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Beyond the tendon: Experiences and perceptions of people with persistent Achilles tendinopathy.

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Abstract

Background: Achilles tendinopathy (AT) is associated with persistent pain leading to a significant physical and psychological burden. Psychosocial factors are considered to be important mediators following exercise interventions. Despite the recognition of the importance of psychosocial variables in persistent MSK disorders, there is a distinct lack of qualitative research investigating psychosocial factors in AT.

Purpose To qualitatively explore the perceptions and experiences of people with AT prior to an intervention study.

Methodology: A qualitative, interpretive description design was performed using semi-structured telephone interviews. The questioning route covered history of AT, perceived cause of AT, effect of AT pain, experience in managing AT, and perspective on prognosis of AT pain. Interviews were transcribed verbatim. The study has been reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) checklist. To facilitate the rigor of methodology and the transparency of the research process an audit trail was created.

Results: Eight participant's (Five male and three female). Four main themes were identified in the data: (i) pain as a feature of everyday life; (ii) experience with the management process; (iii) identifying with and self-managing AT, and (iv) looking to the future.

Conclusions: This study suggests that persistent AT is associated with a significant psychosocial impact, particularly in terms of participation in daily life and valued activities. Better understanding the experiences and personal impacts of AT may enhance management of this persistent disorder, and facilitate individuals with AT complying with evidence-based approaches including exercise and pain reconceptualization.

Keywords: Achilles, Tendinopathy, Qualitative, Beliefs,

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INTRODUCTION:

Pain, a cardinal feature in Achilles tendinopathy (AT), results in alterations on an individuals daily activities or recreational pursuits (Cook and Purdam 2013). Furthermore, AT is often associated with persistent or chronic pain, and is associated with **high recurrence rates and persistent functional impairments** (Gajhede-Knudsen *et al.* 2013).

To date, research in AT has mainly focused on the physical or structural implications of the disorder, utilising quantitative methods. Despite **the importance** of quantitative methodologies in scientific exploration, these study designs fail to reflect and capture **the complex and multifactorial nature of persistent pain. Persistent musculoskeletal (MSK) pain is often associated with the presence of psychosocial factors such as fear avoidance beliefs, vigilance, low self-efficacy and anxiety amongst others** (Jones *et al.* 2013, MacKay *et al.* 2014, Bunzli *et al.* 2015). Furthermore, psychosocial factors are considered to be **important prognostic indicators of rehabilitation in a host of musculoskeletal disorders** (Vlaeyen and Linton 2000, Ardern *et al.* 2011, George and Stryker 2011, Chester *et al.* 2016, Forsdyke *et al.* 2016).

Qualitative methods provide the opportunity to understand complex psychosocial processes, to capture essential aspects of a phenomenon from the perspective of study participants, and to uncover beliefs, values, and motivations that underlie individual health behaviors (Curry *et al.* 2009). This has become increasingly relevant with the move towards a patient-centered paradigm of healthcare (Hush *et al.* 2011). Of these qualitative methodologies, interviews are seen as an essential research method with the interview being referred to as the primary method used in qualitative research and "the most direct, research-focused interaction between research and participant" (Oltmann 2016)

Despite the recognition of the importance of psychosocial variables in persistent MSK disorders, **there is a distinct lack of qualitative research investigating psychosocial factors in AT. Awareness of psychosocial factors and participants experiences with treatment outcomes may help improve the management of this complex and often disabling MSK disorder.** Consequently, this paper seeks to qualitatively explore the

experiences and perceptions of pain in individuals with AT.

METHODOLOGY:

Study Design

A qualitative interpretive description design was chosen as an appropriate methodological approach (Thorne *et al.* 1997). Interpretive description is a non-categorical methodological approach created to allow healthcare practitioners explore clinically occurring phenomena within a conducive framework (Thorne *et al.* 2004). This methodological approach facilitates the exploration of complex experiential clinical phenomena and provides direction in the creation of an interpretative account using techniques of reflective, critical examination (Thorne *et al.* 1997, Hunt 2009). Due to the individual experiences of AT, semi-structured interviews were employed. To ensure that the questions had a valid and meaningful theoretical scaffolding, the questioning route or topic guide for this study was generated based on a literature review of relevant research (Hunt 2009). The route was then refined following discussion within the research team to ensure the questions, content and structure were suitably open-ended, neutral and sensitive (Gill *et al.* 2008). Ethical approval for the study was granted by the local Education and Health Sciences Research Ethics Committee in the University of Limerick (Ethics Number: EHSREC2014-05-14). This included obtaining written consent from participant's for the publication of their anonymised data.

Participant's

Participant's were recruited from local running clubs and the local community by means of e-mail and through word of mouth. Participant's were recruited as part of a single-arm non-RCT intervention study investigating the **effects of a 12-week exercise intervention for individuals with persistent AT in the local community**

Inclusion and Exclusion criteria

Men and women, 18-60 years of age with AT symptoms for **more than 3 months** were included. A diagnosis of AT was determined by a combination of Achilles tendon

pain, tenderness and impaired physical performance. The exclusion criteria were: under the age of 18, non-English speakers, injury to the foot, knee, or hip on the same side of the AT, injury to the back and/or history of rheumatoid arthritis or any other injury or illness thought to interfere with the participation in the study. The four point sampling approach as described by Robinson (2014) was used in order to enhance coherence, transparency, trustworthiness of the research.

Data collection

Semi-structured telephone interviews were carried out by a final year undergraduate physiotherapy student (HC), who was unknown to the participants and was guided by a flexible questioning route. The telephone interviews were recorded by HC at the University of Limerick, with participation in the telephone interviews occurring before commencement of an intervention study. **The questioning route explored: participants history of AT, perceived cause of AT, experience in managing AT, and perspective on future prognosis** (Supplementary file 1). Prior to conducting the interviews, the interviewer (HC) undertook a number of practice interviews with feedback provided by the primary investigator (SMA). Interviews lasted from approximately 30-60 minutes. Interviews were recorded using a digital voice recorder. During the interviews the researcher took notes, as needed, and statements of relevance and contextual field notes were written verbatim. At the conclusion of each interview, the researcher debriefed the participant on the main content of the interview, and time was permitted for any additional commentary to facilitate the emergence of new unanticipated information (Gill *et al.* 2008).

Data analysis

Interviews were transcribed verbatim. Three transcripts were randomly selected and initial inductive codes were formed individually by two authors (SMA and AS). The two initial code lists were then amalgamated and a comprehensive code list was finalised, in view of the codes most representative of the dataset informed by background reading related to the research question. The finalised code list was then applied to all transcripts by the study author (SMA). Coded data was categorised and through a process of repetitive interpretation, synthesising and theorising – themes were identified (Thorne *et al.* 1997). Transcripts were then re-read several times and

the selected themes were finalised based on consensus discussion between three study authors (SMA, AS and KOS). Four categories were identified to account for all identified themes. Throughout data collection and analysis, widely accepted strategies for ensuring quality in qualitative analysis were maintained, including auditability, fit and transferability (Lincoln and Guba 1985). The consolidated criteria for reporting qualitative research (COREQ) checklist provided guidance during the reporting of this study (Tong *et al.* 2007). To facilitate the rigor of methodology and the transparency of the research process an audit trail was created. Audit trails are a principal technique for establishing the dependability and confirmability of qualitative research findings or to help in assessing the degree of trustworthiness of a naturalistic inquiry (Lincoln and Guba 1985, Bowen 2009).

RESULTS:

Participants

Eight participants (five male and three female) with AT were invited to participate in the telephone interviews. The sample size of eight participants reflects the time constraints associated with the intervention study, and the feasibility regarding recruitment. The use of an interview study design and a flexible questioning route ensures no restriction on learning about individual experiences. Table 1 details the characteristics of the included participant's. Elements of the audit trail are detailed in supplementary file 2.

Key themes

Four main themes were identified from the data: (i) pain as a feature of everyday life; (ii) participant's experience with the management process; (iii) identifying with and self-managing AT, and (iv) looking to the future. Table 2 presents the categories constituting each theme.

Table 1: Characteristics of the study participants

Participant	Age (Years)	Height (Cm)	Mass (kg)	VISA	Unilateral/Bilateral	Mid Tendon/Insertional	Sex	Symptom Duration (Months)	Running per week (Minutes)
1	36	170.5	71	83	Bilateral	Mid Tendon	Male	5	210
2	39	158.4	79	38	Bilateral	Mid Tendon	Female	17	0
3	49	160.4	59	54	Unilateral	Mid Tendon	Male	5	0
4	37	170.3	71	78	Bilateral	Mid Tendon	Male	96	200
5	39	169.7	65	73	Bilateral	Mid Tendon	Male	7	215
6	51	160.0	50	74	Bilateral	Mid Tendon	Female	17	95
7	33	191.7	106	28	Unilateral	Mid Tendon	Male	8	0
8	36	174.1	73	81	Unilateral	Insertional	Male	9	360

Table 2: Identified Themes

Pain as a feature of everyday life	Participant's experience with management process	Identifying with and self-managing AT pain	Looking to the future
<ul style="list-style-type: none"> • <i>Pain and daily activities</i> 	<ul style="list-style-type: none"> • Treatment experience 	<ul style="list-style-type: none"> • Beliefs surrounding causation 	<ul style="list-style-type: none"> • Fear of the future prognosis
<ul style="list-style-type: none"> • Loss of self 	<ul style="list-style-type: none"> • Frustration with treatment process 	<ul style="list-style-type: none"> • Rest as a management approach 	<ul style="list-style-type: none"> • The desire to run

Theme 1: Pain as a feature of everyday life***Pain and daily activities***

Many participants stated that the pain associated with AT resulted in a substantial highlighted their experience of pain and the ability to perform daily activities. The physical disruption was varied and contingent on participant's symptoms, however morning pain and its associated consequences was a commonly cited issue.

“But in the morning times in particular, very sore in the mornings. You're literally hobbling around the place until you get moving as such.” Participant 8

*“The morning pain oh its constant. I'd say I haven't had a morning since the start of the year where coming down the stairs i haven't been very tentative about it.”
Participant 5*

While symptoms did not cause disruption at work for all participants, it did have significant consequences for some individuals, depending on the demands of the job. One participant reported not working due to their symptoms, while others reported the pain with their daily work routine.

“Aww, it's just when you have to go anywhere, walk around the office, walking to go get a coffee. You get up; you've forgotten about it sitting down ... once you get up it's like ouch. Then you're almost limping everywhere. It's noticeable enough in that people would say are you all right, what are you limping for”. Participant 5

Loss of self

AT could also affect personal activities, with participant's highlighting the implications of giving up recreational activities (e.g. running) on their social life and sense of personal achievement and sense of self.

“Frustration, needing Wanting to run. Seeing my peers going to races, winning races or getting PBs. Progressing ... and I'm stuck here. That has been horrendous I

have to say. Now, I know there are worse things in life that can happen. But it's been horrible." Participant 6

"I get frustrated with myself, you know like feels there nothing at the end of the tunnel you know like. Like I'm not saying me life is around the running but Like I was an alcoholic and I haven't had in drink twelve and a half year ago. And i took up running and it's me life since, you know like." Participant 3

Theme 2: Participant's experience with management process

Frustration with treatment process

Participants frequently outlined their frustration with the treatment process as well as outlining their lack of confidence in the various health care practitioners they had encountered.

"For me there were a lot of grey areas. Everybody was giving me, like telling me different things. So like nobody knew 100% everything about Achilles and it was varying, you know people opinions were varying." Participant 2

Experience with treatment process

The participants expressed the belief that, in order for a treatment to be beneficial, a forceful hands-on treatment was required.

"He wore a kind of a knuckle duster and really rubbed them hard. And I think that's the only thing that got rid of the morning stiffness." Participant 6

Participants also highlighted the expected role of exercise interventions in the management of their AT.

“but i know there are some exercises you should be doing and things like but that. I probably haven’t done as much strength work. I don’t go to the gym. I don’t do any strength work or anything like that.” Participant 1

However, in contrast participants also discussed their disbelief and lack of confidence in relation to a proposed exercise intervention.

“There was a therapy that was recommended to me maybe at the start of the year, it was called heel drops or painful heel drops? They’re on the edge of the steps and you basically flex, you basically flex down and flex up...Was it 10 minutes a night every night for 12 weeks but in my head that was crazy.” Participant 5

Theme 3: Identifying with and self-managing AT

Beliefs surrounding causation

Participants outlined a range of factors which they felt were associated with the onset and development of AT.

“It might be just maybe the step up in miles like. Might be the miles. Might have gone too... gone from 40 miles up to 70 miles too fast kinda.” Participant 3

“Obviously there’s some weakness there i suppose. Or some, or is it down to running style or something. Footwear yeah”. Participant 2

Despite the numerous factors proposed by participants there was also a considerable amounts of confusion in relation to the causation of AT.

“I don’t know. It’s a question people often ask. Definitely people would say to you it’s an overuse. And well I’m not doing enough for it to be overuse. That’s what wrecks me.” Participant 4

Rest as a management approach

Rest was often cited as a self-management strategy in many of the interviews. Often participants expressed the belief that rest would be appropriate in allowing the pain to settle or ensure that time necessary for healing. The adoption of this management approach was as a result of participants own belief system or as a result of advice from health care practitioners or non health care practitioners.

“I possibly didn't rest it enough. That's the only assumption I can come up with that I didn't rest it enough Yeah. As in I've stopped running altogether in the hope that the rest will allow it to recover. The problem is its back to the whole thing of not knowing is that the problem.” Participant 5

However the concept of rest as a successful management approach was also contradicted in some of the interviews where participant's outlined their lack of belief in rest as a management approach and expressed a desire to continue running despite this advice.

“I've gone to a lot of physios and they tell me its an overuse injury but I don't think it is 'cause I've stopped. People say stop and don't do anything for 6 or 8 weeks but if I did stop and went back even for a jog a couple of miles after not doing anything for a period of time id still be in pain like it never stopped.” Participant 4

Theme 4: Looking to the future

Fear of future prognosis

A common theme reported in the study was fear, concerns and uncertainty surrounding potential future damage to participant's Achilles tendon. Many participants felt that if they continued to exercise and or failed to address their AT it may lead to greater disability but more specifically the risk of rupturing their Achilles tendon in the future.

“Yeah it could like. It probably... I’d be thinking that like. By running on it as it is, i think it would. It might get to the stage where it will rupture... If I don’t get it fixed like.” Participant 3

The desire to run

During the course of the interviews participants were asked to discuss what they would define as a cure in relation to their AT. Some participants spoke about reduction of pain.

“Being able to go to a class and not have pain like after a class. Being able to touch my heel without it being painful is a big thing. That would be it really, not to have pain really.” Participant 2

However, the majority of the participants outlined their desire return to previous running levels or even re-engaging in running to some capacity.

“I suppose being able to get back to running in some shape or form. In an ideal world obviously back to full health and going back to running marathons again. But at the other end of the scale being able to run in some shape or form, any distance just to get out and something.” Participant 7

DISCUSSION:

The prime focus of research and scientific investigation to date in AT has utilised quantitative methodologies which has helped improve the management of the physical impairments associated with AT. Despite the relative success of such approaches, AT can often remain resistant to treatment, and dominance of peripheral tissue focused interventions are unlikely to address complex psychosocial adaptations associated with persistent pain (Rio *et al.* 2015, Mallows *et al.* 2016). This is the first study to utilise a qualitative methodological approach in AT to investigate participant's beliefs and experiences of AT. Four main themes emerged from the data: (i) pain as a feature of everyday life (ii) participant's experience with the management process; (iii) identifying with and self-managing AT and (iv) looking to the future.

The psychological burden of AT and the loss of self

One of the main findings of this study highlighted the physical, emotional and social disruption associated with persistent AT. Participants reported disruption and change in their ability to perform and engage in normal daily activities. This was particularly evident in the morning, with participants also describing an extension of physical symptoms into their daily work routine.

Perhaps of most interest was the effect of persistent AT on individual's social and emotional wellbeing. Pain and injury is often a traumatic event where emotional and psychological reactions are produced, often based on an individual's perception of loss (Green and Weinberg 2001). Although the concept of a perceived loss affects individuals differently, injury or pain can often prevent an individual from pursuing a self-defining activity. As a result, they are particularly vulnerable to a milieu of psychological reactions such as anxiety, depression, fear, and loss of self-esteem or identity (Brewer 1994, Smith 1996, Green and Weinberg 2001). A common theme highlighted in the interviews was participant's experiences of giving up recreational activities (e.g. running) on participant's social life, and its effect on the participant's sense of self. The disruption to social and recreational activities experienced by participants may be closely attributed to reductions in individuals self-esteem or loss of what is known as athletic identity. Individuals who are intensely involved with

athletic activities (e.g. running) and receive encouragement for their participation may focus their self-identity on the role of an athlete (Rotella 1993). If an individual then becomes injured, his or her identity might be threatened due to the inability to fully engage in athletic pursuits which may lead to emotional and psychological reactions, which are typically negative (Green and Weinberg 2001). Results of the current study suggest that in individuals with persistent AT, the inability to engage in recreational or athletic activities may result in loss of an individual's identity. Similar findings have been expressed in other qualitative MSK studies in adults with Osteoarthritis (OA) (Turner *et al.* 2002, Maly and Krupa 2007, Ong *et al.* 2011, MacKay *et al.* 2014).

Cognitive appraisal and associated coping strategies in AT

Research exploring the psychological consequences of injury suggests that once an injury occurs, an individual begins a process of cognitive appraisal resulting in the generation of emotional and behavioural responses (Albinson and Petrie 2003). The cognitive appraisal may involve two processes; primary and secondary appraisal. For the primary appraisal, the individual asks, "Is this harmful to me?" Once this initial assessment is made, the secondary appraisal begins with the question "Will I be able to deal with this situation, and, if so, how?". The concept of primary appraisal was highlighted in the current study where participants consistently reported concerns and fears surrounding potential future damage and/or risk of rupturing their Achilles tendon. In order to deal with this situation, participants commonly outlined a view that rest was a necessary management strategy in order to allow the tendon necessary time to heal and prevent what they perceived as future potential damage. This avoidance as a result of a cognitive appraisal by decreasing physical activity levels was in spite of the associated negative effect on their recreational activities and identity as outlined previously. Such concerns or associated behaviours may be labeled fear-avoidance beliefs. The concept of fear avoidance beliefs was first proposed in the Fear Avoidance Model (FAM) of musculoskeletal pain (Vlaeyen and Linton 2000). According to this theory, some individuals consider a painful stimulus as negative, and avoid or postpone the event that is considered painful (Sindhu *et al.* 2012). Over a long period of time, hypervigilance and avoidance of physical activity may result in deconditioning or atrophy of the musculoskeletal system (Littlewood *et*

al. 2013). Ongoing fear, anxiety or catastrophising regarding one's Achilles tendon (fear of damage, apprehension about loading the tendon, distress due to restricted activities) may lead to ongoing sensitisation of the central nervous system. This may ultimately affect pain and/or motor output or reinforce avoidance of loading their Achilles tendon. Research in other persistent MSK conditions has highlighted the negative influence of fear-avoidance beliefs on recovery times (Landers *et al.* 2008, George and Stryker 2011, Westman *et al.* 2011, Kromer *et al.* 2014, Ross *et al.* 2002). However, the process and outcome of cognitive appraisal is highly variable between individuals. Despite a dominance of fear and restriction of activities within the study, some participants outlined their desired to continue to run despite the pain which would appear to contradict the FAM and highlights the diversity of individuals response to pain. Additionally, cognitive appraisal and associated behavioural responses are influenced by societal factors and social support (Green and Weinberg 2001). Social support appears to facilitate the coping process by providing additional resources such as advice, information, and material services that could increase an individuals coping resources (Pearson 1986). Results of this study appear to indicate that participant's beliefs surrounding rest and its potential role in the development of fear avoidance beliefs may have been contributed to by advice from health care practitioners and non- health care practitioners.

Active interventions in AT: The need to combine exercise with pain reconceptualization

The variability in participants' perceptions in terms of coping strategies was further reiterated in participants' experience with the treatment process. The concept of rest expressed by many of the participants in the study appeared to be contradicted by some participants who highlighted the belief that forceful hands on treatment was beneficial for their AT. Despite this, many participants expressed their frustration at their experiences with the management process to date. Interestingly despite the evidence to support the use of strengthening interventions in AT (Alfredson *et al.* 1998, Malliaras *et al.* 2013, Beyer *et al.* 2015), few participants reported a history of, or a belief in, the use of strengthening interventions. This finding highlights the potential importance of aligning exercise prescription and instructions with the key messages of pain education in AT. The manifestation of avoidance behaviours as a

result of cognitive appraisal resulting in avoidance of loading a painful tendon would seem a sensible approach given that pain is normally a necessary protective mechanism by your body. However, while relative rest and avoidance of loading a painful tendon may be appropriate in the early stage of AT, research suggests that progressive strengthening interventions in AT may be important to improve pain and disability. Thus, **prescribing exercise interventions to individuals without spending appropriate time rationalising their importance using pain neuroscience education may affect compliance with an exercise program. Pain neuroscience education is a** cognitive approach which seeks to change beliefs and cognitions related to pain (Blickenstaff and Pearson 2016). It appears that when individuals understand more about pain neuroscience they will alter the manner in which they approach movement, exercise and activity (Blickenstaff and Pearson 2016). Pain with movement is no longer seen as an experience to endure, or as an experience from which to flee or avoid (Blickenstaff and Pearson 2016). Pain neuroscience education has been shown to be effective in changing pain beliefs and improving health status and reducing healthcare expenditure in chronic pain disorders (Moseley 2002, Moseley 2004, Meeus *et al.* 2010, Louw *et al.* 2011, Louw *et al.* 2014). Unfortunately the concept of aligning pain education with rehabilitation of MSK disorders is still relatively new, with research to date focused mainly on chronic spinal conditions (Moseley 2002, Louw *et al.* 2014).

Limitations

There are a number of methodological considerations that may influence the generalisability of the research. One potential limitation relates to the recruitment of the participants which may have resulted in “volunteer bias”. Participants included in this study were predominantly athletic or recreationally active, interviewed prior to engaging in an exercise intervention. The fact that these participants were willing to engage in an exercise intervention study may indicate that these participants displayed similar views and experiences relating to their AT pain, and were at least willing to consider an active intervention for their AT. This affects the generalisability of the results considering the prevalence of AT in non-athletic populations. A further limitation relates to the **sample size of the study.** As a result of time constraints it was not possible to perform additional interviews, which may have provided further

insights. Another limitation of the current study relates to patient and public involvement (PPI). The interview route was designed through a process of consultation amongst the study authors, with interviews undertaken by a final year undergraduate student. Although the interviewer did probe other issues that arose and encouraged people to discuss whatever they felt pertinent, participant's data was not used to inform future questioning and is a potential limitation of the study. Finally, the sample set of participants recruited for this study excluded individuals with acute AT which may have gone on to be resolved and their experiences may not be reflected in the current sample.

Conclusion:

Research in AT has mostly focused on the associated physical impairments utilising quantitative means. Despite the often persistent nature of AT, no studies have look at the psychosocial aspects of AT using qualitative methods. This study suggests that persistent AT is associated with a significant psychosocial burden, particularly in terms of participation in daily life and valued activities. Considerable confusion and frustration regarding management of AT, and its course, were reported. Better understanding the personal experiences of AT may enhance management of this persistent disorder, and facilitate individuals with AT complying with evidence-based approaches including exercise and pain reconceptualization.

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Highlights

- Research in tendinopathy has focused on the physical impairments utilising quantitative means.
- No study has qualitatively investigated the psychosocial aspects of Achilles tendinopathy.
- Persistent Achilles tendinopathy is associated with a significant psychosocial burden.
- Understanding experiences and personal impact of Achilles tendinopathy may enhance management.