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Patient experience of the diagnosis and management of patellofemoral pain: A qualitative exploration

--Manuscript Draft--

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Abstract:	Background Patellofemoral pain (PFP) is common and long-term treatment outcomes are unsatisfactory. Qualitative exploration of diagnosis and management from the perspective of people with PFP is lacking. Objectives To inform care and improve intervention delivery by exploring the experience of people with patellofemoral pain (PFP) regarding diagnosis and management. Design Qualitative study Method Online recruiting yielded a convenience sample of participants with PFP for semi-structured interviews. Interviews were recorded, transcribed verbatim and analysed until theoretical saturation by multiple investigators to determine themes and sub-themes. Results 12 participants were interviewed, with three themes identified; the value of diagnosis, the need for tailored (individualised) care, and the role of education. Participants viewed a diagnosis as essential to guide management, yet this was rarely provided, causing uncertainty about pain mechanisms; “it's nice to be told what it is that's wrong” . Interventions needed to be tailored to the individual as not all participants responded in the same way to treatment(s) or had the same needs; “everyone copes and reacts differently” . Finally, participants viewed education as essential to empower them to understand and manage the condition; “if I’d have been given more information, I think I’d know how to deal with it more” . Conclusions

	The overarching narrative from three themes was a desire for clearly communicated personalised care that meets individual needs. People with PFP desire a diagnosis to explain their pain, tailored interventions, and appropriate education to optimise their experience and outcomes.
Suggested Reviewers:	Claire Robertson clairerobertson@wimbledonclinics.co.uk Has published previous qualitative research in the field.
Response to Reviewers:	

Barts and The London
School of Medicine and Dentistry

Sports and Exercise Medicine
Bart's and the London School of Medicine and Dentistry
Queen Mary, University of London

Saturday, 2nd October 2021

Professor Ann Moore, CBE, PhD

Editor, Musculoskeletal Science and Practice

Re: Patient experience of the diagnosis and management of patellofemoral pain: A qualitative exploration.

Dear Professors Jull and Moore,

Thank you for once again reviewing our paper so promptly, and for giving us the opportunity to resubmit after further insightful comments of the peer review team. This has undoubtedly strengthened our submission and increased its potential to influence diagnostic and therapeutic processes and patient centered care.

This manuscript represents the result of many months of qualitative work investigating the diagnosis and treatment of patellofemoral pain from the patients' perspective. Our study was designed to have an over-arching applied clinical focus, and identified three key themes, which offer rich clinical insight into how patients wish to be provided with a diagnosis, desire individualised care and hold education in high regard. We have attempted to discuss why these themes are of importance to clinicians treating patellofemoral pain and believe that our findings can directly influence clinical practice. We are also preparing a second manuscript exploring this question from the perspective of expert clinicians, which we will also aim to submit to Musculoskeletal Science and Practice for consideration when ready (estimated within the next month).

All of the authors have read and concur with the final content in the manuscript. The material within has not been and will not be submitted for publication. Neither I, nor any of my co-authors have any competing interests. All authors made substantial contributions to the conception, design and delivery of the study and all authors contributed to the final manuscript preparation before I gave final approval for this version to be submitted.

With my best wishes,

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1 & 2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	4

Introduction

Problem formulation – Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	5 & 6
Purpose or research question - Purpose of the study and specific objectives or questions	Page 6 Lines 56-58

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 7 Lines 61-62 Page 9 Lines 106-111
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 9 Lines 102-105
Context - Setting/site and salient contextual factors; rationale**	Page 8 Lines 83-84
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 7 Lines 69-70 Lines 77-81
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 7 Lines 64-67
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 8 Lines 83-93

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 8 Lines 83-93
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	See table 2
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 9 Lines 106-120
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 9 Lines 106-120
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 9 Lines 106-120

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 11-22
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pages 11-22

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 23-26
Limitations - Trustworthiness and limitations of findings	Page 27 Lines 486-493

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Pages 1 & 2
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Pages 1 & 2

We thank the reviewers for their detailed and insightful comments on our manuscript, which have undoubtedly aided us in improving our submission. Detailed acceptance of all additional comments is provided below, with additions indicated by underlined/italicised text.

Reviewer 1

Thank you for your considered responses to the reviewers' comments and your resubmitted manuscript.

The amendments have enhanced this piece and provided further clarity. I still think there is an excessive use of quotations but accept the team's justification for inclusion.

I do note a couple of errors that need addressing:

Comment 1: L89 This should read 40 years not 50.

Response 1: thank you for spotting this further typographical error. It has been amended and now reads as follows:

"37 participants volunteered for this study, with 14 failing to meet the eligibility criteria (sudden/traumatic onset symptoms=five, aged >*4*0=two, incorrect aggravating factors=one, yet to receive treatment=six)."

Comment 2: L94 I was asked to review the first version of this manuscript in July 2021, so suggesting that interviews were conducted between June and August 2021 is not correct. Do the authors mean 2020?

Response 2: we do indeed mean 2020, thank you for spotting this typographical error, it has been amended and now reads as follows:

"Twelve PwPFP, seven women and five men, with a mean age (26.5 ± 4.7) and symptom duration (43.3 months ± 42.3), living in England (eight), Europe (one) and North America (three) were interviewed between June and August 202*0* (see table 1), ranging from 45 to 80 minutes."

Comment 3: L420 Grammatical error: Complement not Compliment.

Response 3: thank you for spotting this grammatical error. It has been amended, and now reads as follows:

"The findings of this study *complement* and extend the existing clinical practice guidelines for PFP[2,14,51], which were developed without including the patient voice."

Comment 4: L454 It may be a little ambitious to suggest that the findings form this study should lead to an update in practice guidelines. I would suggest this is somewhat moderated to be considered by clinicians when managing this patient group.

Response 4: we accept the reviewer's thoughts here and have softened this sentence accordingly. It now reads as follows:

"These data are an important addition to the existing literature and should be *considered by clinicians when treating people with PFP*."

Reviewer 2

Thank you for the opportunity to continue to be involved in the review process for this manuscript that uses qualitative methods to report the patient experience of diagnosis and management of patellofemoral pain. Thank you to the authors for addressing feedback on the original version of the manuscript. I have only very minor comments. Line numbers correspond to the version of the revised manuscript where changes were marked.

Comment 5: Line 59: authors refer to the topic guide for the interview being presented in Appendix 1. However, in the document available to me as a reviewer, I did not see this appendix.

Response 5: we apologise for this. We have checked that the appendix was uploaded to our submission, but have also included appendix one at the bottom of this document for the reviewer to see if desired.

Comment 6: Addition of the 6-phase model of Braun and Clarke used for thematic analysis is very helpful.

Response 6: we thank the reviewer again for this suggestion and are pleased that they are satisfied with our addition.

Comment 7: Line 89: enrolment criteria in the methods updated the age range to 18-40 to correct a typographical error in the original manuscript that read 18-50. However, the authors also need to update this upper limit of the age range when describing volunteers who did not meet enrolment criteria.

Response 7: this further typographical error was also spotted by reviewer one and has been amended. Please see response one for further clarification if required.

Comment 8: Line 104: because of the newly added figure on the 6-phase model of Braun and Clarke, the figure showing themes and subthemes is now Figure 2, not Figure 1. The caption for this figure is accurate, but this place in the text of the manuscript needs to be corrected to Figure 2.

Response 8: thank you for spotting this typographical error. It has been amended and now reads as follows:

“Three themes and nine sub-themes were devised from 801 initial codes, which are detailed here and mapped in figure *two*.”

Subject area	**Questions**
Living with PFP	Please can you describe for me what it has been like living with kneecap pain? a. Duration b. Changes over time / recurrence c. What impact has it had on your life: i. Physically ii. Emotionally (fears/anxieties) iii. Social consequences iv. Occupational consequences v. Financial consequences Why do you think your kneecap pain started?
Assessment & diagnosis	Tell me about your experience of being told the cause of your kneecap pain. a. Who did you see? (doctor/physiotherapist/podiatrist/etc.) b. Were any MRI scans or x-rays used to explain the cause of your pain? c. What terms were used? d. What information do you feel you needed to know? Why do you think you still have kneecap pain now?
Information	Were you given any educational material or resources about your kneecap pain? a. How was this information given to you and by whom? b. Did you have any preferences? c. Have you accessed any information yourself (e.g., websites, apps)? d. Are there any you would want to share with others with PFP? How would you explain your diagnosis to a family member or friend?
Treatment	Where any guidelines or research about your management discussed with you? a. What did you think of this information? Tell me about the treatment you have had for your kneecap pain? a. What approach(es) were used and by whom? b. How many episodes/sessions? c. Was your previous treatment reviewed? What was the outcome? a. How did you feel about that? b. Were there any strengths and weaknesses? Did you have any expectations regarding your treatment? Were there any treatments the clinician included that you weren't expecting to receive? Please can you tell me if you received any other support? a. Psychological support b. Return to work/sport advice Were the advantages and disadvantages of all treatment options discussed with you? Is there anything else that you discovered to manage your kneecap pain?
The future	What does the future look like for your knee? a. Are there aspects that are still not clear to you, and if so, what? b. Have your activity levels changed? Do you have any advice for clinicians to help them manage patients with kneecap pain?
Follow up questions to seek gain clarification/ elaboration:	Can you tell me more about that? Tell me what that was like for you? Why is that? Can you clarify more about ……? You mentioned ……. can you describe what you meant by ………? Reflection of answer/summarising to check and prompt

Click here to view linked References

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INTRODUCTION

Patellofemoral pain (PFP) is characterised by insidious onset retro-and/or peri-patellar pain, aggravated by loading a flexed knee[14]. PFP affects 22.7% of the United Kingdom population[45], has a poorly understood aetiology[33], and affects occupational, social, and sporting activities[14]. Research aimed at managing PFP is primarily quantitative[44], with randomised control trials of varying methodological quality[24] recommending addressing the biomechanical impairments associated with PFP[50]. Despite the strength of this research PFP has a poor prognosis, with >50% of people reporting persistent pain five years post-treatment[29].

One proposition to improve outcomes in PFP is to apply a biopsychosocial (BPS) approach, focusing on holistic care[41] rather than traditional biomechanical methods[1]. The focus should be the person, rather than their painful joint, understanding their personal experience and impact on their life[50]. Other factors that influence PFP, such as fear and anxiety, should be addressed[3,9]. There is a paucity of qualitative research on the lived experience of people with PFP (PwPFP), with research focusing on pathophysiological causes despite patients' concerns about the impact of pain on their quality of life[40].

Qualitative research provides rich insight into patient experiences[6], allowing a greater understanding of the factors influencing these experiences to inform healthcare provision[20]. Two qualitative studies on the lived experience of PwPFP have been conducted[40,44], reporting a loss of self-identity[44] and fear avoidance due to crepitus and pain[40,44]. The negative experience of living with PFP was compounded by uncertainty about the cause of pain[40,44], conflicting advice[44], and an overall lack of empathy[40,44]. These studies focussed on exploring living with PFP, rather than understanding patients’ experience of their diagnosis and treatment.

The high prevalence and poor prognosis demonstrate a clear need to optimise PFP management. This study aimed to inform care and intervention delivery by exploring patient experiences of the diagnosis and treatment of PFP using semi-structured interviews.

METHODOLOGY

Design

A qualitative study using semi-structured interviews following the Standards for Reporting Qualitative Guidelines (SRQR)[34] was conducted.

Ethical approval

The xxxxx Ethics of Research Committee granted approval (QMERC/2018/48036). All participants confirmed eligibility and provided written informed consent prior to interview using Google Forms (Google Inc., California, USA).

Recruitment

A convenience sample of potential participants were recruited online via social media. Participants were eligible if they met the diagnostic criteria for PFP[15], including insidious onset retro-and/or-peri-patellar pain reproduced by one or more of the following: squatting/lunging, running, jumping/hopping or stair ambulation[15]. Eligible participants also needed experience of treatment for their PFP, speak fluent English and be aged between 18-40. Participants aged ≤18 or ≥40, or with traumatic symptoms, patellar instability, intra-articular pathology, systemic pathology, or a diagnosis of other anterior knee pain sources were excluded. Sample size was revisited during data collection in an evaluative way[4] and theoretical sufficiency[17] guided when sufficient data were collected.

Data collection

Eligible participants completed an online, one-to-one interview with a single investigator (PB) using Zoom video (San Jose, California, USA). Interviews were semi-structured with open-ended questions and followed a topic guide developed based on input from a patient and public involvement group at the design stage. Dependability was enhanced by a reflective researcher self-audit, completion of a reflexive journal and use of a peer-reviewed topic guide[26].

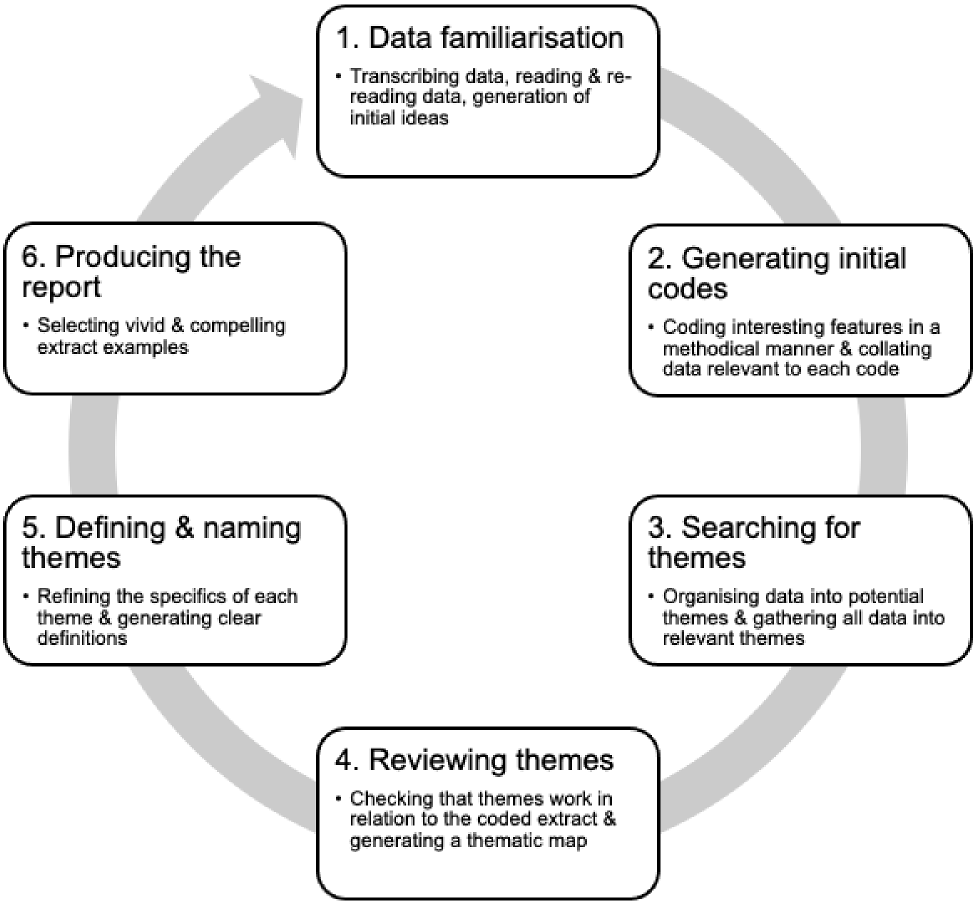
The topic guide (see appendix 1) included questions about living with PFP, assessment and diagnosis, educational material and resources, treatment provided, and the future. Questions related to lived experience were included to understand the impact of PFP treatment.

Data analysis

Interviews were audio recorded, anonymised, and uploaded onto a password-protected online transcription software Otter.Ai (Los Altos, California, USA). Files were removed once the computer-generated transcription was produced for data protection. Audio files were transcribed verbatim, and error corrected by a single investigator (PB). PB is a physiotherapist with 15-years' experience, working as a clinical lead in a musculoskeletal service that covers a large geographical area in southeast England not used to facilitate recruitment.

Data were analysed under the constructivist paradigm, as its central endeavour is to study phenomena through the eyes of people in lived situations[17]. Thematic analysis was used, moving backwards and forwards through the six-phase model of Braun and Clarke[5] (see figure 1), chosen to understand participant experiences and patterns of meaning across the dataset[10].

Figure 1: six-phase model described by Braun and Clarke



Transcriptions were read multiple times for familiarisation and generation of preliminary ideas. Data were coded by the lead author (PB), which involved theme development, naming, and refinement. Peer review on interview technique, early coding, and theme development was provided by a single investigator (CML). Data collection and analysis was performed iteratively to deepen the richness of the findings[11]. A single investigator (CB) independently verified all codes and themes against the transcripts. Contradictions to the findings[32] and verbatim quotes[21] were included to enhance rigour.

RESULTS

Participants

37 participants volunteered for this study, with 14 failing to meet the eligibility criteria (sudden/traumatic onset symptoms=five, aged >40=two, incorrect aggravating factors=one, yet to receive treatment=six). A further 11 participants did not respond to repeat invitations to interview. Twelve PwPFP, seven women and five men, with a mean age (26.5 ± 4.7) and symptom duration (43.3 months ± 42.3), living in England (eight), Europe (one) and North America (three), were interviewed between June and August 2020 (see table 1), ranging from 45 to 80 minutes. The final two interviewees reported no new information and theoretical sufficiency was deemed achieved.

Table 1: participant information

Participant, Sex, Age	Symptom duration	Aggravating factors	Management	Imaging	Modalities	Outcome
J Female Age 28	12 months	Running	One course of physiotherapy (Private: UK) Orthopaedic assessment Private: UK)	Nil	Exercise Foot orthoses	Full recovery
T Female Age 22	10 months	Stairs Running	Multiple courses of physiotherapy (Private: Europe) Multiple orthopaedic assessments (Private: Europe)	MRI scan	Exercise Foam rolling Taping	No recovery
B Female Age 28	12 months	Running squatting	One course of physiotherapy (Private: UK)	Nil	Exercise Foot orthoses Knee brace Return to running advice	Partial recovery
N Female Age 27	3 years	Running Squatting Lunging	One course of physiotherapy (Private: UK) Orthopaedic assessment (Private: UK)	MRI scan US scan	NSAIDs Exercises	Full recovery
L Female Age 23	12 months	Running	One course of physiotherapy (Private: UK) Orthopaedic assessment (Private: UK)	MRI	Exercise/stretching Foot orthoses Running re-training Taping	Partial recovery
D Male Age 24	3 years	Stairs Running Squatting Lunging	Multiple courses of physiotherapy (NHS and private: UK) Orthopaedic assessment (NHS: UK)	X-ray	Exercise Massage NSAIDs	No recovery
A Female Age 19	12 months	Stairs Running Squatting Lunging	Multiple courses of physiotherapy (NHS: UK) Orthopaedic assessment (NHS: UK)	MRI scan	Exercise Foot orthoses Surgery	No recovery
Z Male Age 35	8 years	Stairs Squatting	One course of physiotherapy (Private: North America)	Nil	Exercise Knee brace	Partial recovery
K Female Age 25	3 years	Stairs Running Squatting Lunging	Multiple courses of physiotherapy (Private: North America) Multiple orthopaedic assessment (Private: North America)	MRI scan X-ray	Exercise Hyaluronic/steroid injection Taping Massage/Acupuncture NSAIDs	No recovery
TN Male Age 25	18 months	Stairs Running Squatting Lunging	One course of physiotherapy (NHS: UK)	Nil	Exercise	Partial recovery
F Male Age 36	12 years	Stairs Running Squatting Lunging	One course of physiotherapy (Private: Europe) Orthopaedic assessment/treatment (Private: North America)	Nil	Exercise/stretching Steroid injection Running re-training	Partial recovery
JA Female Age 26	8 years	Running	One course of physiotherapy (NHS: UK)	Nil	Exercise	Full recovery

Key: NHS; National Health Service, MRI; Magnetic resonance imaging, US; ultrasound, NSAIDs; Non-steroidal anti-inflammatory drugs.

Thematic analysis

Three themes and nine sub-themes were devised from 801 initial codes, which are detailed here and mapped in figure two.

Theme one: The value of diagnosis

Over half the participants reported clinicians infrequently discussing a diagnosis or providing an explanation for their pain:

> *"Basically no one told me, oh…that's the main reason for it"*

(participant J)

> *"They were like, this is a problem, we don't really know what causes it...we can't really tell you exactly what it is"* (participant K)

The lack of a cause was viewed as a barrier, facilitating biomedical beliefs:

> "*The main problem is that uncertainty in diagnosis"* (participant T)

> *"I think it's some sort of cartilage damage"* (participant N)

This perception of faulty structures hindered recovery, with faith placed in diagnostic tests for reassurance and prognosis:

> "*I'm thinking is there damage structurally I'm not gonna fully recover from. So that's kind of why I would like to know"* (participant D)

> "*the fact that you have an MRI and it's, it's thorough, I think as a patient it gives you peace of mind"* (participant N).

However, a lack of diagnostic findings created confusion and feeling disbelieved by clinicians:

> *“It was confusing at the time; I knew what I felt. I know when it's not in my head...I know that sometimes MRIs look perfectly fine, but pain is there*” (participant T).

Only four participants reported receiving a diagnosis, often delayed if seeing a physiotherapist versus an orthopaedic consultant, with a subsequent negative emotional impact:

> “*It was quite frustrating because since July last year until end of May this year, I didn't know the cause”* (participant L)

A diagnosis was desired by participants, believing it was necessary to facilitate resolution and legitimise their pain:

> “*The first step is that certain diagnosis…when you have that you're halfway”* (participant T)

> “*It was helpful, because sometimes it's nice to be told what’s wrong. So, you know it can be fixed…helps you feel validated”* (participant B).

Conversely, one participant learned that a diagnostic label wasn’t key to their recovery. They instead found gaining knowledge through biopsychosocial explanations more useful:

> “*Now I realise that having a name is not that important to get better, it's more understanding what’s wrong and a more holistic kind of view”* (participant L).

PFP was the commonly used diagnostic label, but half the participants felt it was not specific enough to provide them with an understanding of their pain:

> *“It's very frustrating because I feel like it's, in my sense, it's kind of a blanket response”* (participant K)

In contrast, one participant was content with a general explanation, finding this more understandable than confusing medical terms, highlighting individual preferences:

> *"I don't know why they just don't say kneecap pain*" (participant A).

Furthermore, two participants stated they were given a diagnosis of patellofemoral syndrome, which had negative connotations:

> *"Is it some sort of a disease if it's a syndrome"* (participant D)

> *"He was like patellofemoral pain syndrome. I don't know if that word syndrome around it makes you catastrophise a bit as well. We've got this syndrome now"* (participant T)

Theme two: The need for tailored (individualised) care

Non-exercise treatment approaches and outcomes

Outcomes were mixed amongst the 12 participants (see table one), with no panacea described. Eight participants had an orthopaedic assessment, but only three received orthopaedic treatment: two an injection and one surgery post-physiotherapy. One participant received a Hyaluronic acid injection and the other steroid. Both reported short-term benefit only and mixed reactions on injection usefulness:

> *"Corticosteroid, it was good. Yeah, it works…because the first one worked a lot so I'm still thinking to get another one"* (participant F).

> *"I got a Synvisc injection, that was the last one I let them put in me, and that one felt good for maybe 10/11 days and then it was the same…back at square one"* (participant K).

Non-steroidal anti-inflammatory drugs also gave some benefit to three participants:

> “*Anti-inflammatories, ibuprofen to kill the pain, that kind of felt good”* (participant N).

All participants received treatment as part of their physiotherapy experience, but half of the participants did not make a full return to previous activity levels (see table one), which did not meet their expectations:

> *“You get physio, you become better, that's what’s supposed to happen. You are not supposed to keep going to physio like me”* (participant A).

Conversely, three participants reported a partial recovery, and another three reported a full recovery with physiotherapy alone. With frequent sessions, participants reported improvements in their pain:

> *“And then since obviously the physio and stuff it’s better now…So I don't get it at the moment”* (participant N)

> “*Seeing the physio weekly, eventually, that's given me the best results”* (participant B)

Two participants experienced knee taping or bracing as part of their physiotherapy, which helped in the short-term, providing reassurance that no harm would come with activity:

> *“I found that using tape is actually quite helpful”* (participant L).

> “*Putting a brace on kind of reduces it a little bit…hopefully that that gives me peace of mind that I'm not doing more damage*” (participant Z).

Three participants were given tailored cues to alter their running biomechanics, which helped all:

> “*I adapted my technique…my foot was like that (shapes hand to suggest heel-strike)...Now I'm more like (shapes hand to show forefoot-strike). I can run longer now”* (participant F).

Outside of physiotherapy, customised foot orthoses were provided to three participants by a podiatrist and were effective for two (of three) for running-related symptoms:

> “*The pain has decreased…It definitely decreased just because I find it more kind of comfortable when I do the heel-strike”* (participant L).

Soft tissue massage had varied results. Massage was provided by a physiotherapist but was not beneficial for one participant, but another participant used a self-applied massage tool, which helped short term:

> “*It feels nice to have your IT bands, adductors, and quads released, but in terms of patellofemoral pain, no difference whatsoever”* (participant D).

> “*Gua Sha has helped me a lot…I'll use it for right below and on the inside of the kneecap and then around my quad and IT band. Basically, anything that feels off or weird or painful*” (participant K).

Exercise prescription and outcomes

All participants were provided with an exercise programme as part of their physiotherapy, reporting varied outcomes. Lower resistance exercises were more helpful for pain and self-efficacy:

> “*We just did some really mild stuff to try and get my quads to fire a bit more…I feel quite better”* (participant D).

“*If I was to go for a run, I would do a mini version of the (exercises)...I could do that with the confidence that I wouldn't get the pain after”* (participant N).

In contrast, higher resistance exercises were more likely to induce pain. The instruction to use additional weight exacerbated pain for one participant, who subsequently recommended using lighter loads and gradually progressing:

“I did the whole leg extension thing. I noticed absolutely no difference, none...and then immediately when adding weight, it was sore right away…If I knew other ways to strengthen my quads in increments, to be able to do the harder exercises, I think that would help” (participant Z).

However, pain was accepted if the outcome was perceived as beneficial, in the form of strength gains and pleasure from the exercise:

“*Before when I've done it, it's just been without weight...Even though they were more painful I think you feel benefit more of doing a weighted exercise”* (participant A).

Progressions and regressions of exercise according to the response, with very gradual increases in resistance, enabled all three participants following this plan to return to running:

“He was able to adjust the programme and then we took it down for one week to give me a break, and then built it up again slowly (participant B).

“*He said to me, use a backpack for your exercises and put one or two bottles...then three bottles and so yeah, that helped also”* (participant J).

Engagement with exercise was a factor in determining outcomes. Exercises performed regularly were more beneficial for the pain:

> *"It feels better, but then if you do keep on top of the…that's probably my advice, keep on top of it"* (participant A)

Differing individual needs

Half the participants stated explicitly that they felt the treatment of their knee pain was formulaic, instead wanting it to be adapted to their individual needs because of the variation in responses:

> *"In a physiotherapy group, others had knee pain and some shoulder pain. I was given exercises, isometric exercises, nothing special, leg raises and clam shells and things like that. But everything for everyone was the same. It wasn't specified for each case…Physical therapy should be individual and specialised for that person"* (participant T)

The suggestion was not to use the same approach for each person, but to consider individual needs and that not everyone responds positively to the same interventions:

> *"So it's kind of individualising patient care...everyone copes and reacts differently"* (participant L)

> "*I think I'm aware that all these things are completely different person to person very specific to the individual*" (participant N)

A collaborative approach with clinicians was recommended by participants, to determine what treatments would be more effective:

> *"you have a physio that you can talk to and actually say, I think this is not working and work with them to kind of find a better way that's always good, and it kind of reassures you and motivates you to do it"* (participant L)

"Understand what treatment I've had, what's worked, what hasn't. So that's kind of how I feel" (participant D)

Building a therapeutic alliance

All participants discussed the psychological and social impact PFP had on their lives, but this was reportedly not addressed. Participants described valuing clinicians taking time to understand their psychological and social needs, contributing to developing strong therapeutic alliance:

"I think that's really, a really good experience that someone is interested in whether it's affects you mentally as well. I think that's important. It should be part of any treatment" (participant J)

"*It's not just treating the knee pain, it's treating the social issues, the depression"* (participant K).

However, half the participants reported feeling that clinicians were apathetic to their concerns:

"It was just my doctor at the time that like, he was passing it off as not a serious problem and that sort of thing. Just the whole demeanour" (participant TN)

"A lot of times with all the doctors that I've seen, it's like, okay, here's your knee, this is your life, goodbye. And it's like, wait a minute…this is my life" (participant K)

In contrast, others had a positive experience if they formed a therapeutic alliance with their clinician, which was enabling:

"*It felt more like you know, like more friendly, and then you build that relationship and it's easier to ask questions*" (participant B)

> *“So, I think it's just, you know, building that rapport with a patient, understanding what's important to them…If you understand what I need to do then we can work together to find ways of kind of work around my situation”* (participant L)

Participants recommended that clinicians focus on being more personable and listen and understand what they were reporting, which may then lead to improved outcomes:

> *“I think the sort of human side of it in when explaining things just helping me feel like it's not just me and lots of people have experienced this, or if they've been through something similar themselves, or can tell me a story to help me relate which, you know, my physio did. I enjoyed that part of it”* (participant B)

Gaining this understanding strengthened therapeutic alliance and was a more positive experience if the participant and clinician came up with a management plan together:

> “*If you understand what I need to do then we can work together to find ways of kind of work around my situation*” (participant L)

Theme three: The role of education

All participants reported being infrequently provided with information or education, despite this being something they desired to inform and empower:

> “*Never. I don't think I've had anything”* (participant D).

> *“I always say that more information is better…that's the way I feel...explaining why glutes are important in controlling your femur, what the role of the quads were, and that kind of just helped me”* (participant D).

It was also felt education could enable self-management and reduce the mental impact of PFP:

“*If I'd have been given more information, I think I'd know how to deal with it more, cope with it, then I wouldn’t feel so worthless”* (participant A).

Most participants had a belief exercise would help, but their queries were sometimes unattended to, leaving them inadequately educated:

“*I believe that exercise is the key. The question is only which, and how to progress and all that”* (participant T).

This caused concerns of possibly doing more harm than good*:*

“About the exercise, I don't understand what may harm it if I'm doing the exercise wrong or something like that” (participant Z).

Conversely, when information was given, largely verbal, it was empowering:

“Because now I had this information. And yeah, then I went to the physio and then we could work on that. So it helped me” (participant J)

“He took the time to kind of sit down and really talk to me and explain what was going on with my knee and what my options were, and he did a very good job” (participant K)

A lack of information consequently led participants to self-searching online, but this approach was deemed unreliable:

“*There's so much stuff out there, that you don't really know what to trust*” (participant L).

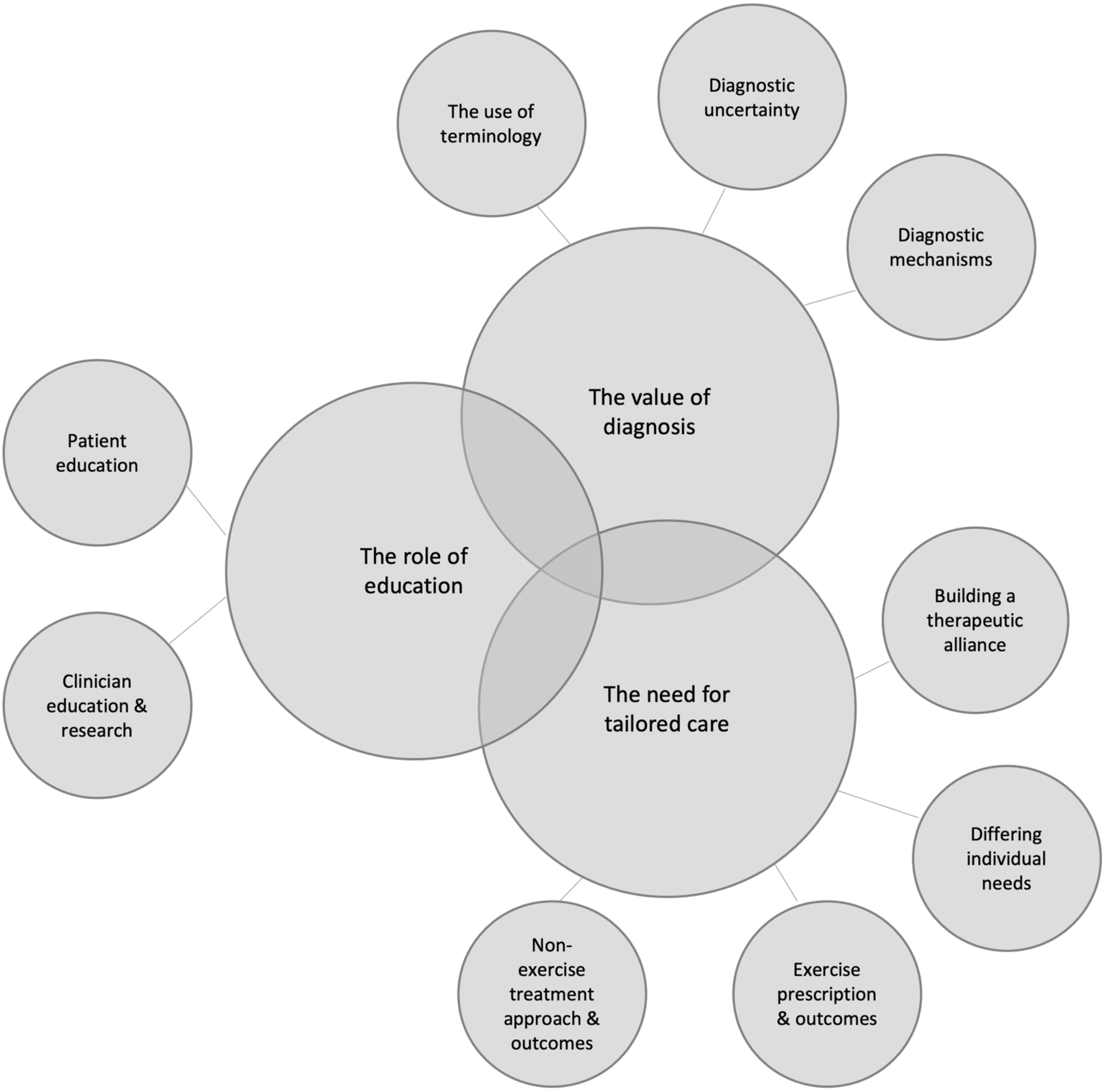
Instead, participants turned to research for guidance, believed to be more dependable:

> *“Because they're talking about research...you kind of have something concrete to hold on to”* (participant D).

Despite this, it was rarely discussed in consultations, but was positively received if a clinician did:

> “*He explains it and has always got some sort of research up his sleeve. It's like, oh, it shows that it, like, it works”* (participant A).

Figure 2: Inter-relationships between themes and associated subthemes that emerged from exploring the diagnosis and management of PFP



Key: study themes (large circles) and associated subthemes (small circles)

DISCUSSION

This study aimed to inform care and intervention delivery for PwPFP by exploring experiences of diagnosis and treatment. An overarching narrative of participants' desire for patient-centred care that meets their individual needs was identified. Three key themes were devised: the value of diagnosis, the need for tailored care; and the role of education.

Theme one: the value of diagnosis

All participants sought a diagnosis but reported one being infrequently provided or discussed. This concurs with previous PFP[40,44], low back pain[8] and shoulder pain[23] research, where the absence of a diagnosis created uncertainty, frustration, and a perceived barrier for participants. A diagnosis was perceived to facilitate a "fix" for their PFP, and participants believed their management would follow the linear diagnosis-treatment-cure model[49]. Consistent with previous research, participants reported that a diagnosis legitimised their pain[43], with diagnostic imaging assisting in providing reassurance and prognosis[49]. Conversely, the absence of an identifiable structural cause left participants feeling disbelieved by clinicians[7]. An inability to understand what pain is (identity beliefs) and what causes pain (cause beliefs), reduces the sense making process and affects cognitive representation. This threatens coping strategies and leads to adverse emotional responses[7]. Although infrequently discussed, a diagnosis was perceived by participants as being key to facilitating their recovery.

The absence of a diagnosis left participants with unattended biomedical concerns over the cause of pain, postulated to be constructed through previous healthcare experiences and pathology-based explanations of pain and treatment[38,39]. Anxiety, depression, and fear of movement are reported to be elevated in PwPFP and can correlate with pain and reduced physical function[18,30]. Consistent with previous research, participants in this study reported a dialectic tension between wanting a biomedical diagnosis and recognising that psychosocial factors contribute to pain[49]. Clinicians should look to deliver a diagnosis to PwPFP to avoid leaving them with unattended biomedical concerns.

The psychological and social impact of living with PFP was evident amongst participants, but they reported little support in this regard despite seeking it. The management described by participants in this study was predominantly biomedical, even with recent evidence advocating a BPS approach for PFP[1,13,28]. This may be because physiotherapists hold biomedical preferences and lack confidence in addressing psychological aspects[48]. There is a paucity of research on the practical application of the BPS model in PFP[1], representing important education and research priorities[16,47].

Theme two: The need for tailored care

The second theme was the described need for tailoring treatment to improve patient outcomes. Exercise therapy, the primary intervention advocated by the most recent PFP consensus statement[12,22], was the dominant treatment that participants experienced, but with variable prescription and outcomes. Participants that received tailored exercises, with regular support and adjustments from their physiotherapist [27,37], did return to activities such as running. However, most participants did not report receiving a tailored exercise programme or an improvement in pain. With no agreement as to which type(s) of exercise(s) are best[52], it is recommended that exercise prescription be individualised[28]. Similarly, foot orthoses, another recommended treatment for PFP[12], were effective when tailored to the individual, though only for two of three participants. Tailored treatment programmes should be considered by clinicians in the management of PFP, considering individual patient presentations and the best available evidence[2,28].

Participants in this study expressed a desire for individualised management, which when combined with strong therapeutic alliance led to a positive experience. A recent systematic review reported that implementing an individualised plan and working through challenges in the patient-clinician relationship, builds a strong therapeutic alliance that may be more effective in addressing musculoskeletal pain[25]. Poor therapeutic alliance and failure to improve with treatment often led to 'health shopping'[3], with participants seeking other opinions or treatments from broader sources, including those without supporting evidence. This typically resulted in poorer outcomes beyond short-term pain relief and led to greater overall dissatisfaction. A strong therapeutic alliance should be nurtured in the management of PFP alongside evidence-informed interventions.

Theme three: The role of education

This third theme was devised according to participants' desire to understand PFP. Education was viewed by participants as fundamental to enabling self-management and without it they felt lost as to how to help themselves. In contrast, if clinicians took time to explain their management options and provide a treatment plan this was perceived as having value. However, limited education was reportedly provided to participants despite its considered vital role[2,13]. A recent systematic review reported that education alone may be as effective as combined education and exercise when delivered by a healthcare professional[35]. There remains a need to understand how education interventions should be delivered to optimise outcomes, with limited resources currently available for use[13,35].

The lack of education from clinicians meant that some participants constructed their own knowledge through self-searching online. These participants were often concerned that such information may be unreliable and demonstrated a preference for information provided by healthcare professionals. The concerns raised by the participants in this study are valid, with De Oliveira Silva et al.,[36] recently reporting that current online information about PFP is inaccurate and should not be used to guide treatment. Clinicians should consider the role of education in the management of PFP to empower patients and facilitate their recovery.

Clinical implications

The findings of this study complement and extend the existing clinical practice guidelines for PFP[2,14,51], which were developed without the patient voice. Clinicians should consider that PwPFP are likely to want a diagnosis, enabling them to make sense of their symptoms and legitimise their pain. Our data also suggest that clinicians explore possible underlying biomedical beliefs that PwPFP have about their knee pain, whilst also exploring the BPS nature of pain. The importance of a strong therapeutic alliance should not be underestimated and may help to improve outcomes alongside evidence-informed interventions. Greater consideration should be given to tailoring treatment and exercise should be adapted according to patient needs and responses. PwPFP should receive education on the nature of their pain, how to tailor or adapt their exercises, and what treatments are most likely to help them. The themes identified in this study are broadly consistent with what is experienced by patients with other common musculoskeletal complaints[9,23,31] and may well have wider relevance for clinical practice.

Limitations

Participants were recruited predominantly from social media, with a younger population more likely to volunteer[19], but the eligible age range was reflective of the demographic who typically experience PFP. Convenience sampling led to a higher than anticipated number of male participants[46] and a greater representation of female participants may have led to different results. Interviews were conducted with Zoom video, which may have impacted the rapport between the interviewer and participants[42]. Online recruitment resulted in a heterogeneous sample of participants from the UK, Europe, and North America, reflective of western healthcare but also different international healthcare systems. We did not identify a wide variation in diagnosis and treatment approaches, strengthening the transferability of our results.

CONCLUSION

The overarching narrative derived from three key themes was participants' desire for clearly communicated, personalised care that meets their individual needs. Clinicians treating PwPFP should consider providing a diagnosis or explanation of the pain to avoid uncertainty and confusion regarding the cause of PFP. Individualised, tailored interventions should be prescribed to reduce the potential for variable outcomes. Clinicians should look to nurture a strong therapeutic alliance and provide appropriate and clear education. These data are an important addition to the existing literature and should be considered by clinicians when treating people with PFP.

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Highlights

- Patients see a diagnosis as essential, but one was rarely provided
- Interventions should be tailored as not all patients will respond in the same way
- Education empowers patients and helps them understand PFP
- People with PFP desire personalised care that meets their individual needs

ABSTRACT

Background: Patellofemoral pain (PFP) is common and long-term treatment outcomes are unsatisfactory. Qualitative exploration of diagnosis and management from the perspective of people with PFP is lacking.

Objectives: To inform care and improve intervention delivery by exploring the experience of people with patellofemoral pain (PFP) regarding diagnosis and management.

Design: Qualitative study with semi-structured interviews.

Method: Online recruiting yielded a convenience sample of participants with PFP for semi-structured interviews. Interviews were recorded, transcribed verbatim and analysed using thematic analysis until theoretical saturation by multiple investigators to determine themes and sub-themes.

Results: 12 participants were interviewed, with three themes identified; the value of diagnosis, the need for tailored (individualised) care, and the role of education. Participants viewed a diagnosis as essential to guide management, yet this was rarely provided, causing uncertainty about pain mechanisms; **“it's nice to be told what it is that's wrong”**. Interventions needed to be tailored to the individual as not all participants responded in the same way to treatment(s) or had the same needs; **“everyone copes and reacts differently”**. Finally, participants viewed education as essential to empower them to understand and manage the condition; **“if I’d have been given more information, I think I’d know how to deal with it more”**.

Conclusions: The overarching narrative from three themes was a desire for clearly communicated personalised care that meets individual needs. People with PFP desire a diagnosis to explain their pain, tailored interventions, and appropriate education to optimise their experience and outcomes.

Key Words: diagnosis, education, management, patellofemoral, qualitative, treatment.

Patient experience of the diagnosis and management of patellofemoral pain: A qualitative exploration

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Patient experience of the diagnosis and management of patellofemoral pain: A qualitative exploration

INTRODUCTION

Patellofemoral pain (PFP) is characterised by insidious onset retro-and/or peri-patellar pain, aggravated by loading a flexed knee[14]. PFP affects 22.7% of the United Kingdom population[45], has a poorly understood aetiology[33], and affects occupational, social, and sporting activities[14]. Research aimed at managing PFP is primarily quantitative[44], with randomised control trials of varying methodological quality[24] recommending addressing the biomechanical impairments associated with PFP[50]. Despite the strength of this research PFP has a poor prognosis, with >50% of people reporting persistent pain five years post-treatment[29].

One proposition to improve outcomes in PFP is to apply a biopsychosocial (BPS) approach, focusing on holistic care[41] rather than traditional biomechanical methods[1]. The focus should be the person, rather than their painful joint, understanding their personal experience and impact on their life[50]. Other factors that influence PFP, such as fear and anxiety, should be addressed[3,9]. There is a paucity of qualitative research on the lived experience of people with PFP (PwPFP), with research focusing on pathophysiological causes despite patients' concerns about the impact of pain on their quality of life[40].

Qualitative research provides rich insight into patient experiences[6], allowing a greater understanding of the factors influencing these experiences to inform healthcare provision[20]. Two qualitative studies on the lived experience of PwPFP have been conducted[40,44], reporting a loss of self-identity[44] and fear avoidance due to crepitus and pain[40,44]. The negative experience of living with PFP was compounded by uncertainty about the cause of pain[40,44], conflicting advice[44], and an overall lack of empathy[40,44]. These studies focussed on exploring living with PFP, rather than understanding patients’ experience of their diagnosis and treatment.

The high prevalence and poor prognosis demonstrate a clear need to optimise PFP management. This study aimed to inform care and intervention delivery by exploring patient experiences of the diagnosis and treatment of PFP using semi-structured interviews.

METHODOLOGY

Design

A qualitative study using semi-structured interviews following the Standards for Reporting Qualitative Guidelines (SRQR)[34] was conducted.

Ethical approval

The xxxxx Ethics of Research Committee granted approval (QMERC/2018/48036). All participants confirmed eligibility and provided written informed consent prior to interview using Google Forms (Google Inc., California, USA).

Recruitment

A convenience sample of potential participants were recruited online via social media. Participants were eligible if they met the diagnostic criteria for PFP[15], including insidious onset retro-and/or-peri-patellar pain reproduced by one or more of the following: squatting/lunging, running, jumping/hopping or stair ambulation[15]. Eligible participants also needed experience of treatment for their PFP, speak fluent English and be aged between 18-40. Participants aged <18 or >40, or with traumatic symptoms, patellar instability, intra-articular pathology, systemic pathology, or a diagnosis of other anterior knee pain sources were excluded. Sample size was revisited during data collection in an evaluative way[4] and theoretical sufficiency[17] guided when sufficient data were collected.

Data collection

Eligible participants completed an online, one-to-one interview with a single investigator (PB) using Zoom video (San Jose, California, USA). Interviews were semi-structured with open-ended questions and followed a topic guide developed based on input from a patient and public involvement group at the design stage. Dependability was enhanced by a reflective researcher self-audit, completion of a reflexive journal and use of a peer-reviewed topic guide[26].

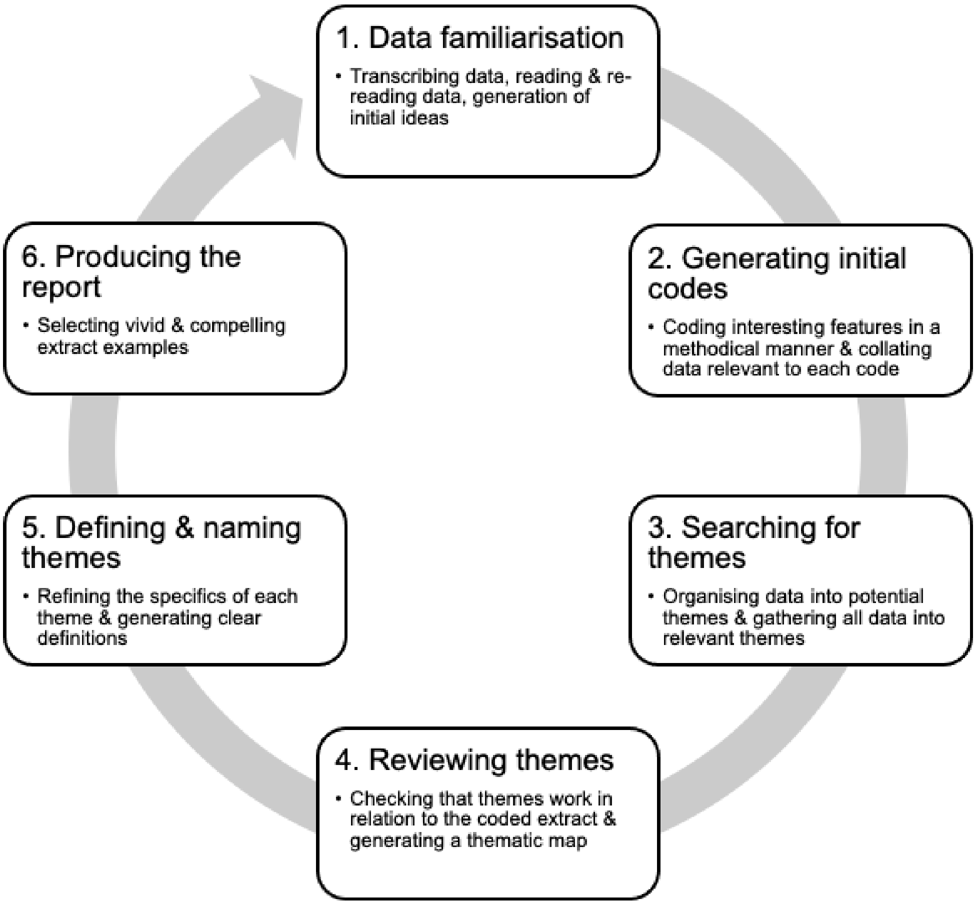
The topic guide (see appendix 1) included questions about living with PFP, assessment and diagnosis, educational material and resources, treatment provided, and the future. Questions related to lived experience were included to understand the impact of PFP treatment.

Data analysis

Interviews were audio recorded, anonymised, and uploaded onto a password-protected online transcription software Otter.Ai (Los Altos, California, USA). Files were removed once the computer-generated transcription was produced for data protection. Audio files were transcribed verbatim, and error corrected by a single investigator (PB). PB is a physiotherapist with 15-years' experience, working as a clinical lead in a musculoskeletal service that covers a large geographical area in southeast England not used to facilitate recruitment.

Data were analysed under the constructivist paradigm, as its central endeavour is to study phenomena through the eyes of people in lived situations[17]. Thematic analysis was used, moving backwards and forwards through the six-phase model of Braun and Clarke[5] (see figure 1), chosen to understand participant experiences and patterns of meaning across the dataset[10].

Figure 1: six-phase model described by Braun and Clarke



Transcriptions were read multiple times for familiarisation and generation of preliminary ideas. Data were coded by the lead author (PB), which involved theme development, naming, and refinement. Peer review on interview technique, early coding, and theme development was provided by a single investigator (CML). Data collection and analysis was performed iteratively to deepen the richness of the findings[11]. A single investigator (CB) independently verified all codes and themes against the transcripts. Contradictions to the findings[32] and verbatim quotes[21] were included to enhance rigour.

RESULTS

Participants

37 participants volunteered for this study, with 14 failing to meet the eligibility criteria (sudden/traumatic onset symptoms=five, aged >40=two, incorrect aggravating factors=one, yet to receive treatment=six). A further 11 participants did not respond to repeat invitations to interview. Twelve PwPFP, seven women and five men, with a mean age (26.5 ± 4.7) and symptom duration (43.3 months ± 42.3), living in England (eight), Europe (one) and North America (three), were interviewed between June and August 2020 (see table 1), ranging from 45 to 80 minutes. The final two interviewees reported no new information and theoretical sufficiency was deemed achieved.

Table 1: participant information

Participant, Sex, Age	**Symptom duration**	**Aggravating factors**	**Management**	**Imaging**	**Modalities**	**Outcome**
J Female Age 28	12 months	Running	One course of physiotherapy (Private: UK) Orthopaedic assessment Private: UK)	Nil	Exercise Foot orthoses	Full recovery
T Female Age 22	10 months	Stairs Running	Multiple courses of physiotherapy (Private: Europe) Multiple orthopaedic assessments (Private: Europe)	MRI scan	Exercise Foam rolling Taping	No recovery
B Female Age 28	12 months	Running squatting	One course of physiotherapy (Private: UK)	Nil	Exercise Foot orthoses Knee brace Return to running advice	Partial recovery
N Female Age 27	3 years	Running Squatting Lunging	One course of physiotherapy (Private: UK) Orthopaedic assessment (Private: UK)	MRI scan US scan	NSAIDs Exercises	Full recovery
L Female Age 23	12 months	Running	One course of physiotherapy (Private: UK) Orthopaedic assessment (Private: UK)	MRI	Exercise/stretching Foot orthoses Running re-training Taping	Partial recovery
D Male Age 24	3 years	Stairs Running Squatting Lunging	Multiple courses of physiotherapy (NHS and private: UK) Orthopaedic assessment (NHS: UK)	X-ray	Exercise Massage NSAIDs	No recovery
A Female Age 19	12 months	Stairs Running Squatting Lunging	Multiple courses of physiotherapy (NHS: UK) Orthopaedic assessment (NHS: UK)	MRI scan	Exercise Foot orthoses Surgery	No recovery
Z Male Age 35	8 years	Stairs Squatting	One course of physiotherapy (Private: North America)	Nil	Exercise Knee brace	Partial recovery
K Female Age 25	3 years	Stairs Running Squatting Lunging	Multiple courses of physiotherapy (Private: North America) Multiple orthopaedic assessment (Private: North America)	MRI scan X-ray	Exercise Hyaluronic/steroid injection Taping Massage/Acupuncture NSAIDs	No recovery
TN Male Age 25	18 months	Stairs Running Squatting Lunging	One course of physiotherapy (NHS: UK)	Nil	Exercise	Partial recovery
F Male Age 36	12 years	Stairs Running Squatting Lunging	One course of physiotherapy (Private: Europe) Orthopaedic assessment/treatment (Private: North America)	Nil	Exercise/stretching Steroid injection Running re-training	Partial recovery
JA Female Age 26	8 years	Running	One course of physiotherapy (NHS: UK)	Nil	Exercise	Full recovery

Key: NHS; National Health Service, MRI; Magnetic resonance imaging, US; ultrasound, NSAIDs; Non-steroidal anti-inflammatory drugs.

Thematic analysis

Three themes and nine sub-themes were devised from 801 initial codes, which are detailed here and mapped in figure two.

Theme one: The value of diagnosis

Over half the participants reported clinicians infrequently discussing a diagnosis or providing an explanation for their pain:

“Basically no one told me, oh…that's the main reason for it”

(participant J)

“They were like, this is a problem, we don't really know what causes it...we can't really tell you exactly what it is” (participant K)

The lack of a cause was viewed as a barrier, facilitating biomedical beliefs:

“*The main problem is that uncertainty in diagnosis”* (participant T)

“I think it's some sort of cartilage damage” (participant N)

This perception of faulty structures hindered recovery, with faith placed in diagnostic tests for reassurance and prognosis:

“*I'm thinking is there damage structurally I'm not gonna fully recover from. So that's kind of why I would like to know”* (participant D)

“*the fact that you have an MRI and it's, it's thorough, I think as a patient it gives you peace of mind”* (participant N).

However, a lack of diagnostic findings created confusion and feeling disbelieved by clinicians:

“It was confusing at the time; I knew what I felt. I know when it's not in my head...I know that sometimes MRIs look perfectly fine, but pain is there” (participant T).

Only four participants reported receiving a diagnosis, often delayed if seeing a physiotherapist versus an orthopaedic consultant, with a subsequent negative emotional impact:

“*It was quite frustrating because since July last year until end of May this year, I didn't know the cause”* (participant L)

A diagnosis was desired by participants, believing it was necessary to facilitate resolution and legitimise their pain:

“*The first step is that certain diagnosis…when you have that you're halfway”* (participant T)

“*It was helpful, because sometimes it's nice to be told what’s wrong. So, you know it can be fixed…helps you feel validated”* (participant B).

Conversely, one participant learned that a diagnostic label wasn’t key to their recovery. They instead found gaining knowledge through biopsychosocial explanations more useful:

“*Now I realise that having a name is not that important to get better, it's more understanding what’s wrong and a more holistic kind of view”* (participant L).

PFP was the commonly used diagnostic label, but half the participants felt it was not specific enough to provide them with an understanding of their pain:

“It's very frustrating because I feel like it's, in my sense, it's kind of a blanket response” (participant K)

In contrast, one participant was content with a general explanation, finding this more understandable than confusing medical terms, highlighting individual preferences:

"I don't know why they just don't say kneecap pain" (participant A).

Furthermore, two participants stated they were given a diagnosis of patellofemoral syndrome, which had negative connotations:

"Is it some sort of a disease if it's a syndrome" (participant D)

"He was like patellofemoral pain syndrome. I don't know if that word syndrome around it makes you catastrophise a bit as well. We've got this syndrome now" (participant T)

Theme two: The need for tailored (individualised) care

Non-exercise treatment approaches and outcomes

Outcomes were mixed amongst the 12 participants (see table one), with no panacea described. Eight participants had an orthopaedic assessment, but only three received orthopaedic treatment: two an injection and one surgery post-physiotherapy. One participant received a Hyaluronic acid injection and the other steroid. Both reported short-term benefit only and mixed reactions on injection usefulness:

"Corticosteroid, it was good. Yeah, it works…because the first one worked a lot so I'm still thinking to get another one" (participant F).

"I got a Synvisc injection, that was the last one I let them put in me, and that one felt good for maybe 10/11 days and then it was the same…back at square one" (participant K).

Non-steroidal anti-inflammatory drugs also gave some benefit to three participants:

“*Anti-inflammatories, ibuprofen to kill the pain, that kind of felt good”* (participant N).

All participants received treatment as part of their physiotherapy experience, but half of the participants did not make a full return to previous activity levels (see table one), which did not meet their expectations:

“You get physio, you become better, that's what’s supposed to happen. You are not supposed to keep going to physio like me” (participant A).

Conversely, three participants reported a partial recovery, and another three reported a full recovery with physiotherapy alone. With frequent sessions, participants reported improvements in their pain:

“And then since obviously the physio and stuff it’s better now…So I don't get it at the moment” (participant N)

“*Seeing the physio weekly, eventually, that's given me the best results”* (participant B)

Two participants experienced knee taping or bracing as part of their physiotherapy, which helped in the short-term, providing reassurance that no harm would come with activity:

“I found that using tape is actually quite helpful” (participant L).

“*Putting a brace on kind of reduces it a little bit…hopefully that that gives me peace of mind that I'm not doing more damage*” (participant Z).

Three participants were given tailored cues to alter their running biomechanics, which helped all:

> “*I adapted my technique…my foot was like that (shapes hand to suggest heel-strike)...Now I'm more like (shapes hand to show forefoot-strike). I can run longer now”* (participant F).

Outside of physiotherapy, customised foot orthoses were provided to three participants by a podiatrist and were effective for two (of three) for running-related symptoms:

> “*The pain has decreased…It definitely decreased just because I find it more kind of comfortable when I do the heel-strike”* (participant L).

Soft tissue massage had varied results. Massage was provided by a physiotherapist but was not beneficial for one participant, but another participant used a self-applied massage tool, which helped short term:

> “*It feels nice to have your IT bands, adductors, and quads released, but in terms of patellofemoral pain, no difference whatsoever”* (participant D).

> “*Gua Sha has helped me a lot…I'll use it for right below and on the inside of the kneecap and then around my quad and IT band. Basically, anything that feels off or weird or painful*” (participant K).

Exercise prescription and outcomes

All participants were provided with an exercise programme as part of their physiotherapy, reporting varied outcomes. Lower resistance exercises were more helpful for pain and self-efficacy:

> “*We just did some really mild stuff to try and get my quads to fire a bit more…I feel quite better”* (participant D).

“*If I was to go for a run, I would do a mini version of the (exercises)...I could do that with the confidence that I wouldn't get the pain after”* (participant N).

In contrast, higher resistance exercises were more likely to induce pain. The instruction to use additional weight exacerbated pain for one participant, who subsequently recommended using lighter loads and gradually progressing:

“I did the whole leg extension thing. I noticed absolutely no difference, none...and then immediately when adding weight, it was sore right away…If I knew other ways to strengthen my quads in increments, to be able to do the harder exercises, I think that would help” (participant Z).

However, pain was accepted if the outcome was perceived as beneficial, in the form of strength gains and pleasure from the exercise:

“*Before when I've done it, it's just been without weight...Even though they were more painful I think you feel benefit more of doing a weighted exercise”* (participant A).

Progressions and regressions of exercise according to the response, with very gradual increases in resistance, enabled all three participants following this plan to return to running:

“He was able to adjust the programme and then we took it down for one week to give me a break, and then built it up again slowly (participant B).

“*He said to me, use a backpack for your exercises and put one or two bottles...then three bottles and so yeah, that helped also”* (participant J).

Engagement with exercise was a factor in determining outcomes. Exercises performed regularly were more beneficial for the pain:

> *"It feels better, but then if you do keep on top of the…that's probably my advice, keep on top of it"* (participant A)

Differing individual needs

Half the participants stated explicitly that they felt the treatment of their knee pain was formulaic, instead wanting it to be adapted to their individual needs because of the variation in responses:

> *"In a physiotherapy group, others had knee pain and some shoulder pain. I was given exercises, isometric exercises, nothing special, leg raises and clam shells and things like that. But everything for everyone was the same. It wasn't specified for each case…Physical therapy should be individual and specialised for that person"* (participant T)

The suggestion was not to use the same approach for each person, but to consider individual needs and that not everyone responds positively to the same interventions:

> *"So it's kind of individualising patient care...everyone copes and reacts differently"* (participant L)

> "*I think I'm aware that all these things are completely different person to person very specific to the individual*" (participant N)

A collaborative approach with clinicians was recommended by participants, to determine what treatments would be more effective:

> *"you have a physio that you can talk to and actually say, I think this is not working and work with them to kind of find a better way that's always good, and it kind of reassures you and motivates you to do it"* (participant L)

"Understand what treatment I've had, what's worked, what hasn't. So that's kind of how I feel" (participant D)

Building a therapeutic alliance

All participants discussed the psychological and social impact PFP had on their lives, but this was reportedly not addressed. Participants described valuing clinicians taking time to understand their psychological and social needs, contributing to developing strong therapeutic alliance:

"I think that's really, a really good experience that someone is interested in whether it's affects you mentally as well. I think that's important. It should be part of any treatment" (participant J)

"*It's not just treating the knee pain, it's treating the social issues, the depression"* (participant K).

However, half the participants reported feeling that clinicians were apathetic to their concerns:

"It was just my doctor at the time that like, he was passing it off as not a serious problem and that sort of thing. Just the whole demeanour" (participant TN)

"A lot of times with all the doctors that I've seen, it's like, okay, here's your knee, this is your life, goodbye. And it's like, wait a minute…this is my life" (participant K)

In contrast, others had a positive experience if they formed a therapeutic alliance with their clinician, which was enabling:

"*It felt more like you know, like more friendly, and then you build that relationship and it's easier to ask questions*" (participant B)

> *“So, I think it's just, you know, building that rapport with a patient, understanding what's important to them…If you understand what I need to do then we can work together to find ways of kind of work around my situation”* (participant L)

Participants recommended that clinicians focus on being more personable and listen and understand what they were reporting, which may then lead to improved outcomes:

> *“I think the sort of human side of it in when explaining things just helping me feel like it's not just me and lots of people have experienced this, or if they've been through something similar themselves, or can tell me a story to help me relate which, you know, my physio did. I enjoyed that part of it”* (participant B)

Gaining this understanding strengthened therapeutic alliance and was a more positive experience if the participant and clinician came up with a management plan together:

> “*If you understand what I need to do then we can work together to find ways of kind of work around my situation*” (participant L)

Theme three: The role of education

All participants reported being infrequently provided with information or education, despite this being something they desired to inform and empower:

> “*Never. I don't think I've had anything”* (participant D).

> *“I always say that more information is better…that's the way I feel...explaining why glutes are important in controlling your femur, what the role of the quads were, and that kind of just helped me”* (participant D).

It was also felt education could enable self-management and reduce the mental impact of PFP:

“*If I'd have been given more information, I think I'd know how to deal with it more, cope with it, then I wouldn’t feel so worthless”* (participant A).

Most participants had a belief exercise would help, but their queries were sometimes unattended to, leaving them inadequately educated:

“*I believe that exercise is the key. The question is only which, and how to progress and all that”* (participant T).

This caused concerns of possibly doing more harm than good*:*

“About the exercise, I don't understand what may harm it if I'm doing the exercise wrong or something like that” (participant Z).

Conversely, when information was given, largely verbal, it was empowering:

“Because now I had this information. And yeah, then I went to the physio and then we could work on that. So it helped me” (participant J)

“He took the time to kind of sit down and really talk to me and explain what was going on with my knee and what my options were, and he did a very good job” (participant K)

A lack of information consequently led participants to self-searching online, but this approach was deemed unreliable:

“*There's so much stuff out there, that you don't really know what to trust*” (participant L).

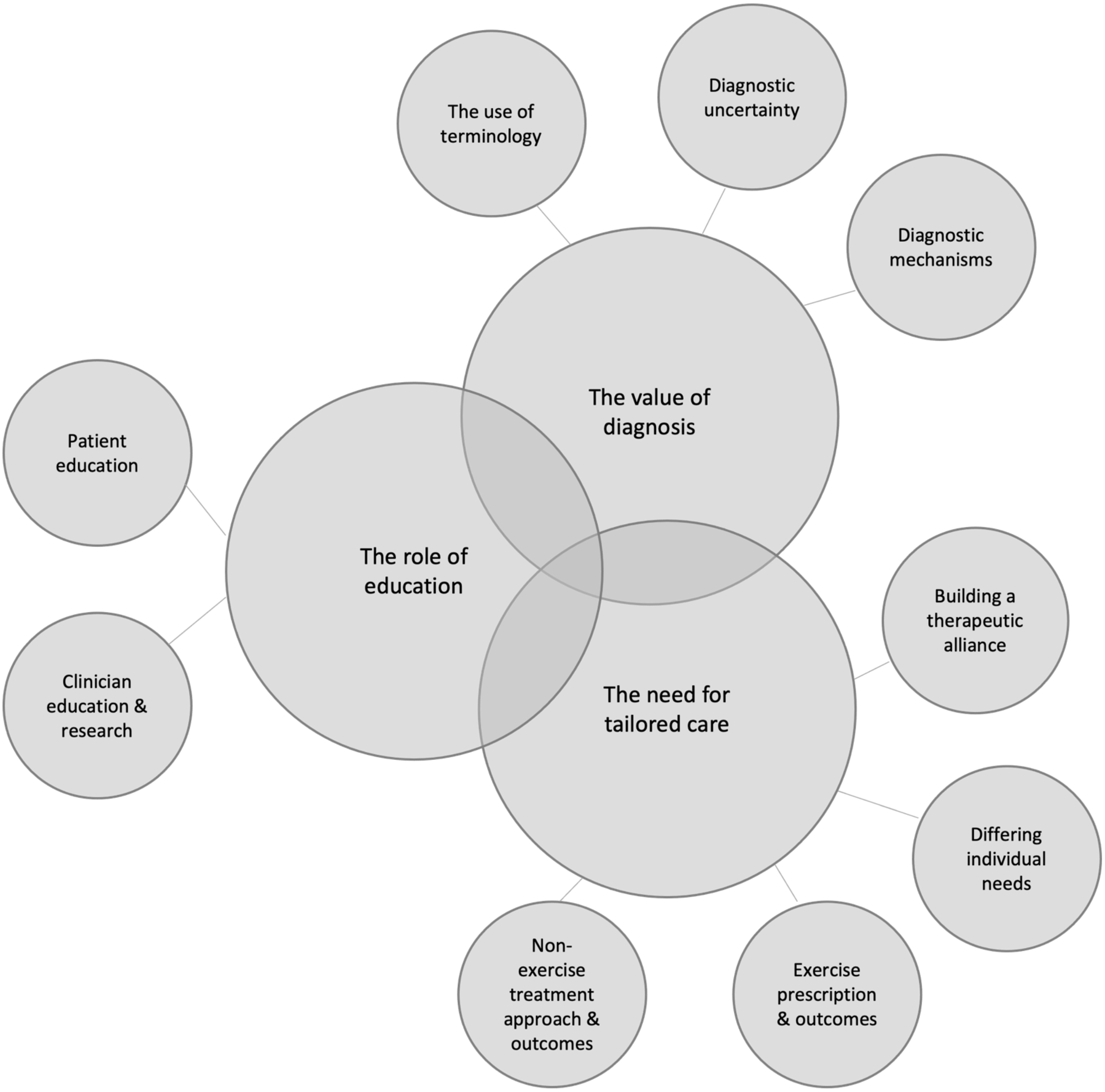
Instead, participants turned to research for guidance, believed to be more dependable:

“Because they're talking about research...you kind of have something concrete to hold on to” (participant D).

Despite this, it was rarely discussed in consultations, but was positively received if a clinician did:

“*He explains it and has always got some sort of research up his sleeve. It's like, oh, it shows that it, like, it works”* (participant A).

Figure 2: Inter-relationships between themes and associated subthemes that emerged from exploring the diagnosis and management of PFP



Key: study themes (large circles) and associated subthemes (small circles)

DISCUSSION

This study aimed to inform care and intervention delivery for PwPFP by exploring experiences of diagnosis and treatment. An overarching narrative of participants' desire for patient-centred care that meets their individual needs was identified. Three key themes were devised: the value of diagnosis, the need for tailored care; and the role of education.

Theme one: the value of diagnosis

All participants sought a diagnosis but reported one being infrequently provided or discussed. This concurs with previous PFP[40,44], low back pain[8] and shoulder pain[23] research, where the absence of a diagnosis created uncertainty, frustration, and a perceived barrier for participants. A diagnosis was perceived to facilitate a “fix” for their PFP, and participants believed their management would follow the linear diagnosis-treatment-cure model[49]. Consistent with previous research, participants reported that a diagnosis legitimised their pain[43], with diagnostic imaging assisting in providing reassurance and prognosis[49]. Conversely, the absence of an identifiable structural cause left participants feeling disbelieved by clinicians[7]. An inability to understand what pain is (identity beliefs) and what causes pain (cause beliefs), reduces the sense making process and affects cognitive representation. This threatens coping strategies and leads to adverse emotional responses[7]. Although infrequently discussed, a diagnosis was perceived by participants as being key to facilitating their recovery.

The absence of a diagnosis left participants with unattended biomedical concerns over the cause of pain, postulated to be constructed through previous healthcare experiences and pathology-based explanations of pain and treatment[38,39]. Anxiety, depression, and fear of movement are reported to be elevated in PwPFP and can correlate with pain and reduced physical function[18,30]. Consistent with previous research, participants in this study reported a dialectic tension between wanting a biomedical diagnosis and recognising that psychosocial factors contribute to pain[49]. Clinicians should look to deliver a diagnosis to PwPFP to avoid leaving them with unattended biomedical concerns.

The psychological and social impact of living with PFP was evident amongst participants, but they reported little support in this regard despite seeking it. The management described by participants in this study was predominantly biomedical, even with recent evidence advocating a BPS approach for PFP[1,13,28]. This may be because physiotherapists hold biomedical preferences and lack confidence in addressing psychological aspects[48]. There is a paucity of research on the practical application of the BPS model in PFP[1], representing important education and research priorities[16,47].

Theme two: The need for tailored care

The second theme was the described need for tailoring treatment to improve patient outcomes. Exercise therapy, the primary intervention advocated by the most recent PFP consensus statement[12,22], was the dominant treatment that participants experienced, but with variable prescription and outcomes. Participants that received tailored exercises, with regular support and adjustments from their physiotherapist [27,37], did return to activities such as running. However, most participants did not report receiving a tailored exercise programme or an improvement in pain. With no agreement as to which type(s) of exercise(s) are best[52], it is recommended that exercise prescription be individualised[28]. Similarly, foot orthoses, another recommended treatment for PFP[12], were effective when tailored to the individual, though only for two of three participants. Tailored treatment programmes should be considered by clinicians in the management of PFP, considering individual patient presentations and the best available evidence[2,28].

Participants in this study expressed a desire for individualised management, which when combined with strong therapeutic alliance led to a positive experience. A recent systematic review reported that implementing an individualised plan and working through challenges in the patient-clinician relationship, builds a strong therapeutic alliance that may be more effective in addressing musculoskeletal pain[25]. Poor therapeutic alliance and failure to improve with treatment often led to ‘health shopping’[3], with participants seeking other opinions or treatments from broader sources, including those without supporting evidence. This typically resulted in poorer outcomes beyond short-term pain relief and led to greater overall dissatisfaction. A strong therapeutic alliance should be nurtured in the management of PFP alongside evidence-informed interventions.

Theme three: The role of education

This third theme was devised according to participants’ desire to understand PFP. Education was viewed by participants as fundamental to enabling self-management and without it they felt lost as to how to help themselves. In contrast, if clinicians took time to explain their management options and provide a treatment plan this was perceived as having value. However, limited education was reportedly provided to participants despite its considered vital role[2,13]. A recent systematic review reported that education alone may be as effective as combined education and exercise when delivered by a healthcare professional[35]. There remains a need to understand how education interventions should be delivered to optimise outcomes, with limited resources currently available for use[13,35].

The lack of education from clinicians meant that some participants constructed their own knowledge through self-searching online. These participants were often concerned that such information may be unreliable and demonstrated a preference for information provided by healthcare professionals. The concerns raised by the participants in this study are valid, with De Oliveira Silva et al.,[36] recently reporting that current online information about PFP is inaccurate and should not be used to guide treatment. Clinicians should consider the role of education in the management of PFP to empower patients and facilitate their recovery.

Clinical implications

The findings of this study complement and extend the existing clinical practice guidelines for PFP[2,14,51], which were developed without the patient voice. Clinicians should consider that PwPFP are likely to want a diagnosis, enabling them to make sense of their symptoms and legitimise their pain. Our data also suggest that clinicians explore possible underlying biomedical beliefs that PwPFP have about their knee pain, whilst also exploring the BPS nature of pain. The importance of a strong therapeutic alliance should not be underestimated and may help to improve outcomes alongside evidence-informed interventions. Greater consideration should be given to tailoring treatment and exercise should be adapted according to patient needs and responses. PwPFP should receive education on the nature of their pain, how to tailor or adapt their exercises, and what treatments are most likely to help them. The themes identified in this study are broadly consistent with what is experienced by patients with other common musculoskeletal complaints[9,23,31] and may well have wider relevance for clinical practice.

Limitations

Participants were recruited predominantly from social media, with a younger population more likely to volunteer[19], but the eligible age range was reflective of the demographic who typically experience PFP. Convenience sampling led to a higher than anticipated number of male participants[46] and a greater representation of female participants may have led to different results. Interviews were conducted with Zoom video, which may have impacted the rapport between the interviewer and participants[42]. Online recruitment resulted in a heterogeneous sample of participants from the UK, Europe, and North America, reflective of western healthcare but also different international healthcare systems. We did not identify a wide variation in diagnosis and treatment approaches, strengthening the transferability of our results.

CONCLUSION

The overarching narrative derived from three key themes was participants’ desire for clearly communicated, personalised care that meets their individual needs. Clinicians treating PwPFP should consider providing a diagnosis or explanation of the pain to avoid uncertainty and confusion regarding the cause of PFP. Individualised, tailored interventions should be prescribed to reduce the potential for variable outcomes. Clinicians should look to nurture a strong therapeutic alliance and provide appropriate and clear education. These data are an important addition to the existing literature and should be considered by clinicians when treating people with PFP.

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