BES) determining data saturation had been reached after 10 interviews, we did not set a specific data saturation point, for example when no new themes can be added during two consecutive interviews. Typically, 12 interviews may be needed to reach higher degrees of data saturation (Guest et al., 2020), so additional themes could have been missed.

Strengths of the study include using no pre-determined themes and an inductive approach to data analysis and coding; a clear, transparent and reproducible methodological approach to data analysis with a second author reviewing data-analysis and coding. Participants felt able and willing to discuss their condition and rehabilitation, often with quite complex and personal topics.

Conclusion

This study provides the first understanding into the experience of patients undergoing rehabilitation for Achilles tendinopathy. Given the uncertainty surrounding the mechanisms of effect of our treatments, the insights provide a platform from which researchers and clinicians can consider further in the management of people with Achilles tendinopathy. Specifically, it has highlighted that patients value factors beyond what can be found in clinical guidelines for managing Achilles tendinopathy; a flexible, supportive approach embracing the biopsychosocial impact on the individual.

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