



From data collection to intervention development: A qualitative study of older people's experience of living with neurogenic claudication

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Abstract

Purpose

The aim of this study was to explore older people’s experiences of living with neurogenic claudication (NC), their preferences for physiotherapy treatment provision and associated outcomes, and to aid development of a testable intervention.

Method

Patients with a diagnosis of NC and/or lumbar spinal stenosis were recruited through a UK NHS tertiary care centre. We used a combination of semi-structured interviews, photo elicitation and a self-report questionnaire to obtain data. We undertook a thematic analysis.

Results

We recruited 15 participants, half of whom were classed as frail older adults. Pain and the threat of pain was a prominent feature of participants’ experience of NC. This led to both a loss of engagement in meaningful activities and a positive sense of self. Discourses of ageing influenced experiences as well as treatment preferences, particularly the acceptability of walking aids. Participants expressed preferences for a mixture of one-to-one and group settings for treatment. Outcome preferences related to re-engagement in meaningful activities, re-gaining a positive sense of self and pain reduction.

Conclusion

We have obtained important messages about older people’s experiences of living with NC and preferences for treatment and outcomes which will be incorporated into an evidence-based intervention to be evaluated in a randomised controlled trial.

Introduction

Active independence is one of the key concerns of older people, and they identify mobility as critically important to this [1,2]. Globally, Low Back Pain (LBP) is the most common cause of disability [3]. Worldwide prevalence of LBP increases with age and is strongly associated with immobility, disability, frailty and falls [4,5].

There is a large body of research in LBP, but this has focused almost exclusively on younger people. Although LBP is painful and results in spinal immobility in younger people, the impact of LBP in older people is more serious, with recent epidemiological studies suggesting a strong association with immobility, disability, frailty and falls [4,5]. There is a critical and recognised need for researchers to study LBP in older people, to generate new intervention strategies, and evaluate the effect of LBP treatments in older populations [6].

In younger populations, non-specific LBP is the most common spinal diagnosis and one which recognises that it is difficult to pin point a cause of symptoms. In later life, specific causes of symptoms become more apparent. Lumbar Spinal Stenosis (LSS) and the associated symptoms which are termed neurogenic claudication (NC) result from age-associated, degenerative changes [7] and a narrowing of the spinal canal which causes pressure on the nerve and blood vessels within the spine [8]. Symptomatic LSS (herein referred to as NC) is known to have a significant impact on a person's ability to walk and stand, and ability to carry out day-to-day activities essential for daily living [9-11].

Surgery is one treatment option for people with NC. It helps some people but not all and exposes older people to considerable risk of complications (including wound infection and

cardiorespiratory problems) [12,13]. Clinical guidelines state that despite an absence of reliable evidence, physiotherapy is an option for patients with lumbar spinal stenosis [14]. Cardinal and well validated signs of symptomatic NC are alleviation of symptoms on flexion of the lumbar spine, a technique which can be used to provide some short term alleviation of symptoms.

As a prelude to a programme of research on NC in older people, including the development and evaluation of a physiotherapy intervention, we have undertaken a qualitative exploration of older patients' experiences of living with NC, including the impact of the condition in the context of ageing, multi-morbidity and the perceptions/acceptability of different types of treatment.

Methods

Qualitative and quantitative data was generated using semi-structured interviews, Photo Elicitation (PE) and a self-report questionnaire. We used semi-structured interviews because, when questions are open-ended, neutral and sensitive to the interviewee, they are an ideal way to explore patient's experiences from their perspectives [15]. Furthermore, interviewing patients is a patient-centred approach to research and clinical care, the adoption of which improves patient experience and clinical outcomes [16].

Taking a patient-centred approach to interviews recognises that participants are 'meaning makers' of their own experiences. Methodologically, this approach is known as social constructivism [17]. An important aspect of social constructivism is the recognition that researchers do not necessarily share the same sets of assumptions, understandings and meanings as their participants. Therefore care is taken to question taken-for-granted or

seemingly ‘common-sense’ perspectives in order to gain deeper understandings of a participant’s world-view and their experiences. Furthermore adopting a social constructivist methodology requires the researcher to take into account his/her subjectivity and positionality (social distance, class, gender, ethnicity etc.) and that of the researcher. In qualitative research denying the relevance of subjectivity and positionality does not serve the research process. Another important means by which research participants’ experiences can be better understood is to recognise that they do not just inhabit certain social identities (such as being old or having NC) in a fixed or static manner but that others such as their gender, ethnicity, social class, sexuality and disability can intersect to inform their experiences in complex and fluid ways [18].

Interviews were organised around three main research questions:

- 1) What are the experiences of older people who suffer from back pain and leg symptoms as a result of NC?
- 2) What types of physiotherapy treatments (content and method of delivery) are preferred by individuals with symptoms arising from NC?
- 3) What outcomes are most important to patients when evaluating if these treatments are effective?

Interviews lasted between one and three hours and the interviewer took care to organise the practicalities of the interview in a way that supported participants’ management of their condition. We met recommended conditions for generation of qualitative data by ensuring that active listening techniques were used, with dialogue, to seek clarification and expand information [17,19].

During the interview we used PE to engage participants in our second research question. PE helps to overcome some of the methodological problems associated with interviews such as researcher-centric questions and/or the lack of shared knowledge about the subject matter [20]. We selected images of older people participating in a range of physiotherapy treatments including assisted stretches, manipulation, acupuncture, independent exercises such as cycling and weights, and, using wheeled walking frames and sticks which are commonly prescribed by physiotherapists. We deliberately chose pictures that showed older people in what we considered to be a positive light, for example images where older people were exercising and smiling. We also consciously chose to represent a range of ages, ethnicities, both genders and a variety of body types. In so doing we hoped to provoke a sense of inclusion amongst participants and that they might consider the possibility of physiotherapy treatments for older people with NC.

Questionnaires were given to participants at the end of the interview and were completed and returned to the research team by post. The questionnaire asked for demographic data such as gender, class, age, ethnicity and occupation, co-morbidities and measured levels of frailty (using the Tilburg Frailty Index [21,22] disability (using the Oswestry Disability Index [23] and symptoms (using the Swiss Spinal Stenosis questionnaire [24]. Neither the qualitative nor the quantitative data in this study is committed to generalisable findings but instead seeks to gain in-depth knowledge about participants' experiences of NC and their physiotherapy treatment and outcome preferences.

Recruitment

All participants had received a diagnosis of NC, LSS or both and were either referred to the research team by physiotherapists working at a tertiary care centre or self-referred in response

to recruitment posters in the same care centre. We reached data saturation after 12 participants had been recruited; we recruited another three for confirmation. No new themes emerged and so recruitment stopped.

Analysis

A thematic analysis was undertaken by a researcher carrying out the interviews (SL) in conjunction with another member of the research team (EW) to ensure the account produced was credible. SL is a sociologist and EW is a research physiotherapist. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within participants' interviews and provides a tool to organise and describe interview transcripts thereby turning them into data [25]. SL and EW held regular meetings both during the interview stage and during analysis and reporting stages. The discussion of themes and codes was iterative, as SL continued with interviews whilst revisiting previous interviews and reading relevant clinical and sociological literature. We used NVivo (V10.0, QSR International), a computerised programme for analysing qualitative data, to assist analysis. To aid the interpretation of data, discussions of the analytic process and findings were shared within the wider research team thereby enabling opportunities for critical reflection and further analytic refinement.

Results

We recruited 15 participants; nine male and six female with a median age of 75 (Inter Quartile Range 69 – 80) (table 1). The majority of participants (n=10) lived with a partner or spouse whilst the rest lived alone. Approximately half of the participants were classified as 'frail' based on the Tilburg Frailty Index and all reported suffering from health conditions in addition to their spinal problems. The most commonly reported comorbidity was high blood pressure followed by hearing and vision problems, osteoarthritis and high cholesterol (table

2). Participants reported a wide range of disability related to their spinal problems with Oswestry Disability Index scores ranging from 7.5% (minimal disability) to 62.2% (severe disability). All the participants were retired apart from one who was still in full-time employment.

Insert table 1 here

Insert table 2 here

Participants’ experiences of living with Neurogenic Claudication

We asked participants to tell us about the problems that they had been having with their back and legs. Pain in the lumbar region, buttocks and radiating down one or both legs were the primary symptom reported. Participants were vague as to when their symptoms had first started and most participants reported they had had some lower back pain during their lives. However all participants described incidents when the onset of symptoms of NC had been sudden and acute. During these incidents pain was described as ‘excruciating’, ‘like a nail driven into their spine’, ‘horrendous’, ‘worse than labour’ and as ‘the worst pain’ they had ever had:

It was New Year’s Eve, I was in terrible, terrible pain...I was you know, practically climbing up the wall, um couldn’t sleep, couldn’t do anything (Participant 24).

There’s one time when I went [for a walk] and I had to lean on this gate and I was hanging onto it and a neighbour asked, “are you alright?” and I said “no I’m not, I’m struggling”, “well”, she said, “I’ll help you”. Then another neighbour came past and between them they got me home but my legs get so weak so easily and they give way (Participant 6).

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3 These incidents subsequently proved to be defining as they provided participants with the
4 impetus to seek medical help. After the defining incident, participants' pain fluctuated on a
5 spectrum of severity and longevity. At the time of interview some participants' symptoms
6 had dampened down to a low level while others were still severe.
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14 When asked about the impact that symptoms had on their lives all participants made explicit
15 links between their pain experiences and their activity levels and, as a consequence, their
16 ability to lead their usual lives.
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20 21 22 23 *Severe pain and activity levels*

24 Severe pain made daily activities such as cooking, cleaning, self-care, shopping and
25 socialising difficult and sometimes impossible. For participants living with severe pain daily
26 life, as they framed it, had ceased. Severe pain resulted in reliance on partners, friends, and
27 family members. These limitations were not just inconvenient but negatively disrupted the
28 usual balance of their familial relationships:
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36 I get so bored sitting about and that I'd rather be on the go all the time. I can't do
37 nothing, nothing to help the wife or working... I used to be able to do all the
38 hoovering, get the dinner done and tidy up in the garden...I mean why should I leave
39 it all up to her to try to do everything. It's not fair on her (Participant 18).
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47 Participants described how the changes in their ability to carry out their usual activities also
48 altered their sense of themselves because 'who they were' was closely connected to what they
49 could do:
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54 I'm usually a very sort of active person and you know I'm used to, if I wanted to just
55 do something I would just get up and go out and do it (Participant 8).
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All but one participant had retired from working life. Those in the early years of their retirement expressed frustration and disappointment that their hopes for this period of their lives were dashed which was a further challenge to their sense of self:

I can't do things that I would like to do. I retired about a year ago and my plan when I retired was to join the Ramblers. I don't think [retirement is] all it's cracked up to be really but that's partly, or mainly because I can't do what I want to do...and that's quite upsetting. I can't do what I want to do. I'm not a lazy person. Um but I think it's um, I've had to become a lazy person (Participant 17).

Mild to moderate pain

At the point of interview many participants were some time from their defining incident. These participants reported that their symptoms gave them pain which fluctuated between mild and moderate but were manageable:

Um it hurts [laughs] that's... but I can manage it hmm, um I just wish um... I can't... I can't really um do the sort of exercises I'd like to do actually. Um I... I... I'm perhaps not as fit as I'd like to be because um I think its... it limits me or I feel it limits me anyway in what I can actually do (Participant 22).

These participants judged that, despite feeling able to manage the pain, their symptoms did negatively impact on their activity levels and this reminds us that when providing treatment we should consider those with mild and moderate symptoms as well as those whose symptoms are severe.

Living with fluctuating symptoms

A high degree in fluctuation of symptoms forms a normal clinical picture of NC [26]. All participants reported that symptoms fluctuated over the course of a day, a week and across months and that fluctuations in symptoms were a difficult aspect of the condition. Living with fluctuations was difficult because the symptoms did not appear to make sense in relation to activity levels:

There appears to be no rhyme nor reason or you can't say I'm going to get a bad back or my legs are going to ache more than because something's happened somewhere um you just can't put your finger on it. I can't put my finger on it (Participant 7).

I just can't sort of um connect... see a reason, I mean I could go out now and I could you know walk and it might be alright, on the other hand I could go outside the door and it kicks in (Participant 15).

For some participants their symptoms were seemingly unpredictable and fluctuated which led to them feeling as though they were living with the ever present threat of pain. This threat of pain led to a curtailment of activities even when symptoms were low:

You just don't know how you're going to be, you keep putting things off because you just don't know how crucial it's going to be at the time as it comes because there is no just knowing how bad it will be (Participant 8).

A few participants had limited success in adopting techniques such as pacing and flexion to manage their symptoms:

Yes I walk [to the supermarket] every day. Sometimes there's a seat in there. I walk down there and if I feel a bit uncomfortable I sit down, I sit down for about two minutes get up and away I go in me own style. I'm not walking properly, I know I'm

not walking properly but I'm getting around.....I [hadn't] had it for about oh say a month or something like that and that was good I thought I was getting rid of that, I'm still stiff and it's come back and I think oh blimey, oh no (Participant 10).

Overall most participants did not adopt such techniques despite recommendations from their physiotherapist and reported trying to do as much as possible for themselves until the pain overwhelmed them. Pain and the threat of pain directly limited their mobility and therefore their ability to live their life in the way they wished to.

Being unable to reliably manage their symptoms meant that participants felt as though they were unable to be spontaneous, plan for future activities or take part in regular activities that were meaningful to them. This resulted in less participation in family life, socialising with friends, taking holidays and engaging in hobbies that required more than sitting down. All of these changes impacted on their emotional as well as their physical well-being and therefore relations with those closest to them as well as their sense of self as Participant 18 reported:

Yes [symptoms are] upsetting. Um I find myself getting a bit anxious, sometimes a bit tearful um yes because it's not onlyit's not only spoiling my life but its spoiling his [husbands] as well [crying] I am normally quite a strong person and uh I keep sort of looking around me and you see things on the television and you think well I can still do so much, I can still move around to a certain degree, I can still you know have a conversation with somebody, I can still you know therefore I feel, I feel guilty at feeling sorry for myself (Participant 18).

Making sense of symptoms

Participants found it difficult to make sense of their symptoms in relation to their daily activity levels. Instead, they situated their symptoms in the context of their spinal health as well as to their life stage. Most participants said that LBP had been an intermittent feature of their adult lives and viewed their symptoms as an extension and worsening of their spinal health. The vast majority of participants did not identify their condition with age-related changes which is in contrast with the clinical perspective that NC due to LSS is strongly associated with age-related changes to the spine. Indeed all but one participant expressed ambivalence about the relevance of their age in relation to their symptoms:

Well I think that you can say certain things are due to old age and some things are not and I'm trying to sort out the bits which are not and do something about it (Participant 12).

Ambivalence about ageing was conceptualised in two main ways; either doom laden, or as a time of upbeat activity and renewal. Retirement was conceptualised as a time of renewal in which participants thought that retirees were supposed to make the most of their new found freedom by busily engaging in leisure activities or other life projects. In contrast to this upbeat version of older age participants were also aware of the ways in which it was stigmatised as a time of inevitable decline, of poor health and social isolation. At the same time, as the quote below illustrates, neither of these two versions of old age were thought to map neatly on to chronological age:

Well I think [ageing] is definitely, its doom laden isn't it, you know, there's no hope. [but] I've met people in their 80s and 90s and they're as bright, they're still active in their work, the research or whatever they're doing in their 80s and 90s...and yet you

can find other people in their 40s and 50s and they've [laughs] got one foot in the [grave] (Participant 15).

Preferences for mode of treatment

Participants were asked to comment on whether they would prefer to receive treatment in a one-to-one appointment or in a group with other NC sufferers. All participants stated a preference for a mixture of one-to-one time with a physiotherapist and group exercise. One-to-one time with a physiotherapist was thought to be an important prerequisite for treatment as it would allow the therapist to really understand the participant, their condition and circumstance.

Participants liked the group exercise class for the opportunities they thought it would present for peer-to-peer support and socialising. However a number of participants were worried that some individuals might dominate the group classes and over-share their health concerns. Consideration was also given to the efficiency of resources that a group might bring, although this came with caveats that too many people in a group might be inefficient if they were sharing equipment. Despite the benefits of a shared class, participants believed that regular attendance at classes was likely to be difficult for a number of reasons. For example, all participants said that too much physical activity could trigger their symptoms and that taking part in an exercise class would be impossible if they were having a bad pain day (despite previously being unsure as to what might trigger symptoms). The lack of reliable public transport, the cost and lack of hospital-based car parking, and the need for someone to take them to classes were all reasons given for the difficulty to participate regularly in exercise classes. It was for these reasons that participants argued the need for very local or highly accessible class venues. Although participants could see a number of potential barriers to

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3 their participation in a group exercise class this did not translate into a greater desire for the
4 alternatives; more one-to-one appointments with a physiotherapist or home-based exercises.
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10 Having a fixed appointment was thought to be important as it would compel participants to
11 attend regularly. Participants thought, based on their past experiences that they wouldn't have
12 enough self-discipline or confidence to keep up with regular exercises at home. Participants
13 knew from ongoing experiences of physiotherapy that they were supposed to continue with
14 unsupervised exercise but offered reasons as to why they had not. The reasons centred on a
15 lack of confidence in; the physiotherapist (who had not properly either understood their
16 condition or prescribed their exercises), their own ability (to carry out the exercises safely),
17 and their belief that physiotherapy exercises could help them. However, those few
18 participants who had had positive experiences of physiotherapy rehabilitation for other
19 conditions were open to the possibilities that physiotherapy may be able to help with their
20 current symptoms. When participants who had previously been able to sustain unsupervised
21 exercise were asked how they had done that, the participants attributed it to their confidence
22 in the individual physiotherapist. This confidence in a physiotherapist combined with a
23 treatment plan was qualities which met the participants' perception of what constituted a
24 'good' physiotherapist. These judgements were often made very early on in their encounters
25 with therapists and were described in nebulous terms:
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45 P: I mean when I first went to [name of therapist], I mean I knew, you know in a few
46 minutes that she knew what she's doing.
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49 SL: How did you know that?
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51 P: Just did. Well you know the way she went about things in a very professional way
52 and she explained... explained what she was doing and why she was doing it. It was
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just something that you just... I felt that she knew what she was doing (Participant 15).

For participants, a display of empathy, feeling listened to and a sense that time and care were being taken were important cues that they were in safe hands and it was these points which ultimately contributed to their commitment to exercise unsupervised.

The role of walking aids

During the PE section of the interview participants were asked to comment on which treatments and exercises they thought would help their back and leg pain. Participants who reported that they were in a great deal of pain said that they would do anything to improve their symptoms. However, such strong statements were undermined by preferences which ruled out the possibility of doing exercises if they were having a bad pain day or on the use of walking aids. Walking aids form part of the armoury of treatments available to physiotherapists and were featured amongst the pictures that were shown to participants. The pictures of people using walking aids provoked a very strong reaction. The first image was of two older women using walking sticks and the second image was of an older woman using a rollator (walking frame with wheels). All but one participant, who used both types of walking aids at the time, utterly rejected the possibility that a rollator was an acceptable form of treatment for their condition. The reason given for this rejection was that the rollator was unambiguously associated with an undesirable form of old age which signified that the person using it was frail, dependent and close to death.

I just can't think about it yet. When I saw [Physio] you know she suggested oh a frame or a walking stick, I thought gosh you know [laughs] the psychological effect

of that is that you know you are... you're becoming a victim of it and you're taking all these devices too, it's a downward road, psychologically you see (Participant 7).

Participants could see how they were helpful for 'other' older people but it was not something that was for them. The two images provoked a lot of discussion around the significance of appearance and its relationship to both positive and stigmatised versions of old age as the following quote explicitly states; appearance matters:

Being old isn't a problem *per se* it's being *seen* to be an old person isn't it? (Participant 17).

In some cases the use of walking aids was necessary for mobility but their use of them is very carefully considered in order to protect the participant from the potentially negative judgement that she associates with the use of walking aids usually associated with older people:

[a rollator is] an old person's tool and yes I know that I'm getting on a bit but that to me is the thin end of the wedge isn't it. I can't see myself walking round the shop pushing one of those. If I walk round the shop with my crutches, which I do if [husband] is with me I could just possibly have sprained my ankle or something. I'm not an old person with a back problem (Participant 17).

Those participants who currently used walking sticks had done so reluctantly and had undergone some degree of identity work that usually involved reflection, negotiation and reorientation towards using a stick following fall-related incidents. This included making the walking stick a positive extension of themselves, a male participant did this by using his

considerable wood carving skills to make his own stick while a female participant did this by purchasing a pretty floral stick that she could discretely fold away in her handbag:

I don't take kindly to um, medical or sort of physical intervention unless I have to, I'm very naughty. They suggested walking stick I said yeah, they gave me one at the physiotherapy department and I thought I'm not an old lady, I'm not having this sort of thing, you know. Used it when I had to and then my son laughed, he said go on mum, get yourself a pretty one you'll feel better, so I have, I've got myself a pretty one that folds down (Participant 23).

In these ways some participants were able to inscribe an otherwise stigmatised walking aid into something with more positive attributes.

Preferences for outcomes

We asked participants what their outcome preferences would be if they took part in a physiotherapy-based intervention. Given the participants' pain experiences and the impact that these had on their lives it was not surprising to learn that participants' outcome preferences were focused on getting rid of the pain in their back and legs. Most participants stated that they wanted to get rid of the pain completely as that would then enable them to get back to their normal activities for example cooking, walking for leisure and purpose, being an active grandparent, gardening, DIY and being spontaneously active enough to socialise. These activities were strongly related to an individual's sense of self in relation to their biography:

[Now] I can't walk any distance. I've never been one for sitting on my arse and waiting for other people to do things for me. Frustrated, frustrated. I've always been active all my life (Participant 20).

Others implied that getting rid of the pain completely was unlikely and that they would be happy if they could get rid of just some of the pain so they could do more of the activities they wanted to:

I'd like to walk further than I can now. In an ideal world I would like to be able to go fell walking like we used to, I know that's not going to happen but just being able to say take a walk down the village and past the Church and across the field and back would be great (Participant 17).

In lieu of not being able to get rid of the pain, some participants wanted to learn how to cope better with their pain and how to increase their mobility. Participants who were not currently in acute pain wanted to learn how to avoid another acute episode in the future.

The final question we posed to participants was "If you had a magic wand which of your health problems would you magic away first?". All but one participant said that they would magic away the symptoms of NC thereby prioritising it over their other health conditions such as atrial flutter, ileostomy, hearing loss, diabetes, high blood pressure and hypertension. Participants argued that they handled all of these other health conditions fairly easily and felt that these were well managed in partnership with health professionals. This finding is consistent with the participants' questionnaire responses to how co-morbidities limited daily activities (see table 2).

Discussion

The purpose of this study was to better understand older people's experiences of NC, their treatment and outcome preferences and the relevance of ageing in order to inform the design,

rationalisation and construction of an intervention to be tested in a Randomised Controlled Trial (RCT). From a clinical perspective NC is considered to be an age-associated condition [7] and, as no other qualitative studies have been published on patient experiences of older people living with NC, we have drawn on studies of other chronic musculoskeletal (MSK) conditions to situate our findings. Even in that well-researched field there is remarkably little literature that explicitly investigates the experiences of older people with chronic MSK pain. However, participants in this study had similar experiences to those reported in a qualitative systematic literature review, a meta-ethnography, which analysed the experiences of 60 qualitative studies of patient experiences of chronic of pain in which just over half of which were non-malignant MSK conditions [27]. Similarities included the difficulty of living with unpredictable of symptoms, negative effects on social life and the loss of sense of self that sociology of health researchers have termed ‘biographical disruption’ to express the totalising impact that chronic pain can have on patients’ lives [28,29].

Despite persistent similarities with Toye et al’s [30] meta-ethnography, this paper illustrates the need for studies on chronic MSK conditions not to assume that older and younger people’s experiences can be conflated. Our findings highlight the complex ways in which older people with NC relate to ageing, specifically the appearance of ageing, age-related decline, pain and activity. Participants own understanding of the relationship between NC and their age was ambivalent due to the variability in their symptoms as well as the complex ways in which they related to normative discourses of ageing. Participants framing of ageing as either a time of up-beat renewal or time of anxiety, infirmity and decline, echoes dominant discourses in circulation since the late 1990s that promote the idea of active ageing as a solution to the consequences of ageing and ailing populations [31-36]. For the participants in this study NC interfered with their ability to engage in activities associated with active ageing

such as the vigorous pursuit of leisure and social activities. From participants perspectives the use of walking aids was so incompatible with the *appearance* of active ageing that their rejection of them had, rather paradoxically, led to decreased engagement in activities for some. Our findings around the rejection and often ambiguous adoption of walking aids echo other qualitative findings which illustrate that older people's relationships to walking aids and ageing are complex [37]. The complexity is due, in part, to a generalised stigma of walking aids and older people. This links to wider discourses around idealised and normative forms of active ageing in which the appearance of the signs of age-related decline are highly undesirable [38-40]. The *appearance* of active ageing in lieu of being old and active was extremely important to participants as this gives credence to the concern that those who are unable to conspicuously engage in regimes of active ageing may be vulnerable to negative moral judgements from themselves and others [35-36].

Impact on the development of an intervention

Our findings have directly informed the design of an intervention to be tested in a large RCT. Full details of the intervention will be outlined in a forthcoming protocol paper. There is currently no national standard for the delivery of physiotherapy treatments for NC. Where surveys on treatment preferences have been conducted, there is an assumption that the usual method of delivery is one-to-one care from a physiotherapist [41,42]. Data from this study suggest that treatment should be delivered via a combination of one-to-one time with a physiotherapist and group exercise classes.

Our findings suggest that participants want to get back to activities that are meaningful to them and that they wished to be symptom free. Failing that, participants hoped to be able to better cope with their pain and thereby be able to increase time spent on meaningful activities. Therefore the intervention designed for our RCT will specifically aim to increase

participants' mobility through a strengthening and walking programme. Based on our findings and what we already know about pain beliefs and recovery [43] the intervention has been developed around the specific needs of older people. We will counter participants' negative beliefs about pain, ageing and walking aids that may act as barriers to engaging with/adhering to a rehabilitation programme by underpinning the programme with cognitive behavioural (CB) principles.

Our findings demonstrate that participants' treatment preferences were informed by their previous experiences of physiotherapy treatment. By definition, chronic conditions are problematic for health professionals and patients to manage due to the lack of curative treatments. Our findings suggest that from older people's perspective a good therapeutic alliance is an important factor in helping them to achieve better physical function, this is not a universally held belief [44-46] and further research would need to be done to better understand the relationship between therapeutic alliance and patient outcomes for those with NC. To promote a good therapeutic alliance from the therapist side in our RCT, physiotherapists delivering the intervention will receive training based on our findings. This will include learning about patient experiences of NC as described in this paper, the complex relationship older people may have to walking aids and understanding the dominant discourses around ageing and activity that might serve as a barriers and facilitators in adherence to a rehabilitation programme.

Conclusion

We undertook a preparatory study in order to inform the design of a physiotherapy intervention that will be tested in an RCT for older people living with disabling symptoms arising from NC. The aims of the study were to elicit the experiences of older people living with symptoms from NC. Based on participant experiences we explored, in relation to the

development of a physiotherapy intervention, their preferences for treatment and which outcomes were important to them. This is the first published study of patient experience of NC due to LSS.

This paper demonstrates that pain and the threat of pain disrupts participants' ability to maintain the physical activity necessary for them to lead their usual lives and maintain a positive sense of self. This paper has argued that participants' experiences of living with NC are similar to those living with other chronic pain conditions. However, this paper has argued that older people's experiences are complicated due to the intersection of a range of circulating discourses regarding old age, ageing, age-related decline and physical activity. We have illustrated the ways in which these findings have fed into the development of a physiotherapy based intervention to be tested in an RCT. Finally, we hope to stimulate discussion about the specific issues that are raised for older people and physiotherapists as they enter into treatments for NC and other disabling MSK conditions.

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Declaration of Interest

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For Peer Review

Implications for rehabilitation

- Older people living with NC want to get back to meaningful activities and learn how to live with the threat of pain.
- Allied health professionals (AHPs) should be sensitive to the complex and ambiguous ways in which older people live with ageing and age-related decline.
- AHPs are in a position to support patients’ successful transition to the use of walking aids thereby reducing stigmatising effects and increasing activity.
- AHPs should consider a mixture of one-to-one and group classes to enable rehabilitation for older NC patients.

Tables

Table 1 – Characteristics of participants

Characteristic	Median (IQR) or n(%)
Age	75 (69-80)
Sex	Male = 9 (60%) Female = 6 (40%)
Marital status	Cohabiting = 1 (7%) Divorced = 4 (27%) Married = 9 (60%) Widowed = 1 (7%)
Ethnicity	English / Welsh / Scottish / Northern Irish / British = 14 (93%) Irish = 1 (7%)
Living arrangements	Lives along = 5 (33%) Lives with spouse or partner = 10 (66%)
Education	Secondary Modern = 2 (13%) O Levels = 1 (7%) A Levels = 1(7%) Matriculation = 1 (7%) Vocational training = 3 (20%) Degree = 2 (13%) Higher Degree = 2 (13%) Missing = 3 (20%)
Disease Burden Questionnaire	12 (9-17)
Number of medical conditions reported	7 (4-7)
Tilburg Frailty Index (max score=15)	5 (3-7)
Classified as frail based on TFI score of 5 or more	Yes = 8 (53%) No = 7 (47%)
Swiss Spinal Stenosis Scale – symptom severity scale (max score=5)	3 (2.6-3.6)
Swiss Spinal Stenosis Scale – physical function scale (max score=4)	2 (1.8-2.8)
Oswestry Disability Index (max score=100)	32 (14-59) (missing n=1)

Table 2 Burden of Disease Questionnaire responses

Condition	I don't have this condition (n)	I do have this condition and it limits my daily activities (n)				
		1 - not at all	2	3	4	5 - a lot
Chronic back pain or sciatica	1	1	0	4	5	4
High blood pressure	5	8	1	1	0	0
Hard of hearing	6	3	2	3	1	0
Vision problem	6	4	1	4	0	0
Osteoarthritis ("regular" arthritis, not rheumatoid arthritis)	6	2	3	4	0	0
High cholesterol	8	4	2	1	0	0
Stomach problem such as an ulcer or gastritis or reflux	10	2	3	0	0	0
Overweight	10	3	1	1	0	0
Colon problem such as irritable bowel or colitis	11	2	1	1	0	0
Poor blood circulation in your legs	11	1	1	1	0	1
Heart disease such as angina (chest pain from heart problem), heart attack, bypass surgery or angioplasty.	12	1	0	1	0	1
Diabetes	13	1	0	0	0	1
Rheumatoid arthritis	13	1	0	1	0	0
Thyroid disorder	13	1	0	1	0	0
Osteoporosis (thinning of the bones)	13	0	0	2	0	0
Cancer during the last 5 years (not including small skin cancers)	13	2	0	0	0	0
Asthma	14	0	0	1	0	0
Congestive heart failure	14	0	2	0	0	0
Stroke	14	0	0	1	0	0
Chronic bronchitis or emphysema	15	0	0	0	0	0
Rheumatic disease such as fibromyalgia or lupus	15	0	0	0	0	0