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# Experiences of recovery and rehabilitation from surgery to treat neurogenic claudication. A qualitative study

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## ABSTRACT

**Purpose:** This study aimed to explore the experiences, expectations, attitudes and beliefs about surgery and recovery in people with neurogenic claudication, and their preferences for rehabilitation.

**Methods:** Semi-structured interviews were conducted with a purposive sample of 16 patients (8 female; mean age 70years) following surgery for neurogenic claudication. Data were transcribed verbatim, analysed using reflexive thematic analysis and interpreted using the five constructs of the Integrative Model of Expectations: treatment, timeline, behaviour, outcome, and generalised expectations.

**Findings:** Three themes were developed: (1) *making sense of recovery through a biomedical model of illness*; (2) *the mismatch between expectation and recovery* (subthemes: *the unanticipated burden of recovery*; *hope versus reality: expectations of the ultimate outcome*); (3) *one size doesn't fit all: the need for tailored rehabilitation*. Participants expressed a preference for tailored, supervised rehabilitation commencing 2-6 weeks post-surgery. Some participants preferred one-to-one and some group-based rehabilitation. Some participants thought pre-operative rehabilitation would be beneficial.

**Conclusions:** Patient's experiences and satisfaction with their care and outcome are heavily influenced by their expectations. Tailored rehabilitation should reframe unrealistic expectations regarding care, recovery, and ultimate outcome; educate patients on the biopsychosocial model of pain; and equip patients with the knowledge and skills to optimise their outcome.

## ARTICLE HISTORY

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## KEYWORDS

Lumbar spinal stenosis; neurogenic claudication; surgery; rehabilitation; expectations; walking; qualitative research

## > IMPLICATIONS FOR REHABILITATION

1. People with neurogenic claudication interpret their condition, symptoms, and recovery from surgery through a mechanistic, biomedical lens.
2. The experience and recovery from surgery for neurogenic claudication can be unexpectedly challenging and burdensome.
3. Healthcare professionals should support patients by helping to set realistic expectations of post-operative care, recovery, and outcome from surgery.
4. People undergoing surgery for neurogenic claudication want rehabilitation, personalised to their individual circumstances and requirements.

## Introduction


Neurogenic claudication (NC) affects approximately 11% of the general population and predominantly affects older people above the age of 60 [1,2]. It is caused by lumbar spinal stenosis (LSS), a degenerative condition that leads to narrowing and compression of the nerves and blood vessels within the lumbar spine. NC is characterised by bilateral leg pain, paraesthesia, and/or weakness often accompanied by low back pain. It is exacerbated by standing and can cause substantial walking restriction [3]. Walking restriction is greater in people with NC than in people with hip or knee osteoarthritis [4]. NC limits engagement in meaningful activities, can result in a loss of sense of identity [5,6] and reduces quality of life comparable to stroke or heart disease [7].

Surgery is recommended for people with NC to improve pain and walking if severe symptoms persist after non-surgical treatment. NC is the most common reason for lumbar surgery in older people [8]. Yet, following surgery, approximately 40% of people

report ongoing pain and walking disability, contrary to their expectations [9]. Furthermore, most people do not meet physical activity recommendations and are at risk of the consequences of inactivity [10].

Rehabilitation has the potential to maximise surgical outcomes and increase postoperative walking behaviour, but few studies have investigated the modifiable factors that could be targeted to maximise outcomes [11]. Provision of rehabilitation following spinal surgery is inconsistent [12–15] and few studies have investigated the experiences or effect of multi-modal rehabilitation programmes [16,17]. One meta-ethnographic synthesis of 18 qualitative studies that explored the experiences of people before and after lumbar spinal surgery reported mixed perceptions of rehabilitation and physiotherapy [18]. However, most included studies recruited younger people with a range of diagnoses, limiting generalisability to older people with NC [19]. Two studies identified patients felt underprepared and desired more information prior to surgery for LSS [20,21]. This lack of pre-operative

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education led to unrealistic expectations and dissatisfaction with surgical outcomes.

The Integrative Model of Expectations in patients undergoing medical treatment outlines five constructs influencing patient outcomes and treatment-related behavior [22]: *treatment expectations* including perceived benefits and side effects; *timeline expectations* for treatment and recovery; *behaviour expectations* incorporating personal control, self-efficacy and behaviour outcome expectancy e.g. the expectation rehabilitation will lead to improvement; *generalised expectations* including generalised self-efficacy and optimism; *outcome expectations* e.g. pain reduction and return to important activities. Expectations are predictors of treatment responses for many conditions [23] including lumbar surgery, although most research is quantitative and only considers outcome expectations [9,24–31]. Qualitative research is required to fully understand the recovery experiences and expectations of older people undergoing surgery for NC. It is crucial to inform the development of acceptable, effective and feasible rehabilitation approaches to improve outcomes after surgery. We aimed to explore the experiences, expectations, attitudes and beliefs of surgery in people with NC and understand their preferences for rehabilitation.

## Methods

### Design

We conducted a qualitative interview study. The study was approved by East Midlands - Nottingham 1 Research Ethics Committee (20/EM/0307). The protocol was published (DOI 10.17605/OSF.IO/BHQJZ) and is reported in line with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) [32].

The study was underpinned by a critical realist philosophical position [33]. This assumes that while there may be an objective reality, this is experienced subjectively and is shaped by social and cultural contexts.

### Participants and recruitment

Participants were recruited from a longitudinal cohort study investigating factors associated with walking post-surgery for NC (DOI 10.17605/OSF.IO/BHQJZ). Participants were >50 years old, recruited while waiting for surgery for NC at one of three NHS hospitals in England, and had conversational level English language. People who reported conditions other than NC, as the primary cause of walking restriction, or required surgery for tumour, fracture or significant deformity (>15 degree lumbar scoliosis; ≥grade II spondylolisthesis, ≥2 level fixation), or cauda equina syndrome were excluded. All participants enrolled on the longitudinal study provided consent to be approached for this interview study. The lead researcher approached potential participants by telephone after a minimum of three months post-surgery.

We purposively sampled for diversity in age, gender, ethnicity, walking capacity (six-minute walk distance) and back-pain related disability (Oswestry Disability Index [34]) at 12-weeks post-surgery. We anticipated requiring between 12–20 participants to ensure sufficient information power, considering the aims of the study, our specific sample, anticipated interview quality and analysis plan [35].

### Data generation

Individual semi-structured interviews were conducted *via* telephone or videocall, dependent on participant preference. Consent was reaffirmed verbally at the start of all interviews. The interviews

were conducted by one researcher (SMc) who had contact with participants at least twice during the longitudinal study but was not involved in their clinical care. SMc is an experienced physio-therapist and PhD student with expertise in spinal surgery. The interviews followed a topic guide, informed by previous studies [6,36,37] and the Capability Opportunity Motivation (COM-B) model [38]. Questions were developed by the research team. Minor wording adjustments were made following pilot interviews with two patient advisors. Questions explored participant's attitudes and beliefs, expectations, and experiences before and after surgery, influencing factors, and preferences for rehabilitation (Supplementary file A). All interviews were audio-recorded, transcribed verbatim and anonymised. Field notes were recorded, alongside a reflexive diary.

### Analysis

Data were analysed inductively using reflexive thematic analysis [39]. This approach was undertaken to allow us to explore the multiple experiences and beliefs across participants and generate shared patterns of meaning, whilst also recognising our active involvement and subjectivity as researchers [39].

SMc reviewed the manuscripts and conducted the initial coding using NVIVO v12 (QSR International Pty Ltd) to manage data. An experienced qualitative researcher (LJB) independently coded four manuscripts and discussed initial codes to consider alternative data interpretation. SMc generated provisional themes by collating codes and patterns. Provisional themes and labels were discussed and refined with the research team. This approach aimed to achieve rich interpretation of the dataset, rather than attempting to achieve accurate or reliable coding and consensus of meaning. Following engagement with reflexive notes and discussion between the research team, recruitment was stopped after 16 interviews as SMc considered that the diverse sample of participants had provided data sufficient to complete nuanced analysis [35]. The themes were subsequently interpreted using the Integrative Model of Expectations [22].

Participants preferences for rehabilitation were mapped onto the relevant items in the Template for Intervention Description and Replication (TIDieR) Checklist [40]. For illustration of codes, code refinement and theme generation see Supplementary file B.

## Findings

### Participant characteristics

Of 17 people invited, 16 were interviewed (8 female, mean age 70 (range 53–83) years; Table 1) between February and October 2022. One person declined due to time commitments. The majority were white British ( $n=9$ ) and retired ( $n=14$ ). Mean time following surgery was 6 months (range 3–11 months). Half of the interviews were conducted *via* videocall, and the median interview duration was 46 min (range 24–59 min).

Participants regarded their experience of surgery and their recovery as an important life event. All participants expressed some satisfaction and gratitude for their surgery however, this was influenced by the outcome of their surgery and if this aligned with their expectations for recovery. Three themes (Figure 1, Table 2) were developed that described patients' experiences and expectations of recovery, and underpinned patients' recommendations for rehabilitation. Table 3 summarises participant preferences for rehabilitation summarised according to the selected constructs of the TIDieR checklist [40].

**Theme 1: Making sense of recovery through a biomedical model of illness**

Most participants made sense of their condition, their need for surgery and their recovery with a mechanistic, biomedical perspective. They focussed on the causes, treatment, and the

Table 1. Participant characteristics.

Characteristics	n=16
Sex	
Female	8 (50%)
Male	8 (50%)
Age	70 (±8)
Years (mean, standard deviation)	
Self-reported ethnicity	
White British	9 (56%)
Mixed white & black Caribbean	2 (13%)
Arab	1 (6%)
Asian Chinese	1 (6%)
Black African	2 (13%)
Black Caribbean	1 (6%)
Retired	
Yes (%)	14 (88%)
No (%)	2 (13%)
Post-operative 6MWD	
≤200 m	4 (25%)
201-300 m	5 (31%)
301-400 m	5 (31%)
≥401 m	2 (13%)
Median (m) (range)	284 (90, 480)
Post-operative ODI	
0-20% minimal disability	5 (31%)
21-40% moderate disability	5 (31%)
41-60% severe disability	6 (38%)
Median (range)	30 (2, 56)
Months since surgery	
Median (range)	4 (3-11)

6MWD: six-minute walk distance. ODI: Oswestry Disability Index, higher number indicated greater back related disability.

expectation that symptoms would be eliminated by surgery. Many participants explained that their condition was caused by something that was trapped or “clogged up” (P13) in their back and they considered that surgery was essential. Clinician’s use of biomedical metaphors to describe the surgery helped participants grasp the procedure but reinforced a mechanistic understanding and requirement for surgery.

“The way they described it as scraping out the gunge between your vertebrae and that made sense. You know it’s a bit like, I don’t know how can I explain it, sort of a washing machine having all gunge in it and just needs clearing out to make it perform better, so you know from that point of view if it just means a little bit of a scrape, all well and good” (P11, female, aged 65 years)

This reassured some patients about the possible risks and benefits of surgery but sometimes contributed to an unrealistic expectation of their treatment recovery and outcome. Some participants expected their symptoms would resolve immediately once the surgery had addressed the mechanical problem and were surprised and disappointed that they had ongoing symptoms. In contrast, other participants were alarmed by the biomedical explanation of their condition and feared substantial deterioration of their condition, such as paralysis, if they did not have surgery. This belief, compounded by long waiting times for surgery, led some people to experience extreme, almost unbearable anxiety and fear about the prognosis of their condition.

“Before the surgery, they told me if I hadn’t had the surgery, it would have gone, and I’ve been paralyzed. Thank God I’ve had it done, but prior to the surgery, I could walk better.” (P01, female, aged 73 years)

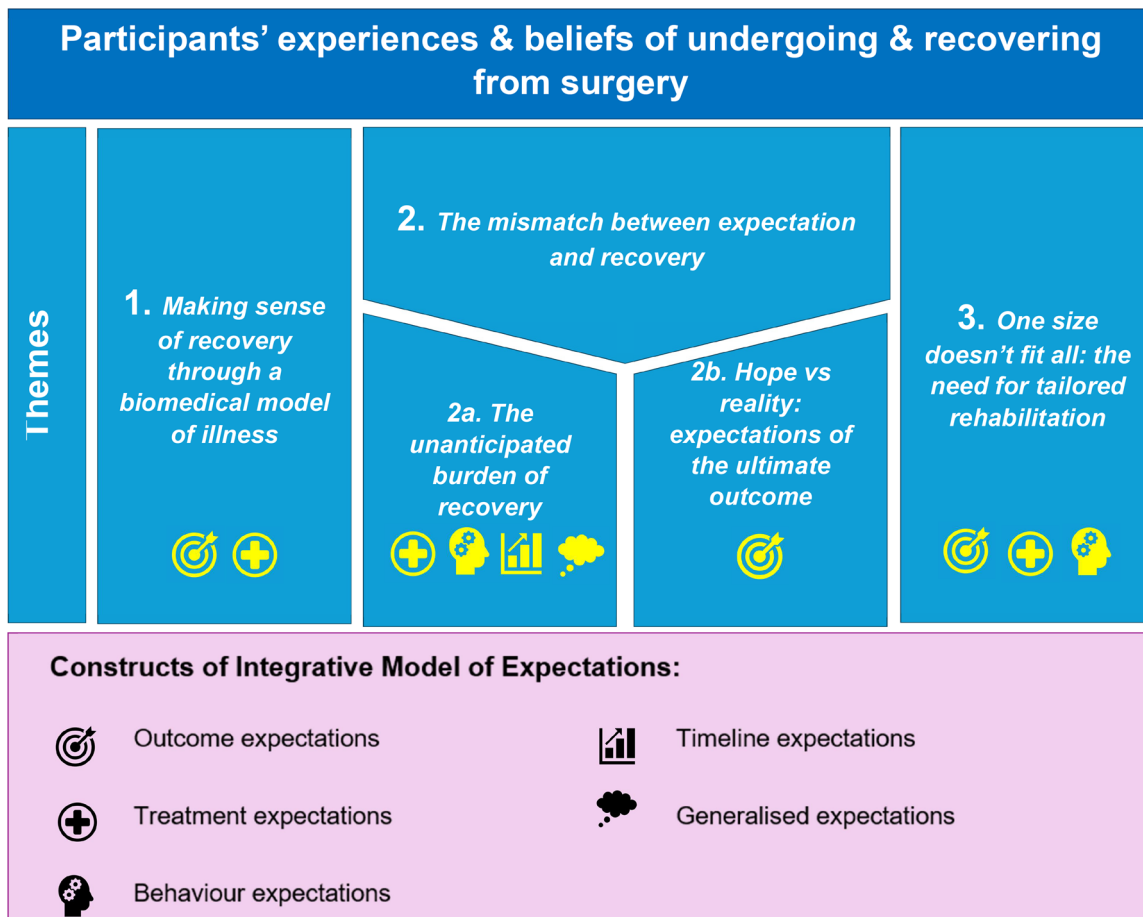


Figure 1. Participants’ experiences and beliefs of undergoing and recovering from surgery, and preferences for rehabilitation, following surgery to treat neurogenic claudication, mapped to the constructs of the Integrative model of expectations.

Table 2. Theme definition.

Theme title	Definition
1 Making sense of recovery through a biomedical model of illness	Examines how the participants perceptions of their condition and their recovery was predominantly viewed through a biomedical model of illness. Their focus was on cause, treatment and elimination of symptoms and was reinforced and unchallenged by health care clinicians.
2 The mismatch between expectation and recovery	This theme explores the mismatch between participant expectations of their recovery and their experience of post-operative recovery, and the ultimate outcome of their surgery. This was underpinned by their understanding of their underlying condition (lumbar spinal stenosis) and symptoms (neurogenic claudication) and the mechanism that surgery would alleviate these symptoms. There were two subthemes: <ol style="list-style-type: none"> <li>1. <i>The unanticipated burden of recovery</i> examines the often effortful and an unanticipated burden of recovery experienced by participants.</li> <li>2. <i>Hope versus reality: expectations of the ultimate outcome</i> looks at the expectations participants had of life after surgery and considers how this aligns with their treatment outcome.</li> </ol>
3 One size doesn't fit all: the need for tailored rehabilitation	Explores how participant navigated the complex requirements of rehabilitation and participants beliefs about the need for personalised rehabilitation.

When reflecting on their experiences of waiting for surgery, some participants suggested that pre-surgery education and exercise sessions would be beneficial to help them understand their condition and prepare them for surgery.

After surgery, participants used their biomedical understanding of their condition to explain any ongoing symptoms or if recovery did not progress as expected. Participants frequently referred to common back pain myths informed by the biomedical model to explain their ongoing symptoms rather than a more multifaceted, holistic biopsychosocial model of pain and illness [41,42]. These beliefs drove participants' behaviour beyond the post-operative tissue healing period. For example, several participants believed that their back must be always kept straight and they blamed themselves if they did not do this and worried that this had contributed to their continued symptoms.

"I remember bending down ... which I shouldn't have done ... well it was a natural thing just to turn a plug off... it was definitely definitely my fault; I shouldn't have done that." (P08, male, aged 69 years)

Lack of information to help understand their ongoing symptoms and recovery meant that participants' biomedical beliefs persisted, and this was often unchallenged and reinforced by healthcare professionals.

"They [health professional] weren't happy either because when they saw that nothing was improving they ...said, look, see if you can get to see the specialist again ...well, that frightened me." (P01, female, aged 73 years)

Many participants wanted rehabilitation shortly after surgery to help them understand and maximise the outcome of their surgery, and they proposed that early post-operative rehabilitation that was easily accessible was needed.

### Theme 2: the mismatch between expectation and recovery

We identified two key areas of mismatch between expectation and recovery: *the unanticipated burden of recovery* and; *expectations of the ultimate outcome*.

#### 2a. The unanticipated burden of recovery

An unanticipated burden of self-management and recovery was experienced by many patients after they were discharged from hospital. Participants were typically discharged from hospital quickly, and this cemented their expectations that their overall recovery would be short. Once at home, many participants reported that their recovery was prolonged, arduous, and painful: "*a bit of a slog really*" (P03). The unanticipated severity and duration of their recovery made participants anxious that surgery was not successful, or something had gone wrong. Key areas of concern were ongoing or returning pain, unexpected back pain, managing side-effects, reducing analgesia, wound healing, difficulty standing upright, mobility, and how to manage their recovery.

"I can't just get up and then... stand up straight. I need to like curve up my back and slowly, slowly and to stand up. I don't know is it anything? Is after the operation, ... my body should feel like this or it just me? I can't just like normal people get up and then you can just go. I have to do it slowly and really curve my back" (P06, female, aged 64 years)

Many participants lacked knowledge and understanding about how to self-manage their recovery. They assumed that, once they were at home, they would be provided with aftercare and rehabilitation. This expectation was often informed by their perspective that their surgery was a major procedure that required ongoing care. After their surgery, participants wanted rehabilitation to help them regain their "*strength*" (P07) and get "*back into shape*" (P16). They wanted a tailored programme that considered their current and anticipated function, their condition and surgery. They particularly wanted a thorough assessment to reassure them that they were safe to increase their activity.

"But I think what was missing was the aftercare. Definitely. No one, that's it, two days, go home. It's over. But it wasn't over. Not for me" (P01, female, aged 73 years)

Many interviewees reported feeling abandoned and dismissed.

"I wasn't seen by the consultant, I saw just a general doctor on duty who, who doesn't know anything about me and I was told everything's fine and I could leave... what else could I done differently? I would have asked what I should do when I get home, in terms of getting back on my feet and walking how soon, how much walking to be done? Is it gradual? I've no idea, nobody said anything. And there's no programme. It's like there we are, it's been done good luck" (P05, male, aged 77 years)

This, coupled with unrealistic recovery expectations and conflicting or limited advice, led to uncertainty, confusion, and fear that something was wrong with their back or that they were doing something wrong. Conversely, the participants who perceived they had been provided with sufficient information about recovery either prior to the operation or from a physiotherapist whilst they were in hospital, appeared to have more realistic expectations of recovery, and were not alarmed by ongoing pain or fear of doing something wrong.

"Before I have the operation the surgeon told me that this operation is it's not 100% will take away your pain. It's 60 over 100, and I said okay, if the 60% can go away from the pain I'm going through now, and it's only 40% that will remain, it's not bad. That's what I said. Well now, I'm feeling much better... When I'm when I was leaving the hospital they told me... it will take about six months to one year before you get yourself back properly, so it's in my mind that, okay the recovery is not going to be just [clicks fingers] like that" (P09, female, aged 74 years)

The participants rarely described their rehabilitation and post-operative walking progress as straight forward. Many



**Table 3.** A summary of the mixed opinions and preferences for rehabilitation categorised according to the selected constructs of the TIDieR checklist.

TIDieR item no.	Item	Participant preferences
2	Why: rationale, theory, or goal of the intervention	<ul style="list-style-type: none"> <li>The main reasons were: <ul style="list-style-type: none"> <li>rehabilitation is required to be to get body back into shape and regain strength, after a major operation.</li> <li>personalised rehabilitation and advice are required, tailored to the individual's needs, to increase confidence and adherence, knowledge, and skills.</li> <li>tailoring should occur after the operation, to factor in how the operation went.</li> </ul> </li> </ul>
3	What: physical or informational materials	<ul style="list-style-type: none"> <li>Information needs identified were: <ul style="list-style-type: none"> <li>clear "dos and don'ts" post-operatively, not just "don'ts"</li> <li>exercises to do at home.</li> <li>information about processes and the operation, specific to their operation and condition</li> <li>expectations for overall recovery and recovery period, including timeframes.</li> </ul> </li> <li>Most participants wanted information to be provided verbally to them, supported by electronic or paper-based resources, preferably all in one place rather than lots of different documents.</li> <li>One participant suggested having a website with case studies and information that they could refer to.</li> </ul>
4	What: procedures, activities and/or processes, including any enabling activities	<p><b>Procedures:</b></p> <ul style="list-style-type: none"> <li>Personalisation was very important to participants with rehabilitation tailored to individual needs.</li> <li>Participants reported they would have liked a comprehensive, holistic assessment to see how they were after their operation and ensure that nothing was wrong.</li> <li>Many participants reported the importance for advice, education, and the opportunity to ask questions.</li> <li>A few participants identified goal setting to be very important. They perceived this allows rehabilitation to be tailored and focussed on achieving the goals and aids with adherence and motivation.</li> <li>A lot of participants discussed exercise. They thought that patients should be provided with a programme of <i>appropriate</i> exercises, these should be exercises that can be done at home, suitable and reflective of real-life environments and functional tasks.</li> <li>A couple of participants discussed they would like adjuncts such as hydrotherapy (aquatic therapy), heat, and massage to help ease pain and stiffness.</li> <li>One participant wanted to practice walking outside and travelling on a bus with a physiotherapist.</li> <li>A couple of the participants identified that pre-operative education sessions would be useful and one participant thought pre-operative rehabilitation to gain fitness would be ideal.</li> </ul> <p><b>Processes:</b></p> <ul style="list-style-type: none"> <li>There was consensus that post-operative physiotherapy should occur automatically and not require the patient to have to instigate the referral.</li> <li>Transport should be provided if required to enable attendance.</li> <li>One participant suggested that when rehabilitation has finished then the opportunity to attend exercise classes in the community should be facilitated.</li> </ul> <p><b>Enabling activities:</b></p> <ul style="list-style-type: none"> <li>The predominant opinion was that supervision, even if this was one off, was required to increase patients' confidence in their exercises and rehabilitation.</li> <li>Supervision and appointments with a physiotherapist were seen as important enablers of motivation for patients to continue and to adhere to their exercise programme.</li> </ul>
5	Who provided	All participants thought rehabilitation should be provided by a physiotherapist or a credible professional who has expertise in the condition.
6	How: mode of delivery	<p><b>Mode of delivery</b></p> <ul style="list-style-type: none"> <li>There was a preference for in-person sessions although some participants thought online sessions would be acceptable if meant they could receive timely rehabilitation and advice.</li> <li>One participant suggested that the first session, early in the post-operative period, should be virtual (telephone or online) and then be followed-up in person.</li> <li>A couple of participants thought that provision of a leaflet containing advice and exercises was sufficient and would meet their requirements to do things at their own pace.</li> </ul> <p><b>Individual or group rehabilitation</b></p> <ul style="list-style-type: none"> <li>There was no consensus on preference for group or individual rehabilitation.</li> <li>Some participants identified that a group would allow for peer support and learning from others undergoing similar experiences. There was also recognition that group may be more efficient.</li> <li>Suggestions were made on how to make group rehabilitation more acceptable: <ul style="list-style-type: none"> <li>The option to have 1:1 during the session, ensuring that components were tailored to the individual.</li> <li>First session be individual then join a group</li> </ul> </li> </ul>
7	Where	<ul style="list-style-type: none"> <li>The majority of participants wanted rehabilitation to be provided locally so that was easily accessible. A couple were happy to travel if they were unable to receive rehabilitation locally.</li> <li>One participant thought the rehabilitation should be delivered in their home.</li> <li>A couple of participants thought the rehabilitation should be either at or, linked to the surgical centre. This was because they thought it important the physiotherapist had knowledge of their condition, operation, and care.</li> <li>One participant thought it should initially be at the surgical centre then care transferred locally as they improved and required less specialist care.</li> </ul>
8	When and how much	<p><b>When</b></p> <ul style="list-style-type: none"> <li>Most participants thought rehabilitation should start approximately two weeks post-operatively, the remainder thought it should start 3-6 weeks post-operatively.</li> <li>A couple of participants thought there should be rehabilitation prior to their surgery in addition to post-operative rehabilitation.</li> </ul> <p><b>Number of sessions, frequency, &amp; duration of rehabilitation</b></p> <ul style="list-style-type: none"> <li>There was no clear consensus in how many sessions of rehabilitation should be offered and over what duration. Some of the participants thought only a few sessions would be required, others suggested it should occur for a two-month duration, other participants thought rehabilitation should continue until the person had made a full recovery, and other participants suggested 6-12 months.</li> <li>There were mixed opinions about frequency of sessions, one thought it should be daily, some thought rehabilitation sessions should be weekly. Others thought the sessions could be spaced out either every fortnight or monthly to allow progress to be made between sessions, while another suggested that the timing between sessions could increase as time went along and the patient improved.</li> <li>One participant spoke about length of rehabilitation sessions and suggested one hour.</li> </ul>

participants described a cycle of overexertion and then underactivity (boom and bust) that hindered their progress and exacerbated fear of activity. However, those who approached recovery with a structured plan, set achievable goals, and monitored their progress regularly, reported more successful recovery journeys. A sense of purpose and control over their recovery motivated these participants to continue with their rehabilitation even when they were in pain or felt despondent.

"I'd do a few of the exercises until I couldn't do it anymore and then 2-3 hours later I was in bloody agony, so it didn't happen very often." (P14, male, aged 71 years)

"I have a watch and when I start a walk, I engage the outdoor walk app and it tells me the speed I'm walking, the distance I walked, the time it's taken so far and so on ...and if I want to walk longer than I did before, I just check that it's, you know, exceeded the time and the distance that I had before. ...I would set a minimum target before I start in my mind and, and I just achieve that target ... and then, I could go, today I'm going to do more." (P05, male, aged 77 years)

Navigating the recovery journey required resilience and optimism, and participants acknowledged the importance of perseverance and personal responsibility. These personal characteristics and mindsets were considered imperative as participants reported that it could be easy to "give up" (P12).

"You will get better. You'll just have to persevere and believe that you will get better. Don't keep worrying for yourself and say the pain you, I mean, the doctors can't work miracle. The doctors are there to help you. But they can't work ...miracle" (P04, female, aged 83 years)

Social support from family and friends was crucial in helping ease the burden of recovery. They offered emotional and practical assistance that motivated participants to continue with their rehabilitation. Social support from healthcare practitioners provided predominantly reassurance and recovery information. Conversely, those participants without regular support felt their recovery was slow and burdensome.

"My best asset is my wife, she's always making sure I do my walk daily. And that is a fact ... without her enthusiasm and monitoring me, I would have taken the lazy way out and not bothered too much about my walking regime and so on but so we either go out walking together, or if she if she's out and or not able to come, she'll make sure that I have a plan for a walk and, will check (chuckle) that I've done that. Which is encouraging for me because I know I'm not going to ignore it" (P05, male, aged 77 years)

### **2b. Hope versus reality: expectations of the ultimate outcome**

Participants agreed to surgery to reduce their pain and increase their walking, so they could increase work, social, and leisure activities.

The degree of improvement varied between participants. Some participants had a complete symptom resolution and expressed that they were "over the moon" (P15) with the outcome of their surgery. Others were disappointed when their outcome did not meet their expectations.

"I thought after the operation, I'll be 100%. And it's not worked out like it. Perhaps I expected too much" (P02, male, aged 76 years)

These participants described unexpected ongoing pain, or, in one case, a deterioration in symptoms. This led to participants re-considering their capabilities, activities, and impact on their families. For some, this led to a loss of identity, guilt, and fear for the future as they anticipated needing long-term care.

"Someone suggested I got, one of those walkers. God, do I have to? My own pride. I'm 74 this year. Coming up 24 in my mind... but I just

don't want to succumb to go and everywhere in a wheelchair or pushing a walker around. One day I'll suppose I'll have to. But I'm not yet, I'm not ready for that yet." (P01, female, aged 73 years)

Interestingly, complete resolution of symptoms was not required to be satisfied with outcomes: people were satisfied with their outcome if the degree of improvement met their expectations. Participants appreciated honest pre-operative discussions with their clinicians around uncertainty of the outcome. They were able to use this knowledge to weigh up the pros and cons of surgery.

"I was told before I had the op that ...because it's quite a difficult op that things can either work, or they may not. I think that is the right way, ...to be honest ...so to be quite frank ...but also to encourage them in that, for some people it's made a big difference to them" (P15, male, aged 73 years)

Dissatisfaction with their ultimate outcome seemed to occur when this uncertainty was not discussed or understood, and expectations were not met. This was linked to participants understanding of their condition, symptoms, and how surgery would alleviate these symptoms.

Some participants had over ambitious expectations of the outcome of their surgery, despite pre-operative discussions. This seemed to be because they were desperate for a solution to their pain and hoped for an unrealistic outcome. These patients had difficulty accepting their outcome following surgery and were left with a mismatch between hope and reality.

"Although I was told that you know, it was more for mobility than the pain. But uh, you know. Along the way you do, you do hope that it's he's gonna fix a multitude of things, not just the one, but you know. It is what it is I suppose ... I don't wanna seem ungrateful because that's what I'm seeming. And I'm not ... But I just feel like I've been sort of led to the to the edge of Paradise and I just can't get in there." (P03, female, age 53 years)

### **Theme 3: One size doesn't fit all: the need for tailored rehabilitation**

Most participants believed that exercise and regular activity were vital to recovery and return to valued activities. However, many believed that activity should be completed cautiously due to their age, healing and recovery. Most participants wanted post-operative rehabilitation sessions focused on teaching self-directed exercises, although some participants wanted frequent supervised exercise sessions. Participants identified goal setting, self-monitoring, and regular reviews with credible clinicians, as methods to aid motivation and adherence.

"I give myself targets, so I was working towards a specific date ...I think it was quite good because it means I had something to you know, to aim for ...it's what kept pushing ...once I completed that particular task ...it felt good, you know. I think that certainly helped." (P08, male, aged 69 years)

While most participants received a post-surgery exercise information leaflet, they found it to be too generic, leading to doubts about its suitability. The lack of specificity regarding their condition, exercise intensity, or how to progress exercises particularly troubled participants. They often sought tailored guidance from physiotherapists, and were disappointed when they were told they "should just follow the book[let]" (P16).

"I can't help feeling that there isn't a one size fits all, so it's not much good in a way having a leaflet which tells you what exercises to do erm if it is too easy for you and maybe not easy enough for someone else". (P07, female, aged 78 years)

Format, timing, and accessibility of the rehabilitation sessions varied. Some participants were automatically referred to see an outpatient physiotherapist, while others had to organise their own appointment and faced long waiting times. Some participants received virtual rehabilitation *via* the telephone or video-call whereas others received in-person appointments. This mattered to participants and divided opinion: some found virtual appointments unacceptable, whereas others appreciated its convenience.

"I have a physio over the phone ...that was a little bit, you know, half fetched ...you can't have physio over phone ...the physio over the phone, is wrong." (P04, female, aged 83 years)

"I mean, these days, [online] meetings are good enough ... you know to it saves time for everybody and ...of course, then you can e-mail the information sheets and so on and we can print it at home that, you know, these days everything's easy. I mean ...it's always encouraging, more cheerful to see the person but, on, online is an acceptable alternative". (P05, male, aged 77 years)

Participants' perceptions of the content and quality of their rehabilitation also varied. Some reported thorough assessments, training, and guidance about their rehabilitation, while others reported a lack of tailored guidance that considered their specific issues, for example with balance or comorbidities.

The lack of specific tailored advice resulted in dissonance in how people viewed the activity and exercise and their confidence to perform them. Previous regular exercise or positive experiences of rehabilitation after different surgeries (e.g. knee surgery) helped some participants to select their own exercises.

"because I've been through, not back surgery, but the knee surgery them before. And I know that, what I have to do, and how I have to try and how you have to exercise and monitor. I was doing that." (P04)

However, many participants lacked confidence or understanding of exercise to do this and this resulted in despondency and inconsistent or discontinued exercise.

"probably six weeks after I did start to have a few problems and think, oh perhaps, should I bother exercising? Should I, you know. Then, I think I spoke to someone else and you know, I went in for my [physiotherapy], which was very good... and gave me a boost." (P15, male, aged 73 years)

Participants described contrasting views on walking aids and their use to help with walking recovery. Many acknowledged their practical necessity in managing pain, unsteadiness, and aiding endurance. However, some found them impractical or viewed their use as a sign of 'being old' or 'giving up'. Progressing (e.g. moving from a frame to a stick) or stopping use of a walking aid was seen as a mark of recovery and independence, signalling successful surgery, and fostering pride and gratification.

"and the first time I went down the shops, and stood in a queue, at the tills without [a walking stick] I come back grinning like a Cheshire cat it was, little things like that people without real back problems take for granted, it was quite a nice moment actually ... things like that are quite quite precious, when you can actually do something again." (P12, male, aged 59)

## Discussion

This is one of the first qualitative studies to explore experiences, expectations, attitudes, and beliefs about rehabilitation and recovery from surgery to treat NC. These were explained by three themes: *making sense of things through a biomedical model, the*

*mismatch between expectation and recovery, and one size doesn't fit all: the need for tailored rehabilitation.* Participant expectations of their care, surgery, and outcome were central, and aligned with all of the constructs of the Integrative Model of Expectations [22]. We identified participant preferences for rehabilitation and a need to address patient's knowledge and skills gaps, confidence to self-manage, and reframe inaccurate recovery expectations to optimise health outcomes and patient experience.

Our findings highlight the limitations of a biomedical lens when explaining and understanding patients recovery from surgery to treat NC. Most participants expected their symptoms to resolve after the mechanical compression had been relieved by the surgery, aligning with the constructs of treatment and outcome expectations of the Integrative Model of Expectations [22]. The biomedical model is easy to understand [43,44] and helped our participants conceptualise their problem, understand the need for surgery and immediate post-operative symptoms. However, this perspective did not help their post-operative recovery for explaining and managing ongoing symptoms. Patients with NC have an increased perception of the threat of pain and low perceived control over their symptoms and treatment [43]. These factors may explain the reliance on some of the back pain myths and fear-avoidance behaviours in our participants [27,45]. It also indicates post-operative advice may not reflect contemporary treatment of spinal pain which draws on a biopsychosocial lens. A qualitative study found that patients awaiting lumbar surgery who were able to explain their symptoms using a biopsychosocial model were more confident that rehabilitation could help [44]. Introducing a biopsychosocial model of persistent pain early in the patient's journey may provide better understanding and tools for managing symptoms, increasing control and reducing distress. Physiotherapists, perceived as credible professionals (Table 3) by our interviewees, are well-positioned to deliver this support.

Mismatched patient expectations and experiences caused distress and dissatisfaction for our participants. This highlights a need to better prepare patients for the recovery journey, a responsibility that should be addressed by all healthcare professionals involved in their care. The subtheme *the unanticipated burden of the recovery* aligns with four of the five constructs of the Integrative Model of Expectations (treatment, timeline, behaviour, and generalised expectations); and the second subtheme *hope versus reality: expectations of the ultimate outcome* can be interpreted through the fifth construct (outcome expectations) [22].

Lack of follow-up with the surgical team and slow recovery heightened the unanticipated burden of recovery. Additionally, lack of information regarding recovery, what to expect and what they could do (as opposed to what they should *not* do) compounded this burden and led to uncertainty and fear. These findings are consistent with those from a qualitative study of patients two weeks after lumbar fusion surgery [45]. Short hospital stays, although recommended for quality care [46], may not prepare patients adequately for recovery. Day-case joint replacement patients received 100 fewer therapy and nursing interactions, leaving patients underprepared for managing the burden of their recovery [47]. Feeling underprepared has been consistently identified in qualitative studies of patients undergoing lumbar surgery [20,48]. Psychological preparation improves post-operative anxiety [49] but has not been comprehensively investigated for patients undergoing surgery for NC. Furthermore, process-related expectations are poorly explored in many spinal surgical studies [18,21]; we propose this is a critical aspect of the patient's journey, and if patients have realistic expectations about the care pathway e.g. when they will receive follow-up etc., then some of the burden of the recovery may be alleviated.



We found that if the ultimate outcome of the surgery was in keeping with the participants' expectations (not necessarily complete symptom resolution) then they were broadly satisfied with their outcome. Where expectations were not met, or expectations were unrealistic and fantastical [22] then a large "expectation-actuality discrepancy" [9] occurred. Larger discrepancies in pre-operative expectations and the actual result are associated with lower satisfaction in patients undergoing elective cervical and lumbar spinal surgery [50]. These mismatches may be due to poor pre-operative counselling and education, and/or poor retention of information from informed consent procedures identified in previous studies [30,51]. Our findings underscore the need for improved pre-operative education to foster realistic expectations about the ultimate outcome of surgery, without inducing pessimism or diminishing the potential benefits of placebo and the positive effects that expectations can bring [9].

Tailored rehabilitation is critical for building self-efficacy, which can influence adherence to self-management and rehabilitation programmes [6]. Self-efficacy is also associated with better outcomes after prehabilitation in patients due to undergo lumbar spinal surgery [52]. This aligns with the behaviour and self-efficacy constructs of the Integrative Model of Expectations [22]. Our participants' expectations and experiences of their rehabilitation highlighted the desire for a personalised approach. UK guidelines recommend post-operative rehabilitation and physiotherapy for spinal surgery care [46], yet rehabilitation is variable, in part due to lack of evidence about optimal rehabilitation content [16,17,53,54]. Notably our interviewees unanimously desired individualised care, which substantiates previous evidence [45,55]. Generic post-operative leaflets were often perceived as inadequate and not patient-centred [56] as they did not sufficiently address patient priorities such as returning to meaningful activities and increasing mobility [6]. Patients wanted rehabilitation to include key topics such as pain management, social support, and walking aids to enable them to self-manage their recovery and rehabilitation.

The participants recognised that resilience and optimism were required to self-manage their recovery and continue with their rehabilitation. Post-operative resilience and pain self-efficacy have been found to be associated with improved outcomes one year after surgery for lumbar degenerative condition [57]. Therefore, tailored rehabilitation programmes must incorporate components that support self-efficacy, motivation, and resilience. With limited guidance available for optimal content of rehabilitation for patients undergoing surgery for NC, our findings will underpin the inclusive co-design of an acceptable, feasible and effective tailored rehabilitation programme.

### Strengths and limitations

This study has several strengths: a robust qualitative approach was used, we engaged in reflexive practice and worked as a team to consider diverse interpretation of the data, and we used an established framework to help interpret our results. Participants were recruited from three different sites and the clinical and social demographics of the participants reflect the diversity of patients undergoing surgery. However, all participants were recruited from hospitals in the Southeast of England, experiences may differ in other regions and other countries. Some participants' experiences may have been affected by COVID-19 pandemic, and the variable time since surgery may have affected recall of the recovery period.

### Conclusion

Undergoing and recovering from surgery to treat NC is perceived as a major life event. Patient's experiences and satisfaction with their care and outcome are heavily influenced by their expectations. There is a need to elicit and reframe unrealistic expectations regarding care, recovery, and ultimate outcome prior to surgery; educate patients on the biopsychosocial model of pain; and ensure patients have a tailored rehabilitation programme. By doing this patient burden may be ameliorated, and patient experience and satisfaction enhanced.

### Disclosure statement

The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, NIHR or the Department of Health and Social Care.

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