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A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder

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Complete List of Authors:	Jones, Susan; Teesside University, Health and Social Care Institute Hanchard, Nigel; Teesside University, Health and Social Care Institute Hamilton, Sharon; Teesside University, Health and Social Care Institute Rangan, Amar; The James Cook University Hospital, Orthopaedics
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A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder
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Jones, Susan; Hanchard, Nigel; Hamilton, Sharon; Rangan, Amar

Abstract:

Objectives: To elucidate patients' perceptions of, and treatment priorities for, frozen shoulder.
Design: Qualitative study design using semi-structured interviews.
Setting: GP and musculoskeletal (MSK) clinics in primary and secondary care in one NHS Trust in England.
Participants: Twelve patients diagnosed with primary frozen shoulder were purposively recruited from a GP surgery, community clinics and hospital clinics. Recruitment targeted the phases of frozen shoulder: pain predominant (n=5), stiffness predominant (n=4), and residual stiffness predominant following hospital treatment (n=2). One participant dropped out. Inclusion criteria: Adult, male and female patients of any age, attending the clinics, who had been diagnosed with primary frozen shoulder.
Primary and secondary outcome measures: not appropriate.
Results: The most important experiential themes identified by participants were: pain which was both severe and inexplicable; inconvenience/disability arising from increasing restriction of movement (due to pain initially, gradually giving way to stiffness); confusion/anxiety associated with delay in diagnosis and uncertainty about the implications for the future; and treatment-related aspects. Participants not directly referred to a specialist (whether physiotherapist, physician or surgeon) wanted a faster, better-defined care pathway. Specialist consultation brought more definitive diagnosis, relief from anxiety, and usually self-rated improvement. The main treatment priority was improved function, though there was recognition that this might be facilitated by relief of pain or stiffness. There was a general lack of information from clinicians about the condition with over-reliance on verbal communication and very little written information.
Conclusions: Awareness of frozen shoulder should be increased among non-specialists and the best available information made accessible for patients. Our results also highlight the importance of patient participation in frozen shoulder research.
Trial registration: not appropriate.

Article Summary

Article focus

- The experiences and perceptions of people living with primary frozen shoulder, and their priorities for treatment.

Key messages

- Primary frozen shoulder causes severe pain and restricts activities of daily living. Incorrect or delayed diagnoses often amplify patient anxiety and hold up treatment.
- Care pathways are needed with prompt diagnosis and access to specialist (or informed) care. Raising awareness of the diagnostic criteria and management options among non-specialist healthcare staff—especially GPs and physiotherapists—should make this more achievable.

- Translation of evidence to the target audience of non-specialist healthcare professionals is a priority.

Strengths and limitations of this study

To our knowledge, this was the first study to capture the experiences of patients with frozen shoulder.

Patients were recruited from care settings representative of those where the condition is typically managed. However, the number of participants was small and data saturation was not achieved, so the findings must be considered indicative rather than conclusive. In addition, two participants' experience of frozen shoulder was retrospective. Compared to recent cases, their contributions are likely to be more open to recall bias, and to reflect less current, earlier approaches to care.

Nevertheless the design included trustworthy methods with clear reporting, allowing readers to make their own judgement on trustworthiness. As the work published on this topic is very limited this article makes a valuable contribution.

INTRODUCTION

Frozen shoulder (FS) is a condition affecting the capsule of the shoulder joint, and is characterised by inflammation and contracture.[1] As reviewed by Hand et al[1] and Kelley, McClure and Leggin,[2] these events may occur for no identifiable reason in "primary" or "idiopathic" FS or in association with, or secondary to, some other event or condition in "secondary" FS. However some authorities label frozen shoulder associated with diabetes—a known risk factor[3]—as a "primary" type.[4]

The prevalence of those seeking help for primary frozen shoulder (FS) has been estimated as 2 to 5%;[1] while in the general working-age population, a large survey has estimated prevalence as high as 10%.[5] The healthcare implications of primary FS are considerable. In the UK, for example, based on a single GP consultation for each case, it costs the National Health Service at least £44.1 million (assuming a prevalence of 2%) or £110.3 million (assuming a prevalence of 5%). And since the usual age at onset is 40-60 years,[6] which is typically within the working-age range, there is a crucial economic impact on individuals and society.

Codman, who coined the term frozen shoulder, described the typical clinical manifestation as early as 1934:

> "The condition [comes] on slowly; pain usually felt near the insertion of the deltoid; inability to sleep on the affected side; painful and incomplete elevation and external rotation; restriction of both spasmodic and mildly adherent type;

> atrophy of the spinati; little local tenderness; X-rays negative except for bone atrophy."[7]

However, the location of pain may be variable[6] and diagnosis may present a challenge, particularly for the non-specialist, and particularly in the early stages, when the signs are not pronounced: not least because false positive responses to standard tests for shoulder impingement (Neer's sign, Hawkins' test) are to be expected.[8] Recognising FS as phasic in nature, the recent UK guidelines for diagnosis, assessment and physiotherapy management of FS recommend a simple dichotomous "pain predominant" or "stiffness predominant" classification, whereby the patient is the arbiter of the stage, and pain takes precedence when there is ambiguity.[8]

Potential interventions include watchful waiting, physiotherapy, steroid injection, distension arthrography, manipulation under anaesthetic (MUA) and arthroscopic capsular release.[4 8] There is some evidence for specific interventions, although none of this is strong,[5,9] and not all observational series have verified the certainty of complete recovery. For example, in a recent study of 223 patients with FS referred to tertiary care, 38% had persistent mild symptoms, mostly pain, at a mean follow-up of 4.4 years (range 2 to 20 years). In 3% the persistent symptoms were severe, with pain and functional deficits.[10]

Despite a general appreciation that the condition imposes a serious burden on sufferers, the research literature demonstrates a lack of interest in the subjective experience of FS and patients' priorities for treatment. A recent systematic review commissioned by the UK Department of Health found no studies on patients' views of treatment.[4] This paucity is surprising, as there is evidence to show that patients' attitude towards treatment significantly affects adherence, including in musculoskeletal (MSK) conditions.[11] Therefore it is important to consider the patient perspective when assessing overall treatment effectiveness.[11] This has become increasingly relevant with the move towards a patient-centred paradigm of healthcare.[11] This paper seeks to provide a qualitative exploration of patients' experiences and perceptions of living with primary FS.

METHODS

A qualitative study design employing semi-structured interviews was used to explore the experiences, priorities and perceptions of those experiencing the different phases of primary FS. Primary FS was chosen as the inclusion of secondary FS might have resulted in excessive heterogeneity.

Participants

Inclusion criteria

Adult, male and female patients of any age, with or without diabetes, who had been diagnosed with primary FS by the following criteria:

- shoulder pain for at least one month;
- reduction in passive external rotation of 50% or more compared to the contralateral side[12] with a clinically significant change in end-feel;
- no clinical suspicion of other pathologies that might present similarly; and
- normal X-rays (only if clinically indicated).

Recruitment

Recruitment occurred in community and hospital settings. Clinical members of the research team who recruited participants from the community worked in a general medical practice; however in addition to their own surgery clinics they also recruited from clinics that they ran in collaboration with other specialist doctors and physiotherapists, which were spread across the community. The patients recruited from the hospital-based clinics had been referred to specialist services.

A purposive sample of patients with a story to tell[13] was selected by the clinicians, who were given a standard protocol to use, which provided basic details of the study and what would be required of participants. Patients were given an introductory pack which included an information sheet and contact details, requesting that they respond directly to the research team. When a potential participant contacted the team they were given the opportunity to ask any questions prior to arranging an interview.

Sampling

While our participants were not chosen as a representative sample, efforts were made to select men and women from a broad age range, and in the different phases of FS defined by the UK guidelines,[8] taking into account that they may be in primary or secondary care. Thus group 1 comprised patients in the pain predominant phase and was drawn exclusively from community care; group 2 were in the stiffness predominant phase, drawn from both community and secondary care (i.e. the hospital setting); and group 3, were in the residual stiffness predominant phase following hospital treatment, and drawn exclusively from secondary care.

Data collection

Interviews took place on NHS or University premises or by telephone. Each commenced by establishing informed consent. Interviewees were then allowed the opportunity to give detailed descriptions of their experiences, with individual interviews lasting approximately 30-45 minutes. Schedules comprising the topics to be covered and a range of prompts relating to specific issues of interest were used to guide data collection during interviews. Questions related to the particular phase currently experienced by participants but also included questions about the previous phase, where applicable. The interviews mainly comprised open questions to encourage the participants to tell their stories. Field notes were made of observations outwith the transcripts. Credibility was demonstrated by confirmation of information from multiple participants leading to identification of common themes. Interviews were audio recorded with the permission of participants and later transcribed.

Interviews, transcription and subsequent data checking were undertaken by researchers with a nursing background and experience in qualitative research (SJ, SH). These researchers were ideally placed, firstly because their core professional role is not directly involved in FS management (this facilitated objectivity); and secondly because their clinical backgrounds gave them insights into the nuances of patient□healthcare provider relationships.

Data analysis

An inductive approach to analysis was taken, using a constant comparative method. Data were analysed after each interview and the findings informed the questions and topics for subsequent interviews. The data were independently analysed by two researchers using the six stage thematic approach outlined by Braun and Clarke.[14] An in-depth familiarisation with the data was followed by the generation of initial codes, using Nvivo 9, which were then applied to the data and collated into potential themes independently by the researchers. These themes were then reviewed, generating a thematic map of the analysis. In the next stage the themes were refined and named. Finally, examples were selected to illustrate the thematic framework.

RESULTS

Participants

Data collection occurred between July 2011 and November 2011. Twelve participants were recruited, and eleven agreed to be interviewed. Five met the criteria for group 1, four for group 2 and two for group 3. They included six women and five men, aged from 40 years upwards, predominantly in their fifties (n=7). Three of the men had diabetes and formed the younger end of the group, with two in their forties and one in his early fifties. Three participants had experienced FS in both shoulders (though none on both sides concurrently). One participant may have experienced FS in both shoulders, but could not remember the diagnosis given for the first-affected shoulder. One participant had a previous history of impingement (not FS) in the contralateral shoulder and appears to have started with the same diagnosis in the instance recorded here, which then developed into a FS. Two of the participants had suffered with FS several years ago and were recruited as their history was known to the physiotherapist.

Contexts of participant journeys

One participant consulted a GP one week after the start of symptoms but all the others waited six to eight weeks before presenting for a consultation. After initial presentation they followed various paths towards specialist treatment. Some participants experienced significant delay in receiving a definitive diagnosis and specialist (i.e. MSK or shoulder specialist) care.

Thematic analysis

Four major patient-reported themes associated with FS were identified and are shown in the thematic map (Figure 1).

Figure 1:
THEMATIC MAP - HERE

Theme 1: Pain

Patients reported that the pain would start quite suddenly and gradually worsen over weeks and months. During the initial (pain predominant) phase the pain would be very intense on certain movements, typically stretching or reaching in specific directions. Unguarded movement, in particular, caused severe pain. Also, sleep was badly disturbed. Once awake, participants struggled to get back to sleep due to constant, "nagging" pain. Sleep deprivation wore participants down, even though they reported taking a resilient approach. In an attempt to manage their pain, participants tried to avoid painful movements, applied ointments and took

medication. The nature of the pain was such that they worried about what could be the cause.

> "The amount of pain that I was in, I didn't believe that it was just a frozen shoulder." Participant 12

Finding a way to deal with the pain and carry on with life as normally as possible was very important to participants.

Theme 2: Inconvenience/disability

Typically the FS lasted from one to three years. In a group of people who were usually active, this was hugely disruptive. The inability to use the arm normally, initially due to pain, gradually giving way to stiffness, affected even very fundamental activities of daily living (ADL), including, among others, hair washing and styling, getting out of a bath, dressing, reaching into a back pocket, opening a door, pegging washing out, washing up and other housework, home maintenance jobs, lifting a kettle, cutting up food, pulling a suitcase or wheeled shopping basket, gardening and, when driving, changing gear or positioning for reversing. In order to continue to drive, one participant had to buy a car with automatic transmission.

> "Try getting out the bath 'cause you can't find a way up. You just cannot find a way to get out the bath! We've got bars on the side of the bath anyway but I couldn't find a way. I just had to snake over the side sometimes." Participant 7

Participants who worked had to change their work routines to accommodate their limitations; one, for whom this was not possible, had to resign

A general observation was that the pain and these major impairments in ADL occurred without obvious outward signs, so that much of the suffering involved was hidden from the casual observer. This led to much less sympathy than would be the case with many conditions.

> " … unless you have or have had a frozen shoulder you don't know how painful it is. It is really excruciating." Participant 8

In general, so long as the FS was seen as temporary and benign, and they could care for themselves and keep their jobs until they recovered, participants accepted their situation; at the same time, they hoped for the earliest possible resolution.

Theme 3: Awareness and expectations

Participants did not successfully self-diagnose their problem. Typically they thought they had 'pulled something', anticipating that it would resolve in a week or two. Diagnosis also presented a challenge amongst non-specialist healthcare staff.

> "I made an appointment at the doctors and the doctor, having examined me, said, 'you are lucky it isn't a frozen shoulder, I think that what you have done is you have trapped a nerve, you have some slight nerve damage, you just need to rest, it will take a couple of months.'" Participant 5

Lack of diagnosis or misdiagnosis led to diverse consequences among the participants e.g. anxiety; denial; and delays in definitive diagnosis and referral. Participants were often left with unanswered questions, uncertainty as to the treatment options and the potential risks and benefits of treatment and, occasionally, with contradictory advice.

> "… you want to know where the final outcome is going to be rather than you suffering week in week out thinking, 'when is it going to end? Fed up with this.' Whereas when you know it is going to last 3 or 4 years down the line, I know it is not going to be forever. Whereas you don't know anything; God, is this ever going to go away? I think I would like to know from the start." Participant 11

> "I don't know whether I wasn't saying the right things to [my GP] or what .... I don't know whether it is my relationship with the doctor or what, but I don't … I'm not very good, if they are vague and I don't understand what they are talking about, I won't sit there any longer, I'll, I'll leave. All I wanted was an answer." Participant 12

Participants who did not receive early informed or specialist care would have preferred a quick, clear pathway; and although they understood the difficulty of diagnosis, some expressed disappointment that they had suffered, for what seemed to them, longer than necessary, due to a lack of awareness of the condition on the part of their healthcare providers

> "With the shoulder, I was saying, 'it's still hurting' and they [the GPs] were saying 'we'll look to see what else it is then.' Every time, something came back as, 'no, it's negative. Have you got any neck problem, shoulder problem, anything like that?' No arthritis, no swelling in it … but every time it come back no, you are thinking, now what?" Participant 7 [first-affected shoulder, 2004]

Theme 4: Treatment

Participants identified functional outcomes e.g. freedom of movement as their main priority from treatment; however they recognised that if the pain or stiffness remained they would be unable to recover the movement. On presentation at the GP's surgery, reflecting the lack of a definitive diagnosis in most cases, there was no standard course of treatment offered. Two participants came via their occupational health physiotherapy services then to their GPs. Neither of them received a diagnosis of FS either. Some GPs opted to wait and see and most prescribed analgesics. As time passed some offered further investigations and/or administered further first-line treatment themselves, while others referred patients to an on-site physiotherapist, or to a primary or secondary care MSK clinic.

The range of first-line treatments experienced by the participants from their GPs included ointment, medications and local injections. On referral to the physiotherapist, treatment might include advice and education, hands-on passive mobilisation, exercises, local injections, heat, massage, ultrasound, transcutaneous electrical nerve stimulation (TENS), acupuncture or hydrotherapy.

All participants had received some physiotherapy due in part to the recruitment pathways into the study. Some participants were referred swiftly to a specialist

physiotherapist, a factor which may have been influenced by the involvement of a surgery with a physiotherapist specialising in MSK and FS and may not be generally representative. In other cases participants were referred, only after lengthy periods of care by an occupational physiotherapist and/or their own GP, to a specialist physiotherapist, a GP with a special interest in MSK conditions or a consultant shoulder and elbow surgeon. Two participants received surgical interventions: manipulation under anaesthetic and an operative capsular release, respectively.

MSK specialists, whether specialist physiotherapists, GPs with a special interest or surgeons, were available in various locations. There were sometimes delays in referral to these specialists, but once referred, participants reported positively on their care in each location. Definitive diagnoses were made or confirmed. Referral also brought an understanding approach, clarity and relief; participants expressed profound relief at knowing what the problem was and being in the care of someone who knew about the condition. Some of their worries could be explained and their questions answered. This was very important to them.

> "[S/he] went into extreme [detail], were there any questions, [s/he] was so incredibly thorough, I can't say enough really. [S/he] went into, straight away what it was, because what I couldn't understand was, why was I getting this pain in the top of my arm when it is a frozen shoulder, but why am I getting pain in the arm and not the shoulder?"
> "What did [s/he] say?"
> "[S/he] did me a diagram; [s/he] showed me a model of a skeleton."
> Participant 10

Relationships with specialists were generally reported as friendly and non-hierarchical, and conducive to the exchange of information. In general, however, there was over-reliance on verbal information, with very limited use of other media.

DISCUSSION

Principal findings

Patients' initial experience was characterised by severe, inexplicable pain followed by increasing restriction of movement. Overcoming these symptoms and recovering functional capacity was their priority. Understanding the cause, seriousness and likely outcome of the condition were also important to them. Reducing delay in diagnosis was a common plea with considerable anxiety, confusion and delay for those in the continued care of non-specialists. This was followed by a sense of relief on meeting a specialist, with gradual improvement ensuing in most cases. Most patients found hope and encouragement through this interaction, although elements of the condition remained inexplicable and uncertain. There was over-reliance on verbal communication and very little written information was provided.

Strengths and weaknesses of the study

A major strength of this study is that to our knowledge, this is the first time the experiences of patients with this condition have been reported.

Patients were recruited from care settings representative of those where the condition is typically managed. However, this was a small study which consequentially included data from a limited number of patients from a single

geographical area. Although their own stories remain valid they would not necessarily be representative of all patients.[15] In addition two participants' experiences of FS was historical, so that, compared to recent cases, their contributions are likely to be more open to recall bias, and to reflect earlier approaches to care. Nevertheless the design included trustworthy methods such as using a standard protocol to introduce the study to prospective participants, selecting patients at different stages in the disease trajectory, using a topic schedule for interviews and recording interviews for transcription.

Strengths and weaknesses in relation to other studies

To our knowledge, and despite extensive searching,[4] there is no literature with which to directly compare our results. Our results are not directly comparable to those of Hush et al,[11] who systematically reviewed studies from Canada, UK, USA and Scandinavia and found high levels of patient-satisfaction with MSK physiotherapy. While our study indirectly encompassed patient satisfaction, it differed in its focus, both in terms of being specific to primary FS, and in terms of including experience of the broader care pathway, not physiotherapy alone. Nonetheless, the aspects of care most consistently identified by Hush et al[11] as important to patients were the personal and professional attributes of the clinician, explanation and communication of information, and treatment outcome. These findings are strongly reinforced by our own work. A consistent international observation is the lack of confidence of GPs in diagnosing subtypes of shoulder pain,[16 17] and this may have a critical bearing on the appropriateness and timing of care pathways for patients with shoulder conditions.

Implications for clinicians and policymakers

A care pathway with prompt diagnosis and access to specialist (or informed) care is required for sufferers of FS. Non-specialist healthcare staff, particularly GPs and physiotherapists, should be made more aware of this condition. This awareness would include diagnostic criteria, expectations, management strategies, and patients' needs for information and reassurance.

It is clear that, in some cases, there is a serious mismatch between clinicians' and patients' perceptions of the impact of FS. Strategies for educating clinicians are required, in order to convey the immense impact that frozen shoulder may have on sufferers' lives. Such education should ensure that active measures, to encourage timely resolution, are always offered.

There is a need to provide standardised, consistent information for patients, designed in collaboration with patients and based on the best available evidence. This information should address patients' questions and concerns, rather than clinicians' perceptions of what patients' questions and concerns should be. The information should be available in multiple formats in order to maximise its accessibility.

The Chartered Society of Physiotherapy's (CSP) clinical guidelines for FS and quick reference summary endeavour to address some of these issues.[8 9] Dissemination is now the key to connecting evidence and target audience. Awareness among other healthcare staff should be raised in order that their interaction with this patient group is apposite.

Future research

Our participants expressed a clear preference for early specialist referral; also a need for reassurance and timely, comprehensible advice and information in a variety of media. The evidence base underpinning the management of FS is not strong[4 8] and studies into the natural history of FS have produced somewhat contradictory results[10 18] A need for more primary research and for research of higher quality on FS has been identified elsewhere.[4 8] But clinicians could make better use of the evidence, limited though it is.

Until recently, with the advent of initiatives such as INVOLVE,[19] the general clinical research agenda has often lacked a focus on patients' perspectives. In relation to FS research specifically, patient involvement has yet to make appreciable inroads, but this must change if such research is to be relevant. Unless the aspects of FS which most concern patients are known, generic shoulder pain Patient Reported Outcome Measures (PROMs)—used to measure condition severity and progress in such research, as well as in clinical practice—cannot be considered completely valid. Nor is it possible to develop a more sensitive, condition-specific PROM.[20] The present study, by exploring which aspects of FS patients most care about, contributes to a foundation for such validation and development.

CONCLUSIONS

Patients' perspectives on the experience of FS and their priorities for treatment have not previously been explored; however it is clear that this has been a major omission. Our study identified a number of issues that were important to patients. These included pain, but recovery from functional disability was often given higher priority. Anxiety was another key theme, and the struggle of living and dealing with FS was compounded, in some cases, by a lack of awareness on the part of healthcare professionals and, foremost, a failure to diagnose the condition.

To address these issues most effectively it is recommended that a diagnosis, even if only tentative, be quickly established for more patients. This would require GPs to recognise the salient diagnostic features. They and other healthcare workers should also be educated on the condition's impact on individuals, and accordingly the findings of the present study should be disseminated and built upon. Advice and information in various formats, reflecting the best available evidence, should be made readily available to patients. Finally, the evidence base for effectiveness of treatments needs to be expanded, maximally utilising patient participation. The present study, by exploring which aspects of FS patients most care about, contributes to this goal.

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Competing interests: Dr. Hanchard, Dr. Hamilton and Susan Jones have nothing to disclose. Dr. Rangan reports grants and personal fees from DePuy Ltd, personal fees from JRI Ltd, outside the submitted work. In addition, Dr. Rangan has a patent UK & European pending. (Statement generated by their system when completed conflict of interest forms).

Author's contribution: AR initiated the concept and design, revised the draft and approved the final article; NH developed the idea for the study with SH and advised

on musculoskeletal and physiotherapy aspects. NH wrote the background section of the article and contributed to the drafting and editing of the whole. SJ conducted the interviews, transcribed and analysed them, wrote up the findings and drafted the body of the article. SH supported SJ, reviewed the analysis, assisted in writing up the findings and contributed to developing and writing the article.

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Provenance and peer review: Not commissioned; externally peer reviewed.

Ethics approval: Approval was received from the School of Health Research Governance & Ethics Committee at Teesside University and South Tees Hospitals NHS Foundation Trust Research and Governance Department.

Data sharing statement: Quotes and further details are available from Susan Jones at Susan.Jones@tees.ac.uk

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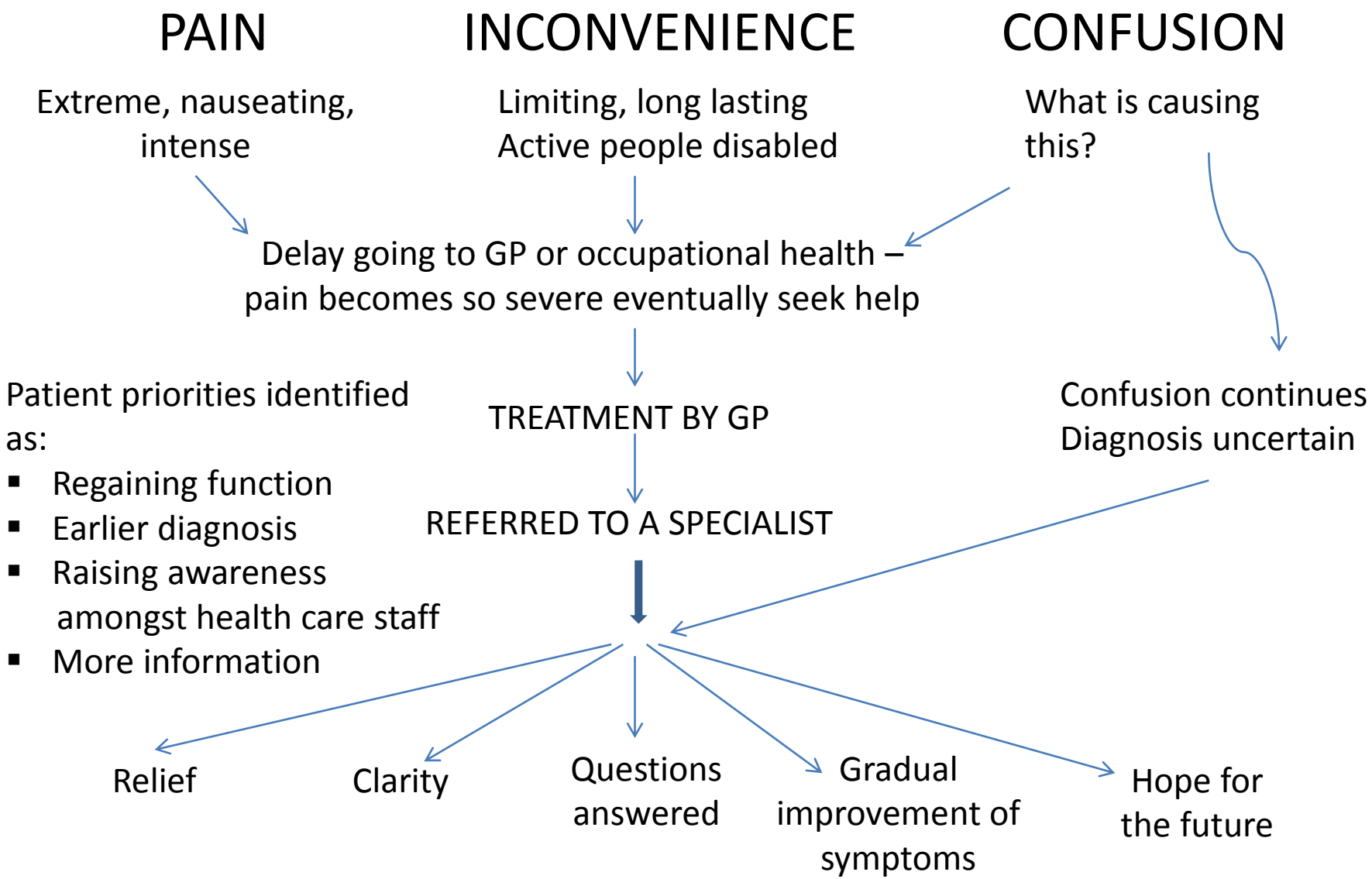
Figure 1: Thematic map



A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder

RESEARCH CHECKLIST FINAL for article for BMJ Open

Research checklist – COREQ (taken from Tong et al 2007)

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group? **SJ**
2.	Credentials	What were the researcher's credentials? E.g. PhD, MD **MSc**
3.	Occupation	What was their occupation at the time of the study? **Research associate**
4.	Gender	Was the researcher male or female? **F**
5.	Experience and training	What experience or training did the researcher have? **Research methods to master's degree level; 5 years' experience of working with qualitative research methods**
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement? **No**
7.	Participant knowledge of the Interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research

Study explained initially by physiotherapist treating their condition; no specific information about interviewer given; invitation and participant information sheet given before interview day with the following information:

We are researchers from Teesside University who are working with doctors and physiotherapists in the community and at James Cook University Hospital. We want to find out your views of living with frozen shoulder and so we would like to invite you to take part in this study.

What is the study for?

This study will help us to find out what is important to people suffering from frozen shoulder. What is found out will be used to design a larger study about treatment of this condition. This second study will give us more information about treatments that are available.

Why have I been asked to take part?
Health care staff will have given this information to you for us. We would like to find out the experiences and views of patients who are suffering from frozen shoulder. This will help us to get a better understanding of what is important to you and how to improve our healthcare services.

8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic

The text states: "Interviews, transcription and subsequent data checking were undertaken by researchers with a nursing background and experience in qualitative

research (SJ, SH). These researchers were ideally placed, firstly because their core professional role is not directly involved in FS management (this facilitated objectivity); and secondly because their clinical backgrounds gave them insights into the nuances of patient□healthcare provider relationships."

Domain 2: study design

Theoretical framework

9. Methodological orientation and Theory — What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis

The text states: "An inductive approach to analysis was taken, using a constant comparative method." "The data were independently analysed by two researchers using the six stage thematic approach outlined by Braun and Clarke." "Data were analysed after each interview and the findings informed the questions and topics for subsequent interviews."

Participant selection

10. Sampling — How were participants selected? e.g. purposive, convenience, consecutive, snowball **Purposive**

11. Method of approach — How were participants approached? e.g. face-to-face, telephone, mail, email

Face-to-face using agreed standard protocol then telephone, email and/or letter from researcher as requested by potential participant.

12. Sample size — How many participants were in the study? **12**

13. Non-participation — How many people refused to participate or dropped out? Reasons? **1, did not agree to interview**

Setting

14. Setting of data collection — Where was the data collected? e.g. home, clinic, workplace

The text states: "Interviews took place on NHS or University premises or by telephone."

15. Presence of non-participants — Was anyone else present besides the participants and researchers? **No**

16. Description of sample — What are the important characteristics of the sample? e.g. demographic data, date **Gender, age, history of condition, dates of data collection**

Data collection

17. Interview guide — Were questions, prompts, guides provided by the authors? Was it pilot tested? **Text states: "using a topic schedule for Interviews" "Questions related to the particular phase currently experienced by participants but also included questions about the previous phase, where applicable. The interviews mainly comprised open questions to encourage the participants to tell their stories." It was not pilot tested.**

18. Repeat interviews — Were repeat interviews carried out? **No** If yes, how many?

19. Audio/visual recording — Did the research use audio or visual recording to collect the data? **Audio recording of interviews**

20. Field notes — Were field notes made during and/or after the interview or focus group? **Yes**

21. Duration — What was the duration of the interviews or focus group? **30-45 minutes**

22. Data saturation — Was data saturation discussed? **Yes**

23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? **No**

Domain 3: analysis and findings

Data analysis

24. Number of data coders	How many data coders coded the data? **1 principal coder; 1 independent checker**
25. Description of the coding tree	Did authors provide a description of the coding tree? **No**
26. Derivation of themes	Were themes identified in advance or derived from the data? **Inductive approach, derived from the data**
27. Software	What software, if applicable, was used to manage the data? **Nvivo 9**
28. Participant checking	Did participants provide feedback on the findings? **No**

Reporting

29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number **Yes**
30. Data and findings consistent	Was there consistency between the data presented and the findings? **Yes**
31. Clarity of major themes	Were major themes clearly presented in the findings? **Yes**
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? **Historical aspect, bilateral cases**

REFERENCE

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007;19(6):349–357.

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A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder

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A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder

Jones, Susan[1]; Hanchard, Nigel[1]; Hamilton, Sharon[1]; Rangan, Amar[2]

[1]Teesside University – Health and Social Care Institute, Middlesbrough, United Kingdom
[2]The James Cook University Hospital – Orthopaedics, Middlesbrough, United Kingdom

Corresponding author:
Susan E. Jones
Health and Social Care Institute
Teesside University
Parkside West Offices
Borough Road
Middlesbrough
TS1 3BA
United Kingdom
Phone: 01642342984
Email: Susan.Kones@tees.ac.uk

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Abstract

Objectives: To elucidate the experiences and perceptions of people living with primary frozen shoulder, and their priorities for treatment.

Design: Qualitative study design using semi-structured interviews.

Setting: GP and musculoskeletal (MSK) clinics in primary and secondary care in one NHS Trust in England.

Participants: Twelve patients diagnosed with primary frozen shoulder were purposively recruited from a GP surgery, community clinics and hospital clinics. Recruitment targeted the phases of frozen shoulder: pain predominant (n=5), stiffness predominant (n=4), and residual stiffness predominant following hospital treatment (n=2). One participant dropped out. Inclusion criteria: Adult, male and female patients of any age, attending the clinics, who had been diagnosed with primary frozen shoulder.

Results: The most important experiential themes identified by participants were: pain which was both severe and inexplicable; inconvenience/disability arising from increasing restriction of movement (due to pain initially, gradually giving way to stiffness); confusion/anxiety associated with delay in diagnosis and uncertainty about the implications for the future; and treatment-related aspects. Participants not directly referred to a specialist (whether physiotherapist, physician or surgeon) wanted a faster, better-defined care pathway. Specialist consultation brought more definitive diagnosis, relief from anxiety, and usually self-rated improvement. The main treatment priority was improved function, though there was recognition that this might be facilitated by relief of pain or stiffness. There was a general lack of information from clinicians about the condition with over-reliance on verbal communication and very little written information.

Conclusions: Awareness of frozen shoulder should be increased among non-specialists and the best available information made accessible for patients. Our results also highlight the importance of patient participation in frozen shoulder research.

Article Summary

Article focus

- The experiences and perceptions of people living with primary frozen shoulder, and their priorities for treatment.

Key messages

- Primary frozen shoulder causes severe pain and restricts activities of daily living. Incorrect or delayed diagnoses often amplify patient anxiety and hold up treatment.
- Care pathways are needed with prompt diagnosis and access to specialist (or informed) care. Raising awareness of the diagnostic criteria and management options among non-specialist healthcare staff—especially GPs and physiotherapists—should make this more achievable.

- Translation of evidence to the target audience of non-specialist healthcare professionals is a priority.

Strengths and limitations of this study

This study is the first to focus on patients' experiences of conventional care pathways for frozen shoulder, and their priorities for treatment.

Patients were recruited from care settings where the condition is typically managed. The number of participants was small, so the findings must be considered indicative rather than conclusive, but enough repetition took place to be confident in the themes identified. In addition, two participants' experience of frozen shoulder was retrospective. Compared to recent cases, their contributions are likely to be more open to error of memory, and to reflect less current approaches to care.

Nevertheless the design included trustworthy methods with clear reporting, allowing readers to make their own judgement on trustworthiness. As the work published on this topic is very limited this article makes a valuable contribution.

INTRODUCTION

Frozen shoulder (FS) is a condition affecting the capsule of the shoulder joint, and is characterised by inflammation and contracture.[1] These events may occur for no identifiable reason in "primary" or "idiopathic" FS. "Secondary" FS is associated with some other event or condition: the most common associated event is trauma,[2] whereas associated conditions include rotator cuff disease, hemiparesis and others.[3] Diabetes is a known risk factor for FS.[4] Some authorities consider FS associated with diabetes to be a "primary" type, and others consider it "secondary".[5]

FS affects around 10% of the general adult population,[6] men and women approximately equally, [6 7] and the prevalence of those seeking help is 2 to 5%.[8] To our knowledge, there are no published data on the relative prevalence of primary and secondary FS. However, FS of no detectable cause is thought to predominate, with patients whose FS is associated with diabetes constituting an additional "substantial" group, [3] accounting for almost one-third of all FS. [7]

The healthcare implications of FS are considerable. In the UK, for example, based on a single GP consultation for each case, it costs the National Health Service at least £44.1 million (assuming a prevalence of 2%) or £110.3 million (assuming a prevalence of 5%). And since the usual age at onset is 40-60 years,[9] which is typically within the working-age range, there is a crucial economic impact on individuals and society.

Codman, who coined the term frozen shoulder, described the typical clinical manifestation as early as 1934:

> "The condition [comes] on slowly; pain usually felt near the insertion of the deltoid; inability to sleep on the affected side; painful and incomplete elevation and external rotation; restriction of both spasmodic and mildly adherent type; atrophy of the spinati; little local tenderness; X-rays negative except for bone atrophy."[10]

However, the location of pain may be variable[9] and diagnosis may present a challenge, particularly for the non-specialist, and particularly in the early stages, when the signs are not pronounced: not least because false positive responses to standard tests for shoulder impingement (Neer's sign, Hawkins' test) are to be expected.[11]

Recognising FS as phasic in nature, the recent UK guidelines for diagnosis, assessment and physiotherapy management of FS recommend a simple dichotomous "pain predominant" or "stiffness predominant" classification, whereby the patient is the arbiter of the stage, and pain takes precedence when there is ambiguity.[11] Potential interventions include watchful waiting, physiotherapy, steroid injection, distension arthrography, manipulation under anaesthetic (MUA) and arthroscopic capsular release.[5 11] There is some evidence for specific interventions, although none of this is strong,[6 12] and not all observational series have verified the certainty of complete recovery. For example, in a recent study of 223 patients with FS referred to tertiary care, 38% had persistent mild symptoms, mostly pain, at a mean follow-up of 4.4 years (range 2 to 20 years). In 3% the persistent symptoms were severe, with pain and functional deficits.[13]

Despite a general appreciation that the condition imposes a serious burden on sufferers, the research literature demonstrates a lack of interest in the subjective experience of FS and patients' priorities for treatment. A recent systematic review commissioned by the UK Department of Health sought studies on patients' views of conventional treatments, but found none.[5] A similar search without restriction on treatment type revealed just one study, focused on Bowen therapy and providing only limited insights.[14] This paucity is surprising, as there is evidence to show that patients' attitude towards treatment significantly affects concordance, including in musculoskeletal (MSK) conditions.[15] Therefore it is important to consider the patient perspective when assessing overall treatment effectiveness.[15] This has become increasingly relevant with the move towards a patient-centred paradigm of healthcare.[15] This paper seeks to qualitatively explore the experiences and perceptions of people living with primary frozen shoulder, and their priorities for treatment.

METHODS

A qualitative study design employing semi-structured interviews was used to explore the experiences, priorities and perceptions of those experiencing the different phases of primary FS. Primary FS was chosen as the inclusion of secondary FS might have resulted in excessive heterogeneity.

Participants

Inclusion criteria

Adult, male and female patients of any age, with or without diabetes, who had been diagnosed with primary FS by the following criteria:

- shoulder pain for at least one month;
- reduction in passive external rotation of 50% or more compared to the contralateral side[16] with a clinically significant change in end-feel;
- no clinical suspicion of other pathologies that might present similarly; and
- normal X-rays (only if clinically indicated).

Recruitment
Recruitment occurred in community and hospital settings. Clinical members of the research team who recruited participants from the community worked in a general medical practice; however in addition to their own surgery clinics they also recruited from clinics that they ran in collaboration with other specialist doctors and physiotherapists, which were spread across the community. The patients recruited from the MSK and hospital-based clinics had been referred to specialist services.

Sampling
A structured, purposive sample of patients in the different phases of FS,[17] as defined by the UK guidelines,[11] with a story to tell,[18] was selected by the clinicians. Group 1 comprised patients in the pain predominant phase and was drawn exclusively from community care; group 2 were in the stiffness predominant phase, drawn from both community and secondary care (i.e. the hospital setting); and group 3 were in the residual stiffness predominant phase following hospital treatment, and drawn exclusively from secondary care. Clinicians were given a standard protocol to use, which provided basic details of the study and what would be required of participants. Patients were given an introductory pack which included an information sheet and contact details, requesting that they respond directly to the research team. When a potential participant contacted the team they were given the opportunity to ask any questions prior to arranging an interview. Twenty-two packs were handed out and twelve patients responded; none were excluded. The demographic characteristics of the sample were consistent with the FS population across the UK at large.[6 7]

Data collection
Interviews took place on NHS or University premises or by telephone. Each commenced by establishing informed consent. Interviewees were then allowed the opportunity to give detailed descriptions of their experiences, with individual interviews lasting approximately 30-45 minutes. Schedules comprising the topics to be covered and a range of prompts relating to specific issues of interest were used to guide data collection during interviews. Questions related to the particular phase currently experienced by participants but also included questions about the previous phase, where applicable. The interviews mainly comprised open questions to encourage the participants to tell their stories. Field notes were made of observations to supplement the transcripts. Credibility was demonstrated by confirmation of information from multiple participants leading to identification of common themes. Interviews were audio recorded with the permission of participants and later transcribed. Interviews, transcription and subsequent data checking were undertaken by healthcare researchers experienced in qualitative research (SJ, SH).

Data analysis
An inductive approach to analysis was taken, using a constant comparative method. Data were analysed after each interview and the findings informed the questions and topics for subsequent interviews. The data were independently analysed by two researchers using the six stage thematic approach outlined by Braun and Clarke.[19] An in-depth familiarisation with the data was followed by the generation of initial codes, using Nvivo 9, which were then applied to the data and collated into potential themes independently by the researchers. These themes were then reviewed,

generating a thematic map of the analysis. In the next stage the themes were refined and named. Finally, examples were selected to illustrate the thematic framework.

RESULTS

Participants

Data collection occurred between July 2011 and November 2011. Twelve participants were recruited, and eleven agreed to be interviewed. Five met the criteria for group 1, four for group 2 and two for group 3 (see Table 1). They included six women and five men, aged from 40 years upwards, predominantly in their fifties (n=7). Three of the men had diabetes and formed the younger end of the group, with two in their forties and one in his early fifties. Three participants had experienced FS in both shoulders (though none on both sides concurrently). One participant may have experienced FS in both shoulders, but could not remember the diagnosis given for the first-affected shoulder. One participant, with a previous history of impingement (not FS) in the contralateral shoulder, was initially given the same diagnosis on the currently affected side, but was subsequently diagnosed with FS. Two of the participants had suffered with FS several years ago and were recruited as their history was known to the physiotherapist.

Contexts of participant journeys

One participant consulted a GP one week after the start of symptoms but all the others waited six to eight weeks before presenting for a consultation. After initial presentation they followed various paths towards specialist treatment. Some participants experienced delay in receiving a definitive diagnosis and specialist (i.e. MSK or shoulder specialist) care (see Table 1).

Thematic analysis

Four major patient-reported themes associated with FS were identified and are shown in the thematic map (Figure 1).

Figure 1:
THEMATIC MAP - HERE

Theme 1: Pain

Patients reported that the pain would start quite suddenly and gradually worsen over weeks and months. During the initial (pain predominant) phase the pain would be very intense on certain movements, typically stretching or reaching in specific directions. Unguarded movement, in particular, caused severe pain. Also, sleep was badly disturbed. Once awake, participants struggled to get back to sleep due to constant, "nagging" pain. Sleep deprivation wore participants down, even though they reported taking a resilient approach. In an attempt to manage their pain, participants tried to avoid painful movements, applied ointments and took medication. The nature of the pain was such that they worried about what could be the cause.

> "The amount of pain that I was in, I didn't believe that it was just a frozen shoulder." Participant 12

Finding a way to deal with the pain and carry on with life as normally as possible was very important to participants.

Theme 2: Awareness and expectations

Participants did not successfully self-diagnose their problem. Typically they thought they had 'pulled something', anticipating that it would resolve in a week or two. Diagnosis also presented a challenge amongst non-specialist healthcare staff.

> "I made an appointment at the doctors and the doctor, having examined me, said, 'you are lucky it isn't a frozen shoulder, I think that what you have done is you have trapped a nerve, you have some slight nerve damage, you just need to rest, it will take a couple of months.'" Participant 5

Lack of diagnosis or misdiagnosis led to diverse consequences among the participants e.g. anxiety; denial; and delays in definitive diagnosis and referral. Participants were often left with unanswered questions, uncertainty as to the treatment options and the potential risks and benefits of treatment and, occasionally, with contradictory advice.

> "… you want to know where the final outcome is going to be rather than you suffering week in week out thinking, 'when is it going to end? Fed up with this.' Whereas when you know it is going to last 3 or 4 years down the line, I know it is not going to be forever. Whereas you don't know anything; God, is this ever going to go away? I think I would like to know from the start." Participant 11

> "I don't know whether I wasn't saying the right things to [my GP] or what .... I don't know whether it is my relationship with the doctor or what, but I don't … I'm not very good, if they are vague and I don't understand what they are talking about, I won't sit there any longer, I'll, I'll leave. All I wanted was an answer." Participant 12

Participants who did not receive early informed or specialist care would have preferred a quick, clear pathway; and although they understood the difficulty of diagnosis, some expressed disappointment that they had suffered, for what seemed to them, longer than necessary, due to a lack of awareness of the condition on the part of their healthcare providers

> "With the shoulder, I was saying, 'it's still hurting' and they [the GPs] were saying 'we'll look to see what else it is then.' Every time, something came back as, 'no, it's negative. Have you got any neck problem, shoulder problem, anything like that?' No arthritis, no swelling in it … but every time it come back no, you are thinking, now what?" Participant 7 [first-affected shoulder, 2004]

Theme 3: Inconvenience/disability

Typically the FS lasted from one to three years. In a group of people who were usually active, this was hugely disruptive. The inability to use the arm normally, initially due to pain, gradually giving way to stiffness, affected even very fundamental activities of daily living (ADL), including, among others, hair washing and styling, getting out of a bath, dressing, reaching into a back pocket, opening a door, pegging washing out, washing up and other housework, home maintenance jobs, lifting a kettle, cutting up food, pulling a suitcase or wheeled shopping basket, gardening

and, when driving, changing gear or positioning for reversing. In order to continue to drive, one participant had to buy a car with automatic transmission.

> "Try getting out the bath 'cause you can't find a way up. You just cannot find a way to get out the bath! We've got bars on the side of the bath anyway but I couldn't find a way. I just had to snake over the side sometimes." Participant 7

Participants who worked had to change their work routines to accommodate their limitations; one, for whom this was not possible, had to resign

A general observation was that the pain and these major impairments in ADL occurred without obvious outward signs, so that much of the suffering involved was hidden from the casual observer. This led to much less sympathy than would be the case with many conditions.

> "I was still doing the workload as such, so you don't get any, it's awful to say, you don't get any sympathy from people because it is not something that stops you doing things but in yourself you feel so frustrated, because when I reached up to do anything, we do a lot of overhead stuff, there was no strength in the arm, it was very painful but nobody would say, "How is it?" You felt that they didn't understand, because you are at work with it and that was the hardest thing, and they still expected you to do things because you didn't have your arm strapped up." Participant 10

A further cause of hidden suffering was that other people relied on their own experiences of pain when trying to understand the participants' perspective but it was outside their lexicon of knowledge. Three participants recognised that they themselves had not understood what it was like or been sufficiently sympathetic towards others with FS until they acquired it themselves.

> "I've heard of other people with frozen shoulders and I'm afraid I haven't given them much sympathy because I didn't know what it involved. You would be in the same boat. I sympathised, say that's terrible, but really unless you have or have had a frozen shoulder you don't know how painful it is. It is really excruciating." Participant 8

In general, so long as the FS was seen as temporary and benign, and they could care for themselves and keep their jobs until they recovered, participants accepted their situation; at the same time, they hoped for the earliest possible resolution.

Theme 4: Treatment

Participants identified functional outcomes e.g. freedom of movement as their main priority from treatment; however they recognised that if the pain or stiffness remained they would be unable to recover the movement. On presentation at the GP's surgery, reflecting the lack of a definitive diagnosis in most cases, there was no standard course of treatment offered. Two participants came via their occupational health physiotherapy services then to their GPs. Neither of them received a diagnosis of FS either. Some GPs opted to wait and see and most prescribed analgesics. As time passed some offered further investigations and/or administered further first-line

treatment themselves, while others referred patients to an on-site physiotherapist, or to a primary or secondary care MSK clinic.

The range of first-line treatments experienced by the participants from their GPs included ointment, medications and local injections. On referral to the physiotherapist, treatment might include advice and education, hands-on passive mobilisation, exercises, local injections, heat, massage, ultrasound, transcutaneous electrical nerve stimulation (TENS), acupuncture or hydrotherapy.

All participants had received some physiotherapy due in part to the recruitment pathways into the study. Some participants were referred swiftly to a specialist physiotherapist, a factor which may have been influenced by the involvement of a surgery with a physiotherapist specialising in MSK and FS. In other cases participants were referred, only after lengthy periods of care by an occupational physiotherapist and/or their own GP, to a specialist physiotherapist, a GP with a special interest in MSK conditions or a consultant shoulder and elbow surgeon. Two participants received surgical interventions: manipulation under anaesthetic and an operative capsular release, respectively.

MSK specialists, whether specialist physiotherapists, GPs with a special interest or surgeons, were available in various locations. There were sometimes delays in referral to these specialists, but once referred, participants reported positively on their care in each location. Definitive diagnoses were made or confirmed. Referral also brought an understanding approach, clarity and relief; participants expressed profound relief at knowing what the problem was and being in the care of someone who knew about the condition. Some of their worries could be explained and their questions answered. This was very important to them.

> "[S/he] went into extreme [detail], were there any questions, [s/he] was so incredibly thorough, I can't say enough really. [S/he] went into, straight away what it was, because what I couldn't understand was, why was I getting this pain in the top of my arm when it is a frozen shoulder, but why am I getting pain in the arm and not the shoulder?"
> "What did [s/he] say?"
> "[S/he] did me a diagram; [s/he] showed me a model of a skeleton."
> Participant 10

Relationships with specialists were generally reported as friendly and non-hierarchical, and conducive to the exchange of information. In general, however, there was over-reliance on verbal information, with very limited use of other media.

DISCUSSION

Principal findings

Patients' initial experience was characterised by severe, inexplicable pain followed by increasing restriction of movement. Overcoming these symptoms and recovering functional capacity was their priority. Understanding the cause, seriousness and likely outcome of the condition were also important to them. Reducing delay in diagnosis was a common plea with considerable anxiety, confusion and delay for those in the continued care of non-specialists. This was followed by a sense of relief on meeting a specialist, with gradual improvement ensuing in most cases. Most

patients found hope and encouragement through this interaction, although elements of the condition remained inexplicable and uncertain. There was over-reliance on verbal communication and very little written information was provided.

Strengths and weaknesses of the study

This study is the first to focus on patients' experiences of conventional care pathways for this condition, and their priorities for treatment. These aspects, and the in-depth nature of our analysis, are major strengths.

Patients were recruited from care settings where the condition is typically managed; however some barriers to recruitment were experienced which have been identified previously, such as an initial hiatus in diagnosing the condition and approaching potential participants within a busy clinical setting. Recruitment issues are not uncommon and are well documented in other studies.[20] This was a small study which consequentially included data from a limited number of patients from a single geographical area. Although their own stories remain valid every possible theme would not necessarily be exhausted.[21] In addition two participants' experiences of FS was historical, so that, compared to recent cases, their contributions are likely to be more open to error of memory, and to reflect earlier approaches to care. Nevertheless the design included trustworthy methods such as using a standard protocol to introduce the study to prospective participants, selecting patients at different stages in the disease trajectory, using a topic schedule for interviews and recording interviews for transcription.

Strengths and weaknesses in relation to other studies

To our knowledge, and despite extensive searching,[5] there is no literature with which to directly compare our results. Carter[14] interviewed patients undergoing Bowen therapy for frozen shoulder, and very briefly described some experiential aspects of living with the condition, including pain, disturbed sleep, stiffness, impact on mood, and a disappointing interaction with a GP and a physiotherapist; all of which accord with our own, more searching, results. But Carter's [14] main focus was on the experience of Bowen therapy itself, limiting the applicability of her results; and patients' perceptions and priorities—dimensions considered critical by ourselves—were not addressed. Nor are our results directly comparable to those of Hush et al,[15] who systematically reviewed studies from Canada, UK, USA and Scandinavia and found high levels of patient-satisfaction with MSK physiotherapy. While our study indirectly encompassed patient satisfaction, it differed in its focus, both in terms of being specific to primary FS, and in terms of including experience of the broader care pathway, not physiotherapy alone. Nonetheless, the aspects of care most consistently identified by Hush et al[15] as important to patients were the personal and professional attributes of the clinician, explanation and communication of information, and treatment outcome. These findings are strongly reinforced by our own work. A consistent international observation is the lack of confidence of GPs in diagnosing subtypes of shoulder pain, [22 23] and this may have a critical bearing on the appropriateness and timing of care pathways for patients with shoulder conditions.

A key theme from our data was delays in diagnosis. Initially this tended to be a patient-initiated delay resulting from the participants waiting to see if the shoulder issues would resolve. Such patient-initiated delays are not unique to FS and can be

seen across a range health conditions. For example, Solbjør et al. highlighted that while some of the breast cancer patients in their study had delayed approaching their GP for 2 weeks, some had waited for longer than 3 months after they had found a lump.[24] When our participants did go to their GP they were often met with a failure to diagnose their condition or they were misdiagnosed. Again, this is not unique to FS; late or missed diagnosis has been cited as a contributory factor in poor outcomes for some cancers.[25 26] Furthermore, Pavey et al[27] in their research with patients with Motor Neurone Disease described the long journey to diagnosis as a 'diagnostic quest'.

Following diagnosis, it was evident from our data that FS had a major impact on the lives of our participants. Although FS is not a longer-term chronic condition such as multiple sclerosis or arthritis, it was clear that the participants in our study travelled along a similar trajectory to patients with such conditions. For example, Bury's notion that chronic health conditions are experienced as a 'biographically disruptive event' resonates very much with the experiences of our participants. Bury[28] identified the disruption of taken-for-granted behaviours such as general activities of daily living and the disruption of self-concept; all of which are supported by our data.

Implications for clinicians and policymakers

A care pathway with prompt diagnosis and access to specialist (or informed) care is required for sufferers of FS. There is potential for non-specialist healthcare staff, particularly GPs and physiotherapists, to be made more aware of this condition. This awareness would include diagnostic criteria, expectations, management strategies, and patients' needs for information and reassurance.

It is clear that, in some cases, there is a serious mismatch between clinicians' and patients' perceptions of the impact of FS. Strategies for educating clinicians are required, in order to convey the immense impact that frozen shoulder may have on sufferers' lives. Such education should ensure that active measures, to encourage timely resolution, are always offered.

There is a need to provide standardised, consistent information for patients, designed in collaboration with patients and based on the best available evidence. This information should address patients' questions and concerns, rather than clinicians' perceptions of what patients' questions and concerns should be. The information should be available in multiple formats in order to maximise its accessibility.

The Chartered Society of Physiotherapy's (CSP) clinical guidelines for FS and quick reference summary endeavour to address some of these issues. [11 12] Dissemination is now the key to connecting evidence and target audience. Awareness among other healthcare staff should be raised in order that their interaction with this patient group is apposite.

Future research

Our participants expressed a clear preference for early specialist referral; also a need for reassurance and timely, comprehensible advice and information in a variety of media. The evidence base underpinning the management of FS is not strong[5 11] and studies into the natural history of FS have produced somewhat contradictory

results.[13 29] A need for more primary research and for research of higher quality on FS has been identified elsewhere.[5 11] But clinicians could make better use of the evidence, limited though it is.

Until recently, frozen shoulder research has lacked a focus on patients' perspectives. Patient involvement has yet to make appreciable inroads but this must change if such research is to be relevant. Unless the aspects of FS which most concern patients are known, generic shoulder pain Patient Reported Outcome Measures (PROMs)—used to measure condition severity and progress in such research, as well as in clinical practice—cannot be considered completely valid. Nor is it possible to develop a more sensitive, condition-specific PROM.[30] The present study, by exploring which aspects of FS patients most care about, contributes to a foundation for such validation and development.

CONCLUSIONS

Patients' perspectives on the experience of FS and their priorities for treatment have not previously been explored; however it is clear that this has been a major omission. Our study identified a number of issues that were important to patients. These included pain, but recovery from functional disability was often given higher priority. Anxiety was another key theme, and the struggle of living and dealing with FS was compounded, in some cases, by a lack of awareness on the part of healthcare professionals and, foremost, a failure to diagnose the condition.

To address these issues most effectively it is recommended that a diagnosis, even if only tentative, be quickly established for more patients. This would require GPs to recognise the salient diagnostic features. They and other healthcare workers should also be educated on the condition's impact on individuals, and accordingly the findings of the present study should be disseminated and built upon. Advice and information in various formats, reflecting the best available evidence, should be made readily available to patients. Finally, the evidence base for effectiveness of treatments needs to be expanded, maximally utilising patient participation. The present study, by exploring which aspects of FS patients most care about, contributes to this goal.

Data sharing

Quotes and further details are available from Susan Jones at Susan.Jones@tees.ac.uk

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None

Competing Interests

Dr. Hanchard, Dr. Hamilton and Susan Jones have nothing to disclose. Dr. Rangan reports grants and personal fees from DePuy Ltd, personal fees from JRI Ltd, outside the submitted work; In addition, Dr. Rangan has a patent UK & European pending.

Contributorship

AR initiated the concept and design, revised the draft and approved the final article; NH developed the idea for the study with SH and advised on musculoskeletal and physiotherapy aspects. NH wrote the background section of the article and contributed to the drafting and editing of the whole. SJ conducted the interviews, transcribed and analysed them, wrote up the findings and drafted the body of the article. SH supported SJ, reviewed the analysis, assisted in writing up the findings and contributed to developing and writing the article.

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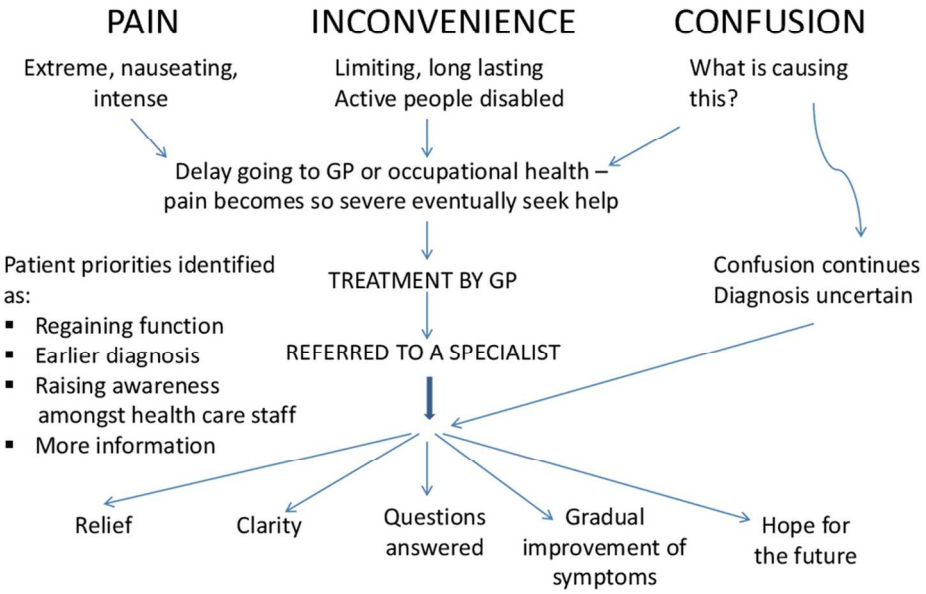
Table 1: Participants' characteristics

Participant number	Age in years	Gender	Diabetic	Group	Dominance of affected side at time of study*	Length of time from onset to 1st consultation	Length of time from 1st consultation to referral to MSK specialist	Where physiotherapy treatment was given
1	60-69	Female	No	1	D	Within 3 months	3 months	Own practice - physiotherapist with MSK interest
2	50-59	Female	No	1 & 2	ND & D	Immediate Within 2 months	Immediate 22 months	MSK community clinic GP at own practice (not referred to MSK specialist)
3	50-59	Female	No	1	D	Within 2 months	0 months	Own practice - physiotherapist with MSK interest
4	50-59	Female	No	2	ND	Unknown	Unknown	Own practice physiotherapist (not referred to MSK specialist)
5	50-59	Male	No	2	D	Within 1 month	5 months	Hospital MSK clinic
6	40-49	Male	Yes	2	D	Within 2 months	3 months	Occupational health physiotherapist Own practice - physiotherapist with MSK interest
7	50-59	Female	No	1	ND	Approx 5 months	0 months	MSK community clinic
8	Over 70	Male	No	1	D	Within 3 months	0 months	Own practice - physiotherapist with MSK interest
10	50-59	Female	No	2	ND	Within 2 months	6 months	Generalist physiotherapist MSK hospital clinic
11	50-59	Male	Yes	3	ND	Within 2 months	8 months	MSK hospital clinic
12	50-59	Male	Yes	3	ND	Within 1 month	16 months	Occupational health physiotherapist MSK hospital clinic

* D = Dominant; ND = non-dominant. Notes: Participant 9 did not return calls/emails. Data in table derived from interviews with patients, medical records not accessed.

Figure 1: Thematic map



119x90mm (300 x 300 DPI)

A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder

RESEARCH CHECKLIST FINAL for article for BMJ Open

Research checklist – COREQ (taken from Tong et al 2007)

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group? **SJ**
2.	Credentials	What were the researcher's credentials? E.g. PhD, MD **MSc**
3.	Occupation	What was their occupation at the time of the study? **Research associate**
4.	Gender	Was the researcher male or female? **F**
5.	Experience and training	What experience or training did the researcher have? **Research methods to master's degree level; 5 years' experience of working with qualitative research methods**
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement? **No**
7.	Participant knowledge of the Interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research

Study explained initially by physiotherapist treating their condition; no specific information about interviewer given; invitation and participant information sheet given before interview day with the following information:

We are researchers from Teesside University who are working with doctors and physiotherapists in the community and at James Cook University Hospital. We want to find out your views of living with frozen shoulder and so we would like to invite you to take part in this study.

What is the study for?

This study will help us to find out what is important to people suffering from frozen shoulder. What is found out will be used to design a larger study about treatment of this condition. This second study will give us more information about treatments that are available.

Why have I been asked to take part?
Health care staff will have given this information to you for us. We would like to find out the experiences and views of patients who are suffering from frozen shoulder. This will help us to get a better understanding of what is important to you and how to improve our healthcare services.

8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic

The text states: "Interviews, transcription and subsequent data checking were undertaken by researchers with a nursing background and experience in qualitative

research (SJ, SH). These researchers were ideally placed, firstly because their core professional role is not directly involved in FS management (this facilitated objectivity); and secondly because their clinical backgrounds gave them insights into the nuances of patient□healthcare provider relationships."

Domain 2: study design

Theoretical framework

9. Methodological orientation and Theory — What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis

The text states: "An inductive approach to analysis was taken, using a constant comparative method." "The data were independently analysed by two researchers using the six stage thematic approach outlined by Braun and Clarke." "Data were analysed after each interview and the findings informed the questions and topics for subsequent interviews."

Participant selection

10. Sampling — How were participants selected? e.g. purposive, convenience, consecutive, snowball **Purposive**

11. Method of approach — How were participants approached? e.g. face-to-face, telephone, mail, email

Face-to-face using agreed standard protocol then telephone, email and/or letter from researcher as requested by potential participant.

12. Sample size — How many participants were in the study? **12**

13. Non-participation — How many people refused to participate or dropped out? Reasons? **1, did not agree to interview**

Setting

14. Setting of data collection — Where was the data collected? e.g. home, clinic, workplace

The text states: "Interviews took place on NHS or University premises or by telephone."

15. Presence of non-participants — Was anyone else present besides the participants and researchers? **No**

16. Description of sample — What are the important characteristics of the sample? e.g. demographic data, date **Gender, age, history of condition, dates of data collection**

Data collection

17. Interview guide — Were questions, prompts, guides provided by the authors? Was it pilot tested? **Text states: "using a topic schedule for Interviews" "Questions related to the particular phase currently experienced by participants but also included questions about the previous phase, where applicable. The interviews mainly comprised open questions to encourage the participants to tell their stories." It was not pilot tested.**

18. Repeat interviews — Were repeat interviews carried out? **No** If yes, how many?

19. Audio/visual recording — Did the research use audio or visual recording to collect the data? **Audio recording of interviews**

20. Field notes — Were field notes made during and/or after the interview or focus group? **Yes**

21. Duration — What was the duration of the interviews or focus group? **30-45 minutes**

22. Data saturation — Was data saturation discussed? **Yes**

A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder

RESEARCH CHECKLIST FINAL for article for BMJ Open

23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? **No**

Domain 3: analysis and findings

Data analysis

24. Number of data coders	How many data coders coded the data? **1 principal coder; 1 independent checker**
25. Description of the coding tree	Did authors provide a description of the coding tree? **No**
26. Derivation of themes	Were themes identified in advance or derived from the data? **Inductive approach, derived from the data**
27. Software	What software, if applicable, was used to manage the data? **Nvivo 9**
28. Participant checking	Did participants provide feedback on the findings? **No**

Reporting

29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number **Yes**
30. Data and findings consistent	Was there consistency between the data presented and the findings? **Yes**
31. Clarity of major themes	Were major themes clearly presented in the findings? **Yes**
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? **Historical aspect, bilateral cases**

REFERENCE

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007;19(6):349–357.

A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder
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Article Summary

Article focus

- The experiences and perceptions of people living with primary frozen shoulder, and their priorities for treatment.

Key messages

- Primary frozen shoulder causes severe pain and restricts activities of daily living. Incorrect or delayed diagnoses often amplify patient anxiety and hold up treatment.
- Care pathways are needed with prompt diagnosis and access to specialist (or informed) care. Raising awareness of the diagnostic criteria and management options among non-specialist healthcare staff—especially GPs and physiotherapists—should make this more achievable.
- Translation of evidence to the target audience of non-specialist healthcare professionals is a priority.

Strengths and limitations of this study

This study is the first to focus on patients' experiences of conventional care pathways for frozen shoulder, and their priorities for treatment.

Patients were recruited from care settings where the condition is typically managed. The number of participants was small, so the findings must be considered indicative rather than conclusive, but enough repetition took place to be confident in the themes identified. In addition, two participants' experience of frozen shoulder was retrospective. Compared to recent cases, their contributions are likely to be more open to error of memory, and to reflect less current approaches to care.

Nevertheless the design included trustworthy methods with clear reporting, allowing readers to make their own judgement on trustworthiness. As the work published on this topic is very limited this article makes a valuable contribution.

INTRODUCTION

Frozen shoulder (FS) is a condition affecting the capsule of the shoulder joint, and is characterised by inflammation and contracture.[1] These events may occur for no identifiable reason in "primary" or "idiopathic" FS. "Secondary" FS is associated with some other event or condition: the most common associated event is trauma,[2] whereas associated conditions include rotator cuff disease, hemiparesis and others.[3] Diabetes is a known risk factor for FS.[4] Some authorities consider FS associated with diabetes to be a "primary" type, and others consider it "secondary".[5]

FS affects around 10% of the general adult population,[6] men and women approximately equally,[6 7] and the prevalence of those seeking help is 2 to 5%.[8] To our knowledge, there are no published data on the relative prevalence of primary and secondary FS. However, FS of no detectable cause is thought to predominate, with patients whose FS is associated with diabetes constituting an additional "substantial" group,[3] accounting for almost one-third of all FS.[7]

The healthcare implications of FS are considerable. In the UK, for example, based on a single GP consultation for each case, it costs the National Health Service at least £44.1 million (assuming a prevalence of 2%) or £110.3 million (assuming a

prevalence of 5%). And since the usual age at onset is 40-60 years,[9] which is typically within the working-age range, there is a crucial economic impact on individuals and society.

Codman, who coined the term frozen shoulder, described the typical clinical manifestation as early as 1934:

> "The condition [comes] on slowly; pain usually felt near the insertion of the deltoid; inability to sleep on the affected side; painful and incomplete elevation and external rotation; restriction of both spasmodic and mildly adherent type; atrophy of the spinati; little local tenderness; X-rays negative except for bone atrophy."[10]

However, the location of pain may be variable[9] and diagnosis may present a challenge, particularly for the non-specialist, and particularly in the early stages, when the signs are not pronounced: not least because false positive responses to standard tests for shoulder impingement (Neer's sign, Hawkins' test) are to be expected.[11]

Recognising FS as phasic in nature, the recent UK guidelines for diagnosis, assessment and physiotherapy management of FS recommend a simple dichotomous "pain predominant" or "stiffness predominant" classification, whereby the patient is the arbiter of the stage, and pain takes precedence when there is ambiguity.[11] Potential interventions include watchful waiting, physiotherapy, steroid injection, distension arthrography, manipulation under anaesthetic (MUA) and arthroscopic capsular release.[5 11] There is some evidence for specific interventions, although none of this is strong,[5 11] and not all observational series have verified the certainty of complete recovery. For example, in a recent study of 223 patients with FS referred to tertiary care, 38% had persistent mild symptoms, mostly pain, at a mean follow-up of 4.4 years (range 2 to 20 years). In 3% the persistent symptoms were severe, with pain and functional deficits.[13]

Despite a general appreciation that the condition imposes a serious burden on sufferers, the research literature demonstrates a lack of interest in the subjective experience of FS and patients' priorities for treatment. A recent systematic review commissioned by the UK Department of Health sought studies on patients' views of conventional treatments, but found none.[5] A similar search without restriction on treatment type revealed just one study, focused on Bowen therapy and providing only limited insights. [14] This paucity is surprising, as there is evidence to show that patients' attitude towards treatment significantly affects concordance, including in musculoskeletal (MSK) conditions.[15] Therefore it is important to consider the patient perspective when assessing overall treatment effectiveness.[15] This has become increasingly relevant with the move towards a patient-centred paradigm of healthcare.[15] This paper seeks to qualitatively explore the experiences and perceptions of people living with primary frozen shoulder, and their priorities for treatment.

METHODS

A qualitative study design employing semi-structured interviews was used to explore the experiences, priorities and perceptions of those experiencing the different phases of primary FS. Primary FS was chosen as the inclusion of secondary FS might have resulted in excessive heterogeneity.

Participants

Inclusion criteria

Adult, male and female patients of any age, with or without diabetes, who had been diagnosed with primary FS by the following criteria:

- shoulder pain for at least one month;
- reduction in passive external rotation of 50% or more compared to the contralateral side[16] with a clinically significant change in end-feel;
- no clinical suspicion of other pathologies that might present similarly; and
- normal X-rays (only if clinically indicated).

Recruitment

Recruitment occurred in community and hospital settings. Clinical members of the research team who recruited participants from the community worked in a general medical practice; however in addition to their own surgery clinics they also recruited from clinics that they ran in collaboration with other specialist doctors and physiotherapists, which were spread across the community. The patients recruited from the MSK and hospital-based clinics had been referred to specialist services.

Sampling

A structured, purposive sample of patients in the different phases of FS,[17] as defined by the UK guidelines,[11] with a story to tell,[18] was selected by the clinicians. Group 1 comprised patients in the pain predominant phase and was drawn exclusively from community care; group 2 were in the stiffness predominant phase, drawn from both community and secondary care (i.e. the hospital setting); and group 3 were in the residual stiffness predominant phase following hospital treatment, and drawn exclusively from secondary care. Clinicians were given a standard protocol to use, which provided basic details of the study and what would be required of participants. Patients were given an introductory pack which included an information sheet and contact details, requesting that they respond directly to the research team. When a potential participant contacted the team they were given the opportunity to ask any questions prior to arranging an interview. Twenty-two packs were handed out and twelve patients responded; none were excluded. The demographic characteristics of the sample were consistent with the FS population across the UK at large.[6 7]

Data collection

Interviews took place on NHS or University premises or by telephone. Each commenced by establishing informed consent. Interviewees were then allowed the opportunity to give detailed descriptions of their experiences, with individual interviews lasting approximately 30-45 minutes. Schedules comprising the topics to be covered and a range of prompts relating to specific issues of interest were used to guide data collection during interviews. Questions related to the particular phase currently experienced by participants but also included questions about the previous phase, where applicable. The interviews mainly comprised open questions to encourage the participants to tell their stories. Field notes were made of

observations to supplement the transcripts. Credibility was demonstrated by confirmation of information from multiple participants leading to identification of common themes. Interviews were audio recorded with the permission of participants and later transcribed. Interviews, transcription and subsequent data checking were undertaken by healthcare researchers experienced in qualitative research (SJ, SH).

Data analysis

An inductive approach to analysis was taken, using a constant comparative method. Data were analysed after each interview and the findings informed the questions and topics for subsequent interviews. The data were independently analysed by two researchers using the six stage thematic approach outlined by Braun and Clarke.[19] An in-depth familiarisation with the data was followed by the generation of initial codes, using Nvivo 9, which were then applied to the data and collated into potential themes independently by the researchers. These themes were then reviewed, generating a thematic map of the analysis. In the next stage the themes were refined and named. Finally, examples were selected to illustrate the thematic framework.

RESULTS

Participants

Data collection occurred between July 2011 and November 2011. Twelve participants were recruited, and eleven agreed to be interviewed. Five met the criteria for group 1, four for group 2 and two for group 3 (see Table 1). They included six women and five men, aged from 40 years upwards, predominantly in their fifties (n=7). Three of the men had diabetes and formed the younger end of the group, with two in their forties and one in his early fifties. Three participants had experienced FS in both shoulders (though none on both sides concurrently). One participant may have experienced FS in both shoulders, but could not remember the diagnosis given for the first-affected shoulder. One participant, with a previous history of impingement (not FS) in the contralateral shoulder, was initially given the same diagnosis on the currently affected side, but was subsequently diagnosed with FS. Two of the participants had suffered with FS several years ago and were recruited as their history was known to the physiotherapist.

Contexts of participant journeys

One participant consulted a GP one week after the start of symptoms but all the others waited six to eight weeks before presenting for a consultation. After initial presentation they followed various paths towards specialist treatment. Some participants experienced delay in receiving a definitive diagnosis and specialist (i.e. MSK or shoulder specialist) care (see Table 1).

Thematic analysis

Four major patient-reported themes associated with FS were identified and are shown in the thematic map (Figure 1).

Figure 1:
THEMATIC MAP - HERE

Theme 1: Pain

Patients reported that the pain would start quite suddenly and gradually worsen over weeks and months. During the initial (pain predominant) phase the pain would be

very intense on certain movements, typically stretching or reaching in specific directions. Unguarded movement, in particular, caused severe pain. Also, sleep was badly disturbed. Once awake, participants struggled to get back to sleep due to constant, "nagging" pain. Sleep deprivation wore participants down, even though they reported taking a resilient approach. In an attempt to manage their pain, participants tried to avoid painful movements, applied ointments and took medication. The nature of the pain was such that they worried about what could be the cause.

> "The amount of pain that I was in, I didn't believe that it was just a frozen shoulder." Participant 12

Finding a way to deal with the pain and carry on with life as normally as possible was very important to participants.

***Theme 2:* Awareness and expectations**

Participants did not successfully self-diagnose their problem. Typically they thought they had 'pulled something', anticipating that it would resolve in a week or two. Diagnosis also presented a challenge amongst non-specialist healthcare staff.

> "I made an appointment at the doctors and the doctor, having examined me, said, 'you are lucky it isn't a frozen shoulder, I think that what you have done is you have trapped a nerve, you have some slight nerve damage, you just need to rest, it will take a couple of months.'" Participant 5

Lack of diagnosis or misdiagnosis led to diverse consequences among the participants e.g. anxiety; denial; and delays in definitive diagnosis and referral. Participants were often left with unanswered questions, uncertainty as to the treatment options and the potential risks and benefits of treatment and, occasionally, with contradictory advice.

> "… you want to know where the final outcome is going to be rather than you suffering week in week out thinking, 'when is it going to end? Fed up with this.' Whereas when you know it is going to last 3 or 4 years down the line, I know it is not going to be forever. Whereas you don't know anything; God, is this ever going to go away? I think I would like to know from the start." Participant 11

> "I don't know whether I wasn't saying the right things to [my GP] or what .... I don't know whether it is my relationship with the doctor or what, but I don't … I'm not very good, if they are vague and I don't understand what they are talking about, I won't sit there any longer, I'll, I'll leave. All I wanted was an answer." Participant 12

Participants who did not receive early informed or specialist care would have preferred a quick, clear pathway; and although they understood the difficulty of diagnosis, some expressed disappointment that they had suffered, for what seemed to them, longer than necessary, due to a lack of awareness of the condition on the part of their healthcare providers

> "With the shoulder, I was saying, 'it's still hurting' and they [the GPs] were saying 'we'll look to see what else it is then.' Every time, something came back as, 'no, it's negative. Have you got any neck problem, shoulder problem, anything like that?' No arthritis, no swelling in it … but every time it come back no, you are thinking, now what?" Participant 7 [first-affected shoulder, 2004]

Theme 3: Inconvenience/disability

Typically the FS lasted from one to three years. In a group of people who were usually active, this was hugely disruptive. The inability to use the arm normally, initially due to pain, gradually giving way to stiffness, affected even very fundamental activities of daily living (ADL), including, among others, hair washing and styling, getting out of a bath, dressing, reaching into a back pocket, opening a door, pegging washing out, washing up and other housework, home maintenance jobs, lifting a kettle, cutting up food, pulling a suitcase or wheeled shopping basket, gardening and, when driving, changing gear or positioning for reversing. In order to continue to drive, one participant had to buy a car with automatic transmission.

> "Try getting out the bath 'cause you can't find a way up. You just cannot find a way to get out the bath! We've got bars on the side of the bath anyway but I couldn't find a way. I just had to snake over the side sometimes." Participant 7

Participants who worked had to change their work routines to accommodate their limitations; one, for whom this was not possible, had to resign

A general observation was that the pain and these major impairments in ADL occurred without obvious outward signs, so that much of the suffering involved was hidden from the casual observer. This led to much less sympathy than would be the case with many conditions.

> "I was still doing the workload as such, so you don't get any, it's awful to say, you don't get any sympathy from people because it is not something that stops you doing things but in yourself you feel so frustrated, because when I reached up to do anything, we do a lot of overhead stuff, there was no strength in the arm, it was very painful but nobody would say, "How is it?" You felt that they didn't understand, because you are at work with it and that was the hardest thing, and they still expected you to do things because you didn't have your arm strapped up." Participant 10

A further cause of hidden suffering was that other people relied on their own experiences of pain when trying to understand the participants' perspective but it was outside their lexicon of knowledge. Three participants recognised that they themselves had not understood what it was like or been sufficiently sympathetic towards others with FS until they acquired it themselves.

> "I've heard of other people with frozen shoulders and I'm afraid I haven't given them much sympathy because I didn't know what it involved. You would be in the same boat. I sympathised, say that's terrible, but really unless you have or have had a frozen shoulder you don't know how painful it is. It is really excruciating." Participant 8

In general, so long as the FS was seen as temporary and benign, and they could care for themselves and keep their jobs until they recovered, participants accepted their situation; at the same time, they hoped for the earliest possible resolution.

Theme 4: Treatment

Participants identified functional outcomes e.g. freedom of movement as their main priority from treatment; however they recognised that if the pain or stiffness remained they would be unable to recover the movement. On presentation at the GP's surgery, reflecting the lack of a definitive diagnosis in most cases, there was no standard course of treatment offered. Two participants came via their occupational health physiotherapy services then to their GPs. Neither of them received a diagnosis of FS either. Some GPs opted to wait and see and most prescribed analgesics. As time passed some offered further investigations and/or administered further first-line treatment themselves, while others referred patients to an on-site physiotherapist, or to a primary or secondary care MSK clinic.

The range of first-line treatments experienced by the participants from their GPs included ointment, medications and local injections. On referral to the physiotherapist, treatment might include advice and education, hands-on passive mobilisation, exercises, local injections, heat, massage, ultrasound, transcutaneous electrical nerve stimulation (TENS), acupuncture or hydrotherapy.

All participants had received some physiotherapy due in part to the recruitment pathways into the study. Some participants were referred swiftly to a specialist physiotherapist, a factor which may have been influenced by the involvement of a surgery with a physiotherapist specialising in MSK and FS. In other cases participants were referred, only after lengthy periods of care by an occupational physiotherapist and/or their own GP, to a specialist physiotherapist, a GP with a special interest in MSK conditions or a consultant shoulder and elbow surgeon. Two participants received surgical interventions: manipulation under anaesthetic and an operative capsular release, respectively.

MSK specialists, whether specialist physiotherapists, GPs with a special interest or surgeons, were available in various locations. There were sometimes delays in referral to these specialists, but once referred, participants reported positively on their care in each location. Definitive diagnoses were made or confirmed. Referral also brought an understanding approach, clarity and relief; participants expressed profound relief at knowing what the problem was and being in the care of someone who knew about the condition. Some of their worries could be explained and their questions answered. This was very important to them.

> "[S/he] went into extreme [detail], were there any questions, [s/he] was so incredibly thorough, I can't say enough really. [S/he] went into, straight away what it was, because what I couldn't understand was, why was I getting this pain in the top of my arm when it is a frozen shoulder, but why am I getting pain in the arm and not the shoulder?"
> "What did [s/he] say?"
> "[S/he] did me a diagram; [s/he] showed me a model of a skeleton."
> Participant 10

Relationships with specialists were generally reported as friendly and non-hierarchical, and conducive to the exchange of information. In general, however, there was over-reliance on verbal information, with very limited use of other media.

DISCUSSION

Principal findings

Patients' initial experience was characterised by severe, inexplicable pain followed by increasing restriction of movement. Overcoming these symptoms and recovering functional capacity was their priority. Understanding the cause, seriousness and likely outcome of the condition were also important to them. Reducing delay in diagnosis was a common plea with considerable anxiety, confusion and delay for those in the continued care of non-specialists. This was followed by a sense of relief on meeting a specialist, with gradual improvement ensuing in most cases. Most patients found hope and encouragement through this interaction, although elements of the condition remained inexplicable and uncertain. There was over-reliance on verbal communication and very little written information was provided.

Strengths and weaknesses of the study

This study is the first to focus on patients' experiences of conventional care pathways for this condition, and their priorities for treatment. These aspects, and the in-depth nature of our analysis, are major strengths.

Patients were recruited from care settings where the condition is typically managed; however some barriers to recruitment were experienced which have been identified previously, such as an initial hiatus in diagnosing the condition and approaching potential participants within a busy clinical setting. Recruitment issues are not uncommon and are well documented in other studies.[20] This was a small study which consequentially included data from a limited number of patients from a single geographical area. Although their own stories remain valid every possible theme would not necessarily be exhausted.[21] In addition two participants' experiences of FS was historical, so that, compared to recent cases, their contributions are likely to be more open to error of memory, and to reflect earlier approaches to care. Nevertheless the design included trustworthy methods such as using a standard protocol to introduce the study to prospective participants, selecting patients at different stages in the disease trajectory, using a topic schedule for interviews and recording interviews for transcription.

Strengths and weaknesses in relation to other studies

To our knowledge, and despite extensive searching,[5] there is no literature with which to directly compare our results. Carter[14] interviewed patients undergoing Bowen therapy for frozen shoulder, and very briefly described some experiential aspects of living with the condition, including pain, disturbed sleep, stiffness, impact on mood, and a disappointing interaction with a GP and a physiotherapist; all of which accord with our own, more searching, results. But Carter's [14] main focus was on the experience of Bowen therapy itself, limiting the applicability of her results; and patients' perceptions and priorities—dimensions considered critical by ourselves—were not addressed. Nor are our results directly comparable to those of Hush et al,[15] who systematically reviewed studies from Canada, UK, USA and Scandinavia and found high levels of patient-satisfaction with MSK physiotherapy. While our study

indirectly encompassed patient satisfaction, it differed in its focus, both in terms of being specific to primary FS, and in terms of including experience of the broader care pathway, not physiotherapy alone. Nonetheless, the aspects of care most consistently identified by Hush et al[15] as important to patients were the personal and professional attributes of the clinician, explanation and communication of information, and treatment outcome. These findings are strongly reinforced by our own work. A consistent international observation is the lack of confidence of GPs in diagnosing subtypes of shoulder pain, [22 23] and this may have a critical bearing on the appropriateness and timing of care pathways for patients with shoulder conditions.

A key theme from our data was delays in diagnosis. Initially this tended to be a patient-initiated delay resulting from the participants waiting to see if the shoulder issues would resolve. Such patient-initiated delays are not unique to FS and can be seen across a range health conditions. For example, Solbjør et al. highlighted that while some of the breast cancer patients in their study had delayed approaching their GP for 2 weeks, some had waited for longer than 3 months after they had found a lump.[24] When our participants did go to their GP they were often met with a failure to diagnose their condition or they were misdiagnosed. Again, this is not unique to FS; late or missed diagnosis has been cited as a contributory factor in poor outcomes for some cancers.[25 26] Furthermore, Pavey et al[27] in their research with patients with Motor Neurone Disease described the long journey to diagnosis as a 'diagnostic quest'.

Following diagnosis, it was evident from our data that FS had a major impact on the lives of our participants. Although FS is not a longer-term chronic condition such as multiple sclerosis or arthritis, it was clear that the participants in our study travelled along a similar trajectory to patients with such conditions. For example, Bury's notion that chronic health conditions are experienced as a 'biographically disruptive event' resonates very much with the experiences of our participants. Bury[28] identified the disruption of taken-for-granted behaviours such as general activities of daily living and the disruption of self-concept; all of which are supported by our data.

Implications for clinicians and policymakers

A care pathway with prompt diagnosis and access to specialist (or informed) care is required for sufferers of FS. There is potential for non-specialist healthcare staff, particularly GPs and physiotherapists, to be made more aware of this condition. This awareness would include diagnostic criteria, expectations, management strategies, and patients' needs for information and reassurance.

It is clear that, in some cases, there is a serious mismatch between clinicians' and patients' perceptions of the impact of FS. Strategies for educating clinicians are required, in order to convey the immense impact that frozen shoulder may have on sufferers' lives. Such education should ensure that active measures, to encourage timely resolution, are always offered.

There is a need to provide standardised, consistent information for patients, designed in collaboration with patients and based on the best available evidence. This information should address patients' questions and concerns, rather than clinicians' perceptions of what patients' questions and concerns should be. The

information should be available in multiple formats in order to maximise its accessibility.

The Chartered Society of Physiotherapy's (CSP) clinical guidelines for FS and quick reference summary endeavour to address some of these issues. [11 12] Dissemination is now the key to connecting evidence and target audience. Awareness among other healthcare staff should be raised in order that their interaction with this patient group is apposite.

Future research

Our participants expressed a clear preference for early specialist referral; also a need for reassurance and timely, comprehensible advice and information in a variety of media. The evidence base underpinning the management of FS is not strong[5 11] and studies into the natural history of FS have produced somewhat contradictory results.[13 29] A need for more primary research and for research of higher quality on FS has been identified elsewhere.[5 11] But clinicians could make better use of the evidence, limited though it is.

Until recently, frozen shoulder research has lacked a focus on patients' perspectives. Patient involvement has yet to make appreciable inroads but this must change if such research is to be relevant. Unless the aspects of FS which most concern patients are known, generic shoulder pain Patient Reported Outcome Measures (PROMs)—used to measure condition severity and progress in such research, as well as in clinical practice—cannot be considered completely valid. Nor is it possible to develop a more sensitive, condition-specific PROM.[30] The present study, by exploring which aspects of FS patients most care about, contributes to a foundation for such validation and development.

CONCLUSIONS

Patients' perspectives on the experience of FS and their priorities for treatment have not previously been explored; however it is clear that this has been a major omission. Our study identified a number of issues that were important to patients. These included pain, but recovery from functional disability was often given higher priority. Anxiety was another key theme, and the struggle of living and dealing with FS was compounded, in some cases, by a lack of awareness on the part of healthcare professionals and, foremost, a failure to diagnose the condition.

To address these issues most effectively it is recommended that a diagnosis, even if only tentative, be quickly established for more patients. This would require GPs to recognise the salient diagnostic features. They and other healthcare workers should also be educated on the condition's impact on individuals, and accordingly the findings of the present study should be disseminated and built upon. Advice and information in various formats, reflecting the best available evidence, should be made readily available to patients. Finally, the evidence base for effectiveness of treatments needs to be expanded, maximally utilising patient participation. The present study, by exploring which aspects of FS patients most care about, contributes to this goal.

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A qualitative study of patients' perceptions and priorities when living with primary frozen shoulder
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Table 1: Participants' characteristics

Participant number	Age in years	Gender	Diabetic	Group	Dominance of affected side at time of study*	Length of time from onset to 1st consultation	Length of time from 1st consultation to referral to MSK specialist	Where physiotherapy treatment was given
1	60-69	Female	No	1	D	Within 3 months	3 months	Own practice - physiotherapist with MSK interest
2	50-59	Female	No	1 & 2	ND & D	Immediate Within 2 months	Immediate 22 months	MSK community clinic GP at own practice (not referred to MSK specialist)
3	50-59	Female	No	1	D	Within 2 months	0 months	Own practice - physiotherapist with MSK interest
4	50-59	Female	No	2	ND	Unknown	Unknown	Own practice physiotherapist (not referred to MSK specialist)
5	50-59	Male	No	2	D	Within 1 month	5 months	Hospital MSK clinic
6	40-49	Male	Yes	2	D	Within 2 months	3 months	Occupational health physiotherapist Own practice - physiotherapist with MSK interest
7	50-59	Female	No	1	ND	Approx 5 months	0 months	MSK community clinic
8	Over 70	Male	No	1	D	Within 3 months	0 months	Own practice - physiotherapist with MSK interest
10	50-59	Female	No	2	ND	Within 2 months	6 months	Generalist physiotherapist MSK hospital clinic
11	50-59	Male	Yes	3	ND	Within 2 months	8 months	MSK hospital clinic
12	50-59	Male	Yes	3	ND	Within 1 month	16 months	Occupational health physiotherapist MSK hospital clinic

* D = Dominant; ND = non-dominant. Notes: Participant 9 did not return calls/emails. Data in table derived from interviews with patients, medical records not accessed.