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Original article

## Exploring the experiences and perceptions of patients awaiting rotator cuff repair surgery: An integrated qualitative study within the POWER pilot and feasibility trial

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| A R T I C L E I N F O   | A B S T R A C T   |  |
|---|---|--|
| Keywords:<br>Rotator cuff<br>Surgery<br>Patient experience<br>Qualitative | <ul> <li>Background: As waiting times for orthopaedic surgery increase, there have been calls to move from 'waiting lists' to 'preparation lists', to better prepare patients for surgery. In this context, a pilot randomised controlled trial (POWER) was conducted, comparing physiotherapist-led exercise to waiting-list control (usual care), for patients awaiting rotator cuff repair surgery. This qualitative study was integrated within the pilot trial. Objectives: Explore the experiences of adults awaiting rotator cuff repair surgery in the NHS. Explore the acceptability of the physiotherapist-led exercise intervention.</li> <li>Explore the barriers and enablers to recruitment, retention, and adherence. Design: Integrated qualitative study with semi-structured telephone interviews.</li> <li>Methods: Adults awaiting rotator cuff repair, consenting to participate in the trial were eligible. Sampling was purposive regarding age, gender, randomised allocation, and hospital site. Interviews were audio-recorded and transcribed. Data were analysed using Reflexive Thematic Analysis.</li> <li>Results: 20 participants were recruited (age range 49–81 years; 12 male, 10 randomised to physiotherapist-led exercise). Many participants were unable to recall their experiences of trial processes; nonetheless, three themes were identified from the data: experience of shoulder pain and pathway to treatment; communication and decision-making in the context of rotator cuff repair surgery; and experiences of the POWER physiotherapist-led exercise intervention and processes.</li> <li>Conclusions: Patients experience significant burden due to shoulder pain. Their journey to surgery can be long, confusing, and associated with perceived abandonment. In a future trial, the intervention should offer opportunity for shared decision-making, optional exit from the surgical pathway, and an individualised exercise programme.</li> </ul> |  |

## 1. Introduction

Tears of the shoulder rotator cuff tendons are a common cause of shoulder pain, disability, and absence from work (Carr et al., 2017). A patient's decision to undergo surgery for a torn rotator cuff may be complex and is likely to be influenced by many factors, including the degree of disability experienced and recommendations from their treating clinician (Weekes et al., 2020).

Once a decision to undergo rotator cuff repair surgery has been made, patients are placed on a waiting list, and it can take weeks or months to receive surgery, a situation that has been exacerbated by the ongoing impact of the COVID-19 pandemic (Wood, 2022). Whilst awaiting surgery, patients may continue to experience pain, limited function, and disturbed sleep, significantly impacting their quality of life (Minns Lowe et al., 2014). In this context, there has been a call to shift away from the current, passive 'waiting list' model, towards active preparation for surgery (Levy et al., 2021). This approach could optimise physical preparation for surgery (Levy et al., 2021; Punnoose et al., 2023), but may also offer increased opportunity to extend the surgical decision-making process and ensure treatment decisions continue to align with patients' evolving preferences (Levy et al., 2021; Waldron et al., 2020).

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We, therefore, conducted a multi-centre pilot randomised controlled trial to evaluate the feasibility of a fully powered randomised controlled trial to compare the clinical and cost-effectiveness of usual care plus physiotherapist-led exercise with usual care control (remaining on the NHS surgical waiting list with no additional physiotherapy input) in adults awaiting rotator cuff repair surgery (Littlewood et al.).

This nested qualitative study was conducted alongside the pilot trial in order to:

- (1) Explore experiences of adults awaiting rotator cuff repair surgery in the NHS
- (2) Explore the acceptability of the physiotherapist-led exercise intervention to participants
- (3) Explore barriers and enablers to recruitment, retention, and treatment adherence

## 2. Methods

This qualitative study was undertaken using individual semistructured telephone interviews, and is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ (Tong et al., 2007)) (see Supplementary file 1 for the completed COREQ checklist). This study was funded by the National Institute for Health and Care Research (NIHR) via a post-doctoral fellowship for the senior author (PDF-2018-11-ST2-005) and was sponsored by the University Hospitals of Derby and Burton NHS Foundation Trust (UHDB/2021/016). A favourable ethical review was granted by the West of Scotland Research Ethics Service on 14th June 2021 (21/WS/0067). Recruitment to the pilot randomised controlled trial took place between September 2021 and August 2022; a total of 76 participants were randomised. Recruitment to this qualitative study took place between the 23<sup>rd</sup> of May 2022 and the 4<sup>th</sup> of January 2023. Patients listed for surgical repair of the rotator cuff were recruited from six English National Health Service Hospitals and randomly allocated to receive physiotherapist-led exercise whilst awaiting surgery or remain on the waiting list without additional intervention. When the six-month patient-reported outcome measures were completed, consent to further contact to discuss participation in this qualitative study was requested. When consent to contact was gained, trial participants were contacted by the lead researcher (CL), by email or post to provide further information about the study. A follow-up telephone call was then made (by CL) to discuss participation, and, where relevant, to organise a mutually convenient date and time for the interview. Sampling was purposive with respect to age, gender, randomised allocation, and hospital site, with the aim of achieving adequate representation of participants across both treatment groups. Verbal consent for participation in this qualitative study was audio-recorded prior to commencing the interview. A recruitment target of up to 25 participants was stated in the study protocol, aiming to collect data with sufficient information power to adequately address the study objectives (Malterud et al., 2016); however, this sample size estimate was continually reviewed as the quality of the dialogue within the interview transcripts was assessed (Malterud et al., 2016).

Individual, semi-structured, telephone interviews were conducted by the lead researcher (CL) who was unknown to participants. CL is a senior male academic, with extensive experience of conducting semistructured qualitative interviews and an interest in optimising outcomes for patients experiencing tears of the rotator cuff. Topic guides were used to provide structure to the interviews (Supplementary file 2); these were informed by methodological literature relating to qualitative process evaluation within clinical trials (Cheng and Metcalfe, 2018) and developed in consultation with a patient and public involvement group involving four NHS patients; one patient had experienced a rotator cuff tear, one had undergone rotator cuff repair surgery, and two had experienced shoulder injuries. The topic guides covered: (1) participants' pathway to surgery (2) the processes of recruitment to the POWER pilot randomised controlled trial; (3) participants' experiences and perceptions of the physiotherapist-led exercise intervention where relevant, and (4) participants' experiences of the study processes (including electronic data collection). The topics were covered flexibly to enable exploration of any new insights revealed during the interview. The interviews were audio recorded and transcribed in an intelligent verbatim format by MM; that is, the words used by participants were transcribed exactly as spoken, except that 'fillers' such as 'erm', 'ahh' and 'hmm' were omitted as they were not seen to add to or change meaning (McLellan et al., 2003). Member-checking was not undertaken.

The six-step approach to thematic analysis outlined by Braun and Clarke was used to analyse the data (Braun et al., 2016). Transcripts were read and re-read in their entirety by the lead researcher (CL) and the first author (MM); they were then independently coded by the same two researchers. An initial list of 59 codes was generated. A refined list of 14 codes was then agreed upon through iterative, reflexive discussion. These codes were then systematically applied to the entire dataset by CL and MM and grouped into overarching themes. All data relevant to each code was reviewed by CL and MM so that themes could be checked for coherence, clarity, and distinctness.

Due to the time that had elapsed between recruitment to the POWER pilot trial and the qualitative interviews taking place, many participants' accounts did not contain sufficient detail about their experiences of recruitment to meet each of the pre-stated objectives. Nonetheless, rich information regarding participants' experiences of living with a rotator cuff tear, engagement in surgical decision-making, the programme of physiotherapist-led exercise, and current treatment pathways was gathered. An alternative analytic direction was, therefore, pursued (Sale, 2022) and is reported in this paper. The concept of analytic direction is a strategy that allows researchers to decide which "story" should be told from their qualitative data (Sale, 2022). In this case, the decision to share insights provided by participants that extend beyond the original objectives of the study was deemed ethical to ensure that issues deemed important to participants were highlighted to clinicians and researchers.

## 3. Findings

Twenty-four participants provided consent to contact. Of these 24 participants, 20 consented to participate in this qualitative study; three could not be contacted, and one was not contacted in line with the purposive nature of the sampling. 20 participants provided consent and participated in a telephone interview (10 = physiotherapist-led exercise group, 10 = waiting list control group). Participant interviews lasted a mean of 20 min (range 10-31); one interview was significantly shorter than the rest with a duration of just 10 min. The reason for this was that it became apparent early in the interview that the participant had limited views to share; it was, therefore, felt that asking further probing questions may cause unnecessary distress. Following the 20 interviews, the option to provide consent to contact was removed from the sixmonth trial follow-up questionnaire because it was deemed the information gathered was sufficiently rich and no additional detail about participants' experiences of recruitment was gleaned from the final three interviews.

The characteristics of the study participants are presented in Table 1 below.

Three themes were identified:

- 1) Experience of shoulder pain and pathway to treatment
- 2) Communication and decision-making in the context of rotator cuff repair surgery
- 3) Experiences of the POWER physiotherapy-led exercise intervention and processes

Each theme will be discussed in detail below. Relevant participant quotations supporting these findings are presented in Table 2.

#### Table 1

Participant characteristics.

| Participant ID<br>number | Gender | Age<br>(Years) | Employment type based on the Standard Occupational<br>Classification (2010) (Emmel and Cosca, 2010) | Reported time since onset of shoulder pain                      | POWER Trial group allocation    |
|--------------------------|--------|----------------|---|---|---------------------------------|
| 01–003                   | Male   | 52             | Caring, leisure and other service   | 10 years  | Physiotherapist-led<br>exercise |
| 01–009                   | Male   | 55             | Skilled trades  | Specific timeframe not given – several<br>year history reported | Waiting list                    |
| 01–049                   | Male   | 49             | Professional  | 3 years   | Waiting list                    |
| 01–064                   | Male   | 50             | Skilled trade   | 4 years   | Physiotherapist-led<br>exercise |
| 01-071                   | Male   | 62             | Skilled trade   | 18 months   | Waiting list                    |
| 03–003                   | Male   | 64             | Process, plant and machine operatives   | 3 years   | Physiotherapist-led<br>exercise |
| 03–014                   | Female | 63             | Sales and customer service  | 19 months   | Waiting list                    |
| 03–016                   | Male   | 55             | Self-employed - Skilled trade   | 14 months   | Physiotherapist-led<br>exercise |
| 03–023                   | Male   | 61             | Skilled trade   | 2 years   | Waiting list                    |
| 04–002                   | Female | 69             | Caring, leisure and other service occupations   | 12–18 months  | Physiotherapist-led<br>exercise |
| 04–016                   | Male   | 65             | Professional  | 18 months   | Physiotherapist-led<br>exercise |
| 04–019                   | Female | 75             | Retired (previous role not disclosed)   | 3 months prior to surgery                                       | Waiting list                    |
| 04–031                   | Male   | 75             | Retired (previous role not disclosed)   | 3 years   | Physiotherapist-led<br>exercise |
| 04–034                   | Female | 55             | Professional  | 12 years  | Physiotherapist-led<br>exercise |
| 04–037                   | Female | 50             | Self-employed Sales and customer service  | 11 months   | Waiting list                    |
| 04–038                   | Male   | 81             | Retired (previous role not disclosed)   | 8 months  | Physiotherapist-led             |
|                          |        |                | ч <b>т</b> ,  |   | exercise                        |
| 04–039                   | Female | 66             | Retired (previous role not disclosed)   | 13 months   | Waiting list                    |
| 05–024                   | Male   | 49             | Unemployed  | 18 months   | Waiting list                    |
| 06–002                   | Female | 67             | Retired (previous role not disclosed)   | 3 years   | Physiotherapist-led<br>exercise |
| 06–008                   | Female | 58             | Administrative and secretarial  | 12 months   | Waiting list                    |

# 4. Theme 1. Experience of shoulder pain and pathway to treatment

#### 4.1. Subtheme 1. Experience and impact of shoulder pain

Participants described the wide-reaching impact of their shoulder problem on their daily lives. The shoulder symptoms reported included shoulder pain, reduced mobility, decreased function, and decreased strength. Participants also described the direct impact of their shoulder problem on work, finances, leisure, socialising, activities of daily living, and sleep.

Two participants explicitly discussed the emotional and cognitive impacts of their ongoing shoulder pain. One participant also reported the development of secondary complications following their rotator cuff tear describing how they had developed a frozen shoulder that required treatment with hydrodistension.

#### 4.2. Subtheme 2. Pathway to treatment

Seven participants described what they perceived to be an excessively convoluted and protracted pathway to being listed for rotator cuff surgery. One participant also expressed a suspicion that limited NHS resources dictate treatment decisions.

Twelve participants discussed their experiences of trialling nonsurgical management options before being listed for rotator cuff repair surgery; these included previous physiotherapy (including physiotherapy-led exercise), corticosteroid injections, and osteopathy. Of the 10 participants who discussed their experiences of prior physiotherapy treatment, nine explicitly stated a failure to reach what they perceived to be an acceptable symptom state.

#### 4.3. Subtheme 3. Sense of abandonment and frustration

Four participants talked at length about the sense of abandonment

experienced once they were placed on the surgical waiting list. They described long periods of waiting with no communication from the hospital and no inkling of when or if a surgical date might be allocated; the frustration that resulted was emphatically communicated.

One participant specifically called for additional consultations to be scheduled in the lead-up to surgery to provide the opportunity to discuss progress and review the available treatment options.

# 5. Theme 2. Communication and decision-making in the context of rotator cuff repair surgery

Where healthcare professionals (HCPs), including surgeons, radiographers, and physiotherapists, were definitive that surgery was required, this set an expectation for participants. Yet, where uncertainty regarding the need for surgery or the likely outcome of surgery was communicated, participants were more open to non-surgical management.

Additionally, participants who decided not to proceed to surgery saw this decision as reversible and expressed that they would reconsider if their symptoms or context changed.

Eight participants discussed their perception that surgical intervention was required to 'repair' or 'fix' their rotator cuff tear. This view was informed by either the information provided by their treating clinician or an unacceptable response to non-surgical management. One participant also spoke of feeling she had no choice but to undergo surgery due to the way the treatment options were communicated to her.

Overall, participants understood the nature of their shoulder problem and that their rotator cuff tendons were torn. However, three participants had a 'catastrophic' view of the problem which informed their perception that surgical intervention was inevitable.

Positive language used by HCPs could motivate participants in their post-surgical rehabilitation, promote adherence to exercise-based treatment, or encourage acceptance of their current symptom state. Conversely, three participants described how the language used by HCPs could also instil fear or cause fear avoidance of activities.

#### Table 2

Theme

Theme 1. Experience of

pathway to treatment

Subtheme 2. Pathway to

Subtheme 3. Sense of

abandonment and

frustration

treatment

shoulder pain and

Subtheme 1.

pain

Experience and impact of shoulder

Themes, key concepts, and relevant

| 1                         |   | Table 2 (continued)    |  |  |
|---------------------------|---|------------------------|--|--|
| Key concept presented     | Example supporting quote                            | Theme                  | Key concept presented within the theme | Example supporting quote                       |
| within the theme          |   |                        |  | on a waiting list, and that                    |
| Symptoms of rotator       | "The injury was sudden<br>and extremely painful and |                        | Additional consultations               | was it." 06-002<br>" rather than just being a  |
| reaching impacts on       | I can pretty much honestly                          |                        | suggested to discuss                   | person on a pile that's                        |
| participants' lives       | say for the best part of the                        |                        | progress and review                    | forgotten about until the                      |
|                           | past year, my life has been                         |                        | treatment options                      | date. You know with                            |
|                           | completely changed by the                           |                        |  | what's gone on in the last                     |
|                           | shoulder injury I                                   |                        |  | couple of weeks [increased                     |
|                           | couldn't enjoy my hobbies                           |                        |  | snoulder pain], I would kind of expect to have |
|                           | swimming anything                                   |                        |  | another appointment with                       |
|                           | active. I was unable to                             |                        |  | the consultant You're                          |
|                           | work properly because of                            |                        |  | just left completely                           |
|                           | the pain It just                                    |                        |  | waiting and not knowing.                       |
|                           | completely controlled my                            | Theme 2                | Where healthcare                       | "I went to see a chan                          |
| Emotional and cognitive   | " it wears you down.                                | Communication and      | professionals were                     | who is a sports                                |
| impact of rotator tear    | That's the thing, it just                           | decision-making in     | definitive that surgery                | physiotherapist who had                        |
| symptoms                  | gradually wears you                                 | the context of rotator | was required, this set an              | been recommended to me                         |
| a 1                       | down." 04-031                                       | cuff repair surgery    | expectation for                        | he confirmed basically                         |
| Secondary                 | "I've actually been into<br>hospital [self funded   |                        | participants                           | need surgery, that no                          |
| developed because of a    | private treatment] two                              |                        |  | amount of physio would                         |
| rotator cuff tear         | weeks ago because                                   |                        |  | help it." 04-037                               |
|                           | somehow, I've got a frozen                          |                        | Participants were more                 | " both my GP and the                           |
|                           | shoulder from having this                           |                        | open to non-surgical                   | doctor in casualty said that                   |
| Convoluted and/or         | "I did see numerous                                 |                        | uncertainty was                        | tendons surgically by                          |
| protracted pathway to     | consultants who did ship                            |                        | communicated.                          | putting a staple in, that at                   |
| treatment                 | me around from place to                             |                        |  | your age, the staple might                     |
|                           | place." 04-031                                      |                        |  | just tear through the                          |
|                           | "the casualty doctor said                           |                        |  | apart again So that's                          |
|                           | have a pathway to refer                             |                        |  | still in the back of my                        |
|                           | you to the shoulder people                          |                        |  | mind" 04-038                                   |
|                           | so you've got to go back to                         |                        |  | "So he [physiotherapist                        |
| Sumision that limited     | the GP"." 04-038<br>"I think though it is a         |                        |  | delivering the POWER                           |
| NHS resources dictate     | money thing: because                                |                        |  | sort of looked at it and he                    |
| treatment decisions       | initially I should have had                         |                        |  | thought well, 'you don't                       |
|                           | an MRI scan and they                                |                        |  | look like the sort of person                   |
|                           | would have known                                    |                        |  | that needs surgery from                        |
|                           | immediately [that the                               |                        |  | that's basically what was                      |
|                           | 016   |                        |  | his assessment. And as I                       |
| Range of non-surgical     | "I seen an osteopath for a                          |                        |  | used his programme, I, you                     |
| treatment options         | while but that just made it                         |                        |  | know, things just                              |
| trialled prior to being   | worse, and no pain relief                           |                        |  | 016  |
| repair surgery            | was working 00-002                                  |                        | Decision not to have                   | "I mean they have said if it                   |
| Failure to reach an       | "Cause the physiotherapy                            |                        | surgery seen as                        | goes painful again, or                         |
| acceptable symptom        | I was having it wasn't                              |                        | reversible                             | anything, just go straight                     |
| state with                | helping, let's put it that                          |                        |  | back to them. So, I have                       |
| being listed for rotator  | way, it was I thought I<br>was getting worse rather |                        |  | but at the moment I                            |
| cuff repair surgery       | than any better with some                           |                        |  | certainly don't think I                        |
|                           | of the physio that I was                            |                        |  | need surgery." 04-002                          |
|                           | doing." 01-071                                      |                        |  | "Well yeah it [shoulder                        |
| Frustration and           | "I paid private, just                               |                        |  | painj could deteriorate                        |
| experienced while on      | there was anything, 'cause                          |                        |  | at the minute it looks                         |
| the surgical waiting list | obviously from January to                           |                        |  | alright." 04-016                               |
|                           | September, I've been in                             |                        | Surgery is needed to                   | " obviously the rotator                        |
|                           | like total agony But, I've                          |                        | "fix" the torn rotator                 | cutt would only get worse                      |
|                           | that I'm going to get the                           |                        | cuii                                   | obviously torn or in mv                        |
|                           | operation date and                                  |                        |  | case, departed from the                        |
|                           | obviously it never arrived"                         |                        |  | bone completely. So, I'm                       |
|                           | 04-037  |                        |  | not sure exercising or                         |
|                           | SO I VE neard nothing                               |                        |  | physic would do ally good                      |

..." 03-023 "Well, I just wanted the operation because I felt it [further physiotherapy treatment] was just

(continued on next page)

from the surgical team,

no ... they just said I was

I've heard no appointment, I've heard

## Tab

| Table 2 (continued)   |   |  | Table 2 (continued)                  |
|---|---|--|--------------------------------------|
| Theme   | Key concept presented within the theme  | Example supporting quote   | Theme                                |
|   |   | dragging the whole<br>procedure out longer." 04-<br>031  |                                      |
|   | Perceived lack of choice<br>about rotator cuff repair<br>surgery  | " part of me felt with the<br>consultant, that he was<br>like "Well, you're having<br>surgery and that's it". And<br>he was the main shoulder<br>surgeon so I felt like it was       |                                      |
|   | Many participants   | you're doing this whether<br>you want it or not." 06-002<br>"End of summer '18, I had  |                                      |
|   | their shoulder problem  | my rotator cuff on my left<br>shoulder." 01-049  |                                      |
|   | A catastrophic view of<br>the nature of the<br>shoulder problem<br>informed the perception                                    | "And they realised [based<br>on the MRI scan findings]<br>that they're all shredded,<br>like they said they're   |                                      |
|   | that surgical<br>intervention was<br>inevitable   | hanging on strings<br>basically my shoulders<br>were, and they were really<br>really, like, torn, badly."<br>01-064  |                                      |
|   | Positive impact of<br>positive language used<br>by healthcare<br>professionals<br>(encourage acceptance<br>of current symptom | " talking to the surgeon,<br>he said 'well that part of<br>your shoulder's gone, and I<br>can't recover that'. So, it's<br>just something you've got<br>to live with really." 03-016 |                                      |
|   | state)<br>Negative impact of<br>language used by<br>healthcare professionals  | " he [the surgeon] said<br>'Oh, you've got to stop<br>doing that straight away'<br>he said 'that's going to<br>ruin it if you keep doing   |                                      |
| Theme 3. Experiences of<br>the POWER<br>physiotherapy-led<br>exercise intervention<br>and processes | Drivers for participation<br>in the POWER pilot trial   | that'. 03-016<br>"For me it's like trying to<br>get advances in medicine,<br>you know like donating<br>blood, it's something<br>along them lines it helps."                          | Subtheme 3 Follow                    |
| and processes<br>Subtheme 1.<br>Recruitment   | Factors considered<br>when deciding whether<br>to participate in the<br>POWER pilot trial                                     | "The question I had right<br>at the beginning was<br>obviously, if I participate<br>in this study, is that going<br>to make me have to wait<br>longer" (04-037                       |                                      |
|   | Positive reflections on<br>recruitment discussions<br>with host site research<br>staff  | "Yeah, a lady called me<br>and she was always<br>extremely easy to talk to<br>and explained things." 04-<br>016  |                                      |
|   | Positive reflections of<br>patient-facing<br>recruitment documents  | "I, personally, I found<br>them [patient-facing study<br>documents] fine because I<br>like to know exactly what<br>I'm getting into before I do<br>it. So, I think it was            |                                      |
|   |   | worded well and it was<br>fairly straightforward."<br>06-008   |                                      |
|   | Cynicism relating to the randomisation process  | "I did wonder if I had been<br>placed at random into the<br>control group, or whether<br>I'd been put there because  | 6. Theme 3. Exp<br>exercise interver |
| Subtheme 2.   | Negative experiences of   | "I was alright like on the   | 6.1. Subtheme 1.                     |
| Physiotherapist-led<br>exercise intervention  | the POWER pilot trial intervention  | forward stroke [shoulder<br>flexion exercise], but it's<br>the side [shoulder  | The drivers for altruism, the possi  |

| Theme                 | Key concept presented within the theme  | Example supporting quote  |
|-----------------------|---|---|
|                       |   | crippled me." 03-003<br>"There was a lot of ticking<br>and exercise to do, which I<br>managed to do as much as<br>possible, but there's only<br>so many hours in the day<br>you can do them, and I<br>think certainly you've<br>gone a bit over the top".<br>04-031   |
|                       | Positive experiences of<br>the POWER pilot trial<br>intervention  | "You know, because you<br>built up the number of<br>times you could do the<br>exercise, and I could feel,<br>that, you know, virtually<br>improving every day. So, I<br>could see right at the<br>beginning how effective it<br>all was." 04-038  |
|                       | Single session with the<br>treating physiotherapist<br>perceived to be<br>insufficient  | "Just the lack of support,<br>that's the only, that's the<br>only issue I had with it [the<br>POWER trial intervention]<br>really. It was quite<br>disappointing really, there<br>was no follow-up about it."<br>01-009   |
|                       | Positive experience of<br>the POWER pilot trial<br>exercise manual  | "So I had a booklet to fill<br>out and then obviously<br>you do more exercises per<br>week just bringing them<br>up a bit each week. So, I<br>just did that on my own<br>really." 03-016  |
|                       | individualising the<br>exercise programme<br>seen as important  | So, when I spoke to<br>[physiotherapist's name<br>removed for anonymity],<br>he put it more into what I<br>could manage as opposed<br>to this regime, which made<br>it a lot easier for me. 06-<br>002  |
| Subtheme 3. Follow-up | Minimal difficulty<br>completing the online<br>follow-up<br>questionnaires<br>Questions posed via the<br>validated outcome<br>measures perceived to<br>be open to<br>interpretation | "Yeah, just clicked the link<br>or if it was text I just filled<br>it in I thought it was<br>quite easy myself." 01-064<br>" the way some of the<br>questions are worded, it's<br>awkward to give an<br>accurate answer" 01-003   |
|                       | Negative perception of<br>questions about mental<br>health and concern that<br>responses to study<br>questionnaires might<br>influence NHS care                                     | " some of them<br>[questionnaires] asked me<br>what state of mind I was in<br>which I thought was<br>absolutely ridiculous<br>and they asked me if I was<br>depressed I said "No",<br>and my wife said I should<br>have answered "Yes"<br>because she thought that<br>put my operation back a<br>bit." 04-031 |

## Theme 3. Experiences of the POWER physiotherapy-led rcise intervention and processes

## Subtheme 1. Recruitment

The drivers for participating in the POWER pilot trial included: uism, the possibility of personal benefit, supporting developments in clinical practice, and personal interest.

Only two participants discussed other factors influencing their

abduction exercise] that

decision regarding participation; these included concerns over privacy and confidentiality, and whether trial participation would increase the time spent waiting for surgery.

Most participants were unable to recall how they were approached for recruitment due to the length of time that had elapsed before the qualitative interviews took place. However, six participants recalled being contacted by a member of site staff via telephone and each reflected positively on their recruitment discussions.

Two participants could recall their experiences of the patient-facing recruitment documents; they reflected that they were easy to read and contained sufficient information to support decision-making.

Of the three participants who discussed their experiences of the randomisation process, two reported acceptance of their allocated treatment whilst one reported cynicism about whether treatment allocation was a truly random process.

## 6.2. Subtheme 2. Physiotherapist-led exercise intervention

Each of the 10 participants allocated to the physiotherapist-led exercise intervention discussed their experiences of their treatment in the POWER pilot trial. Two participants received their surgery before the POWER trial intervention could be delivered, and three reported the exercises to be excessively difficult, painful, or time-consuming.

Nonetheless, five participants reported positive experiences; four described excellent symptomatic relief and a subsequent decision not to proceed to surgery, and one reported a perceived gain in shoulder strength.

For many, the POWER pilot trial intervention was delivered as a single session with the physiotherapist. However, four participants perceived that increased contact with the treating physiotherapist would have been preferred.

Only one participant discussed their experience of using the POWER study exercise manual in any detail. They felt the manual was easy to follow and was valuable in supporting adherence to the exercises. Nonetheless, four participants highlighted the important role of the treating physiotherapist in individualising the exercises in the manual to ensure they were manageable.

## 6.3. Subtheme 3. Follow-up

Most participants were able to complete the online follow-up questionnaires without difficulty. However, three participants recruited early in the study (whilst database refinements were ongoing) reported problems accessing the online questionnaire using the links received by email. Two participants perceived the questions in the validated outcome measures to be frustratingly repetitive, whilst two others perceived the questions to be ambiguous or open to interpretation.

One participant expressed contempt at being asked about his mental health via one of the validated tools within the participant questionnaires (the EQ-5D). He also expressed concern that the responses given to questions about his mental health might impact on the timing of surgery.

## 7. Discussion

Due to the length of time that had elapsed between recruitment to the POWER pilot randomised controlled trial and invitation to participate in this qualitative study, participants' accounts lacked sufficient detail to meet the initial study aims. The findings of this study did, however, highlight the significant and wide-reaching impact of shoulder pain on every aspect of participant's lives. The language used by clinicians, and how participants interpreted this, were important in determining future treatment pathways. For example, where clinicians were clear that surgery was needed, this set an expectation for participants and often informed the perception that non-surgical treatment options would not be of benefit. Participants described long waits for surgery and a sense of abandonment due to a lack of communication and support while waiting. The POWER pilot trial intervention comprised physiotherapist-led exercise and was acceptable to the majority of those who engaged with it; however, a single physiotherapy session was felt to be insufficient and structured follow-up would have been welcomed by some participants. Although structured follow-up was intended as a key component of the physiotherapist-led exercise programme (Littlewood et al.), it is apparent that this did not always materialise in practice and approaches to facilitate shared decision-making were sometimes lacking. The role of the treating physiotherapist in individualising the exercises was described as an important vehicle to facilitate adherence to and engagement with the exercise programme.

The fact that many participants were unable to recall their experiences of recruitment to our pilot trial six months later is an important finding of this study. Qualitative process evaluations of clinical trials are common (Cheng and Metcalfe, 2018), and researchers often choose to collect data after participants have completed trial follow-up to avoid influencing behaviour or outcomes (Grant et al., 2020). However, for the findings of a process evaluation to be useful, data collection should occur within a timeframe during which participants can reasonably be expected to recall relevant experiences (Grant et al., 2020; Moore et al., 2015). In this case, the decision to delay qualitative data collection until after completion of the six-month follow-up proved to be unhelpful; researchers should consider this when designing future trials to ensure their objectives can be achieved.

The significant and far-reaching impact of shoulder pain in the presence of rotator cuff tears reported in this study has been identified previously (Minns Lowe et al., 2014). Given the impact on an individual's ability to undertake daily activities, work, socialise, and sleep, the individual burden can be substantial and needs to be recognised by clinicians, researchers, policymakers, and funders. In the context of this persisting burden, the need to support people to make the best treatment choices, including whether to proceed to surgery, is essential, as their personal circumstances evolve over time.

In a healthcare context, shared decision-making is a collaborative process between patients and clinicians that allows patients to reach an acceptable decision about their treatment (Elwyn et al., 2017). A robust approach to shared decision-making combines the clinician's knowledge of available treatments, including their effectiveness, risks, and benefits, with the patient's preferences, personal situation, values, and beliefs (Waldron et al., 2020; Hoffmann et al., 2022). The recommended approach to shared decision-making includes openly discussing any uncertainties regarding the effectiveness of the treatments and, crucially, explaining the potential outcomes if the condition were left untreated (Waldron et al., 2020; Elwyn et al., 2017; Hoffmann et al., 2022). Four participants in this study decided not to proceed with surgery after engagement with the physiotherapist-led exercise programme as an acceptable symptom state had been reached. This highlights that patients' treatment preferences can change over time. A single opportunity for shared decision-making at the outset of treatment, for example, when listed for rotator cuff repair surgery, may, therefore, be inadequate; repeated opportunities to review surgical decision-making are warranted as the patient's symptoms and situation evolve (Levy et al., 2021).

An individual's decision to undergo surgery for a torn rotator cuff can be affected by many factors, including the opinions of clinicians they encounter on their treatment pathway (Weekes et al., 2020). The way in which the treating clinician frames the benefits and harms of treatment also strongly influences patients' decision-making (Torrens et al., 2019). The findings of this study reflect this thinking and underscore the importance of clinicians' choice of language during shared decision-making conversations. Relatedly, this study suggests that use of catastrophic language to describe the rotator cuff tear can not only instil fear in patients but can also inform the belief that surgery is the only available option. The aim should, therefore, be to take a balanced approach to condition-related information provision to ensure patients adequately consider all available treatment options. This includes the equivocal findings from previous research comparing surgery to non-surgical approaches (Longo et al., 2021) and the high prevalence of asymptomatic rotator cuff tears (Hinsley et al., 2022). The use of a recognised model of shared decision-making, such as the 'Three Talk Model' (Elwyn et al., 2017) recommended by the National Institute for Health and Care Excellence (NICE (National Institute for Health and Care Excellence, 2021)), may facilitate this process.

The sense of abandonment experienced by some participants in this study was largely due to the perceived lack of communication and support offered by the treating clinicians while participants waited for surgery; participants suggested additional consultations in the lead-up to surgery to address this. A 2020 report published by National Voices, the leading coalition of health and social care charities in England, suggested that patients' experiences of waiting for elective care could be improved if patients were given advice and information on exercise and symptom control during the period of waiting, and if connections with clinicians could be maintained to allow condition and treatment-related queries to be dealt with as they arise (National Voices, 2020). Combined with findings of this study, this evidence suggests the need to better support patients awaiting rotator cuff repair surgery to improve their experiences of NHS care. This insight will inform intervention development for the future fully powered randomised controlled trial to maximise acceptability to participants and optimise shared decision-making.

The POWER pilot trial intervention was deemed acceptable by most participants allocated to receive it. However, the important role of the physiotherapist in individualising the exercises to facilitate engagement was also described. The way exercises are prescribed, and the quality of communication with the treating clinician, are known to influence adherence to exercise-based interventions (Bailey et al., 2023). Therefore, within a future fully powered randomised controlled trial, training for treating physiotherapists must emphasise their role in tailoring the exercises to the needs of individuals to ensure they are acceptable and manageable. This, in turn, may promote exercise adherence and engagement with the programme (Argent et al., 2018).

The findings of this qualitative study have several implications for the design of a future fully powered randomised controlled trial: (1) Treatment-related discussions between patients and clinicians should be conducted in line with recognised models of shared decision-making; (2) The intervention should include opportunity for ongoing support to participants while they await rotator cuff repair surgery with the option to revisit decision-making in relation to surgery; and (3) The exercises prescribed as part of the trial intervention should be individualised to promote acceptability and adherence.

## 8. Strengths and limitations

The strengths of this study include the involvement of more than one researcher at every stage of data analysis, and reporting that is aligned with available guidance. The use of interview topic guides ensured consistency across all interviews but allowed additional insights to be explored (DeJonckheere and Vaughn, 2019); this flexibility helped uncover participants' experiences of surgical decision-making and their anxieties whilst waiting for surgery.

This study was designed during the COVID-19 pandemic; telephone interviews were, therefore, used to ensure data collection could continue if further social distancing measures were reintroduced after the study commenced. Telephone interviews may be criticised due to perceived difficulty building rapport and lack of access to non-verbal cues (Novick, 2008). Despite this, research suggests that telephone interviews can generate data comparable to in-person interviews (Drabble et al., 2016), and the relative anonymity experienced during telephone interviews may encourage participants to disclose controversial views (Ward et al., 2015). The decision to use telephone interviews in this study is, therefore, not perceived as a threat to rigour. Over recent years, video

conferencing platforms have proved a viable alternative for undertaking qualitative interviews (Archibald et al., 2019). However, evidence suggests that there remains a proportion of the UK population who do not have access to the appropriate devices, WiFi connectivity, or digital literacy skills to engage with such platforms (Harvey et al., 2023; Holmes and Burgess, 2022). Given this, in future research, it would seem sensible to offer participants the option to select their preferred mode of virtual interview (telephone or online), to ensure that those unable to engage with online platforms are not systematically excluded from taking part.

The decision to pursue an alternative analytic direction was deemed ethical to ensure that issues deemed important to participants were highlighted in the literature; however, it is acknowledged that despite the high-quality dialogue between the interviewer and participants, broadening the scope of the study may well have reduced the overall information power of the data (Malterud et al., 2016). Readers should consider this when interpreting the findings of this study.

'Abandonment' was selected as a specific subtheme despite only being explicitly discussed by four participants. This decision was made following reflexive discussion between the research team and our patient representative. It was felt that the length and quality of the related dialogue and the information power subsequently obtained justified this decision (Malterud et al., 2016; Braun and Clarke, 2019)).

Finally, this study focused on the views of study participants and did not include those of the clinicians delivering the intervention. Clinician interviews might have provided further insight in relation to evaluation of trial processes and acceptability of the intervention.

#### 9. Conclusion

The pathway to surgery can be long, and some participants experienced a sense of abandonment due to the lack of support offered while they waited. Participants often conceptualised their shoulder problem in a way that led them to infer that surgery was the only treatment option, and they were not always adequately involved in making decisions about their treatment. For some participants, treatment preferences changed over time, suggesting a definitive decision regarding surgery cannot be made at a single point in time. A future fully powered randomised controlled trial should include an intervention that offers opportunities to revisit the decision to undergo surgery, and an individualised approach to physiotherapist-led exercise.

## Data statement

Requests for sharing of anonymised data can be submitted via email to the lead author.

## Role of contributing authors

CL, JW and NEF conceived of the study and were involved in developing the design and protocol. CL, JW and NEF secured funding for the study. CL conducted the data collection, whilst data analysis was undertaken by MM and CL. MM drafted the manuscript and all other authors reviewed and provided feedback on drafts. All authors read and approved the final version of the manuscript.

#### Declaration of competing interests

We declare no conflicts of interest.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.msksp.2023.102893.

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