

BMJ Open Patients' experiences of living with patellar instability before and after surgery: a qualitative interview study

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ABSTRACT

Objectives To explore the experience of living with patellar instability before and after surgery.

Design Qualitative individual semistructured interviews of patients with patellar instability using a four-step thematic cross-case analysis strategy (systematic text condensation).

Setting Two orthopaedic units within two large Hospitals in Norway.

Participants A convenience sample of 15 participants, aged between 16 and 32 years, who had undergone surgery for patellar instability within the last 6–12 months.

Results Participants offered rich and detailed descriptions of the impact and lived experience of patellar instability, including fear of new dislocations, increased awareness of the knee and adaptations to avoidance behaviour in everyday life both before and after surgery. The four major themes that emerged from the data were: (1) fear of patella dislocations governs everyday life activities, (2) adaptation to avoidance behaviour, (3) feeling different, misunderstood and stigmatised affects self-esteem and (4) feeling stronger, but still not fully confident in the knee after surgery.

Conclusions These findings offer insight into the experience of living with patellar instability. Patients reported that the instability had major impacts on their everyday life, affecting ability to participate in social life and physical activities both before and after surgery. This may imply that an increased attention towards cognitive interventions may be useful in the management of patellar instability.

Trial registration number NCT05119088.

INTRODUCTION

Patellar instability (PI) is painful and disabling, mainly affecting adolescents and young adults.^{1–3} The patient group is heterogeneous regarding symptom burden, type and level of activity and underlying causes for the instability.⁴ Some patients experience only a single dislocation as a result of knee trauma, while the majority experience recurrent dislocations due to underlying predisposing factors.⁵ This may lead to long-standing complaints such as pain,¹ kinesiophobia⁶ and overall functional impairment.^{2,3}

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first study to use a qualitative method of inquiry on the patients' experiences of living with patellar instability.
- ⇒ Data were analysed by systematic text condensation, a thematic, cross-case strategy suited for exploratory analysis of patients' experiences.
- ⇒ For pragmatic reasons, a convenience sampling strategy was used.

Mental health⁷ and health-related quality of life^{1 8–10} are also reported to be negatively affected, making the condition complex.

PI is challenging to manage due to this heterogeneity, but also due to the negative consequences of not being able to trust the knee in everyday life activities.^{1 11} However, increased knowledge of functional anatomy of the patellofemoral joint has improved the assessment of underlying pathophysiology and surgical management.¹² Current guidelines recommend patellar stabilising surgery for recurrent dislocations regardless of functional activity level.^{11 13–15} Although surgical treatment provides a structurally more stable patella, many patients still experience pain,¹² reduced knee function^{2 16–19} and psychological concerns such as fear of new dislocations after surgery.^{20 21}

Persistent pain and reduced knee function is reported to reduce physical ability and increase pain-related fear-avoidance behaviour in other long-lasting knee disorders, such as patellofemoral pain^{22 23} and anterior cruciate ligament injury.^{24 25} Similarly, such activity limitations and avoidance behaviour has been reported quantitatively in cross-sectional studies in PI.^{10 26 27} However, knowledge regarding the patients' own experiences of living with an unstable kneecap, and how this affects daily life activities, is scarce. Consequently, there is a need for a deepened understanding of how PI affects patients' lives and how they manage the

**Table 1** Participant characteristics at the time of interview

ID number	Hypermobile	Bilateral problems
1	Yes	No
2	No	Yes
3	No	No
4	Yes	Yes
5	No	Yes
6	Yes	Yes
7	Yes	Yes
8	Yes	No
9	No	Yes
10	Yes	Yes
11	Yes	No
12	Yes	No
13	No	Yes
14	No	No
15	Yes	Yes

condition. Therefore, the aim of this study was to provide more detailed descriptions of the experiences of living with PI.

MATERIALS AND METHODS

Recruitment and participants

We conducted a qualitative individual interview study with patients who had undergone surgery for recurrent patellar dislocation at two orthopaedic units in Norway. The participants were recruited from an ongoing clinical trial on PI, either face to face after a postoperative assessment or by telephone. To obtain rich data with a variation in experiences, a sample of 15 participants (11 women), from age 16 to 32 years, with different levels of physical activity and a time span of 1–18 years from their first dislocation episode, were included (table 1). None of the participants had redislocated their patella at the time of interviews. All participants received an information letter before entering the clinical trial, informing them that they could be asked to take part in the qualitative interview study. All participants invited gave their written consent.

All participants attended postoperative rehabilitation with their local physiotherapist and had completed a 6-month follow-up at the hospital.

Data collection

Data were collected between November 2021 and September 2022. All interviews were conducted by first author TH-D, using a semistructured interview guide, inviting the participants to reflect on their experiences of living with PI. We wanted information about the years living with PI before surgery, but also if and how experiences had changed after surgery. The three overall themes in the interview guide were; function in everyday

life, sports and leisure activities and changes after surgery (online supplemental file 1). Preconceptions about the participants were extensively discussed between the first (TH-D) and the senior author (LHM) throughout the analysis process. TH-D is a PhD candidate and an experienced physiotherapist working with orthopaedic patients for over 10 years. LHM is professor of physiotherapy with extensive experience within qualitative research. She has 20 years of clinical experience as a physiotherapist, mainly from primary care. AGHF works as an orthopaedic physiotherapist (PhD) and EI works as an orthopaedic surgeon (PhD). EI was the surgeon of one of the participants and TH-D conducted the 6 months postoperative follow-up of all participants. No other direct relationships were present between any of the participants and the authors of the study.

The interviews took place at one of the orthopaedic centres or by telephone from 6 to 12 months postoperatively. LHM was an observer of one interview, otherwise no other people than TH-D and the participant were present during the interviews. The interviews, which had a duration of 16–35 min, were audiotaped before they were transcribed verbatim. In addition, short fieldnotes were made to capture the atmosphere, and to validate the transcripts and analysis. Open-ended questions were used to facilitate the participants to speak freely about their experiences to avoid being influenced by the researcher's assumptions. Transcripts were not sent to participants for comments since the validity of using this method is questionable.²⁸

Data analysis

The transcribed text resulted in 57 pages of text. Data were analysed by TH-D and LHM using systematic text condensation (STC) which is a thematic, cross-case strategy suited for exploratory analyses.²⁹ The analysis has four steps: (1) reading all the material to get an overall impression and to identify preliminary themes; (2) identifying and sorting meaning units concerning the participants' experiences with living with an unstable knee, and establishing code groups and sorting the meaning units correspondingly; (3) abstracting condensates from each code group and subgroups exemplifying essential aspects of each group and (4) synthesising the material and presenting a reconceptualised description of each subgroup. As recommended by Malterud,²⁹ preliminary analyses were conducted after the first four interviews, allowing for adjustments of the interview guide and aim of the study. No adjustment was made. Data were reported in line with the COnsolidated criteria for REporting Qualitative research checklist.³⁰

Patient and public involvement

This research project was driven by the views of participants experiencing recurrent PI. In the first four interviews, participants were consulted for their views and thoughts about the questions asked in the current study.

The participants reported the questions to be relevant, comprehensive and no new topics were raised.

RESULTS

Four key themes emerged from the data analysis. The first three themes are related to the experiences during the years before surgery, while theme 4 concern experiences after surgery: (1) fear of patellar dislocations governs everyday life activities; (2) adaptation to avoidance behaviour; (3) feeling different, misunderstood and stigmatised affects self-esteem and (4) feeling stronger, but still not fully confident in the knee after surgery.

Theme 1: fear of patella dislocations governs everyday life activities

Fear of dislocating the patella was always on the minds of the participants, and this worry was with them all day, every day. Many participants expressed that this fear constituted the main concern of their knee-problem and resulted in a lack of trust in their knee. The unpredictable threat that the patella could dislocate at any moment influenced their ability to carry out many activities. The participants gave detailed descriptions of dislocations during everyday movements such as turning around in bed, straightening the knee and walking downhill. In specific situations, the patella always dislocated. This led to avoidance of these situations. However, the dislocation could also occur suddenly and unexpectedly. This uncertainty led to intrusive fear and a more general avoidance behaviour. Such hyperawareness of the knee was commonly described and the participants felt a need to control any situation to prevent dislocation. Sometimes they felt that the knee had improved so that they could trust it more. However, such periods always ended with a new dislocation aggravating the fear. The experience of dislocation in a variety of situations had a negative impact on their self-confidence and well-being. A male in his 20s expressed:

I think that the kneecap can pop out all the time, it is almost unconscious, the focus on my knee, it's always in the back of my mind. I think about how I lay weight on the leg, how I walk. It is always an extra focus there, but you get used to it. After so many years, it is almost automatic because it can dislocate in almost every possible situation, you never know. (ID5)

Most participants described fear and avoidance during daily activities, while a few described this fear only in connection with sports, for example, when playing soccer. In those situations, they felt similar awareness towards their knee and put the same restrictions on activity as the others. One young male expressed:

I don't go into tackling as hard as before with my affected leg. Therefore, my knee limits me in those situations, but the rest of the time, I don't think about it. (ID3)

Theme 2: adaptations to avoidance behaviour

Most participants expressed some level of lifestyle modifications caused by PI. The participants made, both conscious and unconscious, adaptations to daily life activities. A commonly described adaptation strategy was to avoid strenuous activities and to constantly pay attention to the knee. This hyperawareness made the participants consider and plan every movement, avoid sudden movements and try to move as carefully as possible. The hyperawareness could lead to changed movement habits (compensatory movements) and restrictions in daily activities. One participant felt totally immobilised, not even being able to descend stairs without dislocating her patella. Activities such as vacuuming, heavy lifting and pushing heavy trolleys in the supermarket were examples of activities some avoided. Several had stopped doing activities that involved running and/or pivoting and cutting manoeuvres, that is, soccer, alpine skiing and paintball, activities that they previously had appreciated. One participant gave a powerful description of her changed movement pattern:

My knee dislocated almost every time I fully straightened the leg. So I started walking on my toes to avoid fully to straighten the knee. (ID4)

Other examples were increased awareness when walking on uneven or slippery surfaces and choosing the easiest paths when hiking. A female participant in her 20s described herself as an 'old lady' when descending stairs, if able to walk stairs at all. She had experienced having to slide downhill on her bottom to make it home safe after hiking. This fear-avoidant behaviour led to reduced physical activity. Many quit sports and recreational activities because of the potential consequences. Several expressed that being physically active was not worth the risk, and this activity restriction made them feel frustrated. Activities assumed to be feasible, such as playing with children on the floor or standing on a crowded bus, were mentioned as challenging, in addition to standing and walking in social gatherings and large crowds.

I did not want people to be near me because if they got too close and pushed me or bumped into me, the kneecap could dislocate. I did not take the bus alone; if there were no seat available and it suddenly stopped, the knee would dislocate. It was extremely unpredictable, and it limited me in several ways. (ID15)

One participant even avoided going places alone throughout her entire childhood because of the fear of dislocating her patella. It should be noted that even though most of the participants reported fear-avoidance, a minority were not afraid of the knee causing problems and they did not adjust their daily life movement habits.

Theme 3: feeling different, misunderstood and stigmatised affect self-esteem

Most participants had lived with PI for many years before surgery, and they shared detailed descriptions of living

with a troublesome knee. This felt extremely stressful, and it affected their lives in many ways like not being taken seriously by parents, friends, teachers and/or healthcare personnel. They felt that the others did not understand the extent of how the knee-problem led to restrictions in leisure and social-activities, or even isolation. They were told not to worry and that their knee-problems would pass by itself.

I was never taken seriously. I remember my father often said to me this is just a wiggled knee. Just walk it off. (ID4)

Self-esteem

Several participants felt that living with PI had a negative impact on their well-being, with subsequent loss of self-esteem and feeling depressed. Dislocations were explained as extremely painful, but also very embarrassing. Friends and schoolmates became afraid of coming too close and treated them differently. Most participants reflected on how their knee-problem had affected them mentally; they felt different and alone, with knee-problems that no one else had. This, in addition to not being able to participate in leisure and social activities, led to social isolation and a feeling of not belonging to others. For a female participant this was the worst part of her knee-problem. She wanted to participate in activities with her friends, and had tried several times, but always ended up with a dislocated patella. Eventually, she gave up. Not being able to participate in physical activities contributed to lower self-esteem, weight gain and becoming gradually more enclosed. The problem with the kneecap was described as leading to a vicious spiral.

Not being able to do the things they loved were described as a punch in the face and a defeat before surgery. One participant said that she usually was present on the soccer field when her team trained because of the social aspect, but she found it tough not being able to play. Waiting for surgery was also hard, it took a long time and the feeling of not being able to do anything to fix the problem themselves was frustrating. They felt that surgery was their only option to regain a stable patella. A female in her 20s summed up all these negative experiences:

You feel very alone, really. I knew nobody else with this problems. I felt so different. I could not participate. I repeat myself, but it is the fact that you don't feel like you belong with the others. It sounds horrible when I talk about it, but it led me into a depression in my youth. And I can transfer it to other problems too. You suddenly don't have the confidence to do what you want to do. (ID4)

Social impact

Detailed stories about the social impact of the problems were frequently mentioned. The younger participants were less socially active as they avoided common activities for children and adolescents. Sometimes they were

stigmatised and perceived as lazy. Some experienced to be excluded from social events such as birthday parties or leisure activities involving physical activity, due to assumptions that they could not participate. The adult participants also described problems with social activities. Some hesitated to go to social gatherings such as parties, because dancing was impossible. They also hesitated to join friends on a hike or similar activities. Such loss directly affected the participants' role and position within their social network, triggering social isolation and frustration.

You feel a bit weird, I got embarrassed - it was so painful. I know I should think about the physical aspects, but I was more concerned with the fact that I was different from the others. That was the worst part for me. Not being able to participate in the activities that the others did. I know how important physical activities are for your mental health. (ID4)

Theme 4: feeling stronger, but still not fully confident in the knee after surgery

After the surgery, all participants experienced the patella to be more stable. They perceived that their patella moved differently, it felt safer to use their knee. Despite this, complete confidence in the knee was not regained. Many experienced some degree of guarding, and therefore, continued to avoid knee-strenuous activities even though they felt safer.

My instability is gone, but my knee is not as expected. Sometimes the pain is worse, and I can't kneel. (ID2)

Even if many participants still had avoidance behaviour and lacked trust in their knee after surgery, several described behaviours that indicated that they gradually exposed themselves to activities they wanted, but previously feared. Examples were hiking alone, walking fast and running. A valuable improvement after surgery was that they no longer had to be aware of how they moved. The fear of dislocation was less prominent, and they had less limitations in their lives. Despite the experience of a 'repaired' knee postoperatively, fear and mental barriers were still present in several as they trusted their knee to a larger extent, but not completely. They were still not able to give full effort in strenuous activities such as running and soccer. A female in her 30s said:

Now, it is like a dream come true compared to before. It is so weird to fully straighten the knee without my patella popping out. But it is still a large mental barrier. Especially whenever I walk stairs and down hills. I have not dared to run downhill yet. I try all the time. But downhill, there is still a mental block. So, I constantly work on the mental aspect, to walk downstairs normally. And I feel a progression, little by little. My knee is stable. It is weird and fantastic. (ID4)

DISCUSSION

Main findings

The current study is, to the best of our knowledge, the first study exploring daily life challenges experienced by patients with PI before and after surgery. Four major themes emerged from the current analysis: (1) fear of patellar dislocations governs everyday life activities, (2) adaptation to avoidance behaviour, (3) feeling different, misunderstood and stigmatised affects self-esteem and (4) stronger, but still not fully confident in the knee after surgery.

Methodological considerations

This study employed a clear, transparent and reproducible methodological approach to data analysis following Malterud's STC.²⁹ We interviewed a broad spectrum of participants experiencing recurrent patellar dislocations, giving them the opportunity to explain in their own words how the condition affects their lives. All participants invited wanted to partake in the study, indicating that they had an interest in, and maybe need for, telling their story. This is a strength of the current study as there is less risk for selection bias. The participants provided vivid and varied information when telling their stories. The higher number of women compared with men, reflects the fact that women have a higher incidence of PI.³¹ Participants were asked to remember how this condition affected their lives before surgery. This could have introduced a certain recall bias. However, these intervening experiences were considered to be strong and long-lasting. Therefore, recall bias is most likely not a prominent problem.

Information power from the data was judged to be sufficient³² with a number of 15 participants. Factors pertaining to high information power included a narrow study aim, sample specificity and strong and clear interview dialogue. We consider the clinical experience within the musculoskeletal field, particularly in orthopaedics, among the authors as a strength when it came to asking relevant questions. On the other hand, this experience could also implicate a prejudice and thereby prevent a sufficiently comprehensive view.

What is previously known: what does this study add?

The results from our study are novel since this is the first study to explore patients' experiences of living with PI. A key finding was that the PI had a large impact on participants' lives. It was described to affect their mental as well as physical well-being. Their stories display a constant fear of dislocating the patella and for the majority, this was present for years before treatment was commenced.

Fear of reinjury and lack of trust in the knee is a dominant theme in research on other knee conditions such as anterior cruciate ligament injury^{24 25} and has been described in relation to returning to and/or participating in sports for PI patients.²¹ Our study reveals that the consequences of fear have a much more far-reaching impact as many participants expressed that fear governs everything from daily life activities to more strenuous activities. Previous

studies have reported that patients more often perceive high-energy activities involving multidirectional movement to cause PI compared with lower-energy uniplanar tasks.^{10 33 34} In contrast to this, most participants in our study experienced PI in both low-energy uniplanar tasks (eg, turning around in bed) as well as more knee strenuous activities (eg, playing soccer). The current study, therefore, offers new insight into the comprehensiveness of having PI by telling the patient's own stories.

The fear described was often accompanied by an enhanced awareness and an increased focus on movement patterns in situations spanning from stair descending to being in large crowds. Individuals with a healthy and pain-free body do not notice their body much when they perform different activities.³⁵ (p.35) They are not aware of their body parts when moving, making complex activities such as walking downhill in uneven and rough terrain possible. However, when a person experiences a disorder such as PI, the body-part becomes a prominent focus that can be a hinder for unfolding. One participant explained this increased awareness by saying 'it's always in the back of my mind'. She perceived her body as dysfunctional and strange and the knee 'always' had her attention, thereby shifting the focus from the tasks to be performed, to the body as an object. A shift in focus like this may interfere with the patient's daily life activities, leading to modifications and restrictions. This implies that some patients may benefit from a more comprehensive treatment focusing on overcoming these mental barriers and adaptations both before and after patella stabilisation.

Although activity modifications and restrictions are previously described in studies on patients with PI,^{26 27} the extent of avoidance behaviour expressed in some of our participants was surprising. The statement that one of our participants did not go anywhere alone throughout her entire youth provides a powerful example of how PI may restrict a person's life. However, those who only experienced dislocations caused by trauma to the knee during sports and/or strenuous activities described only minor adaptations when, for example, playing soccer. This variety in avoidance behaviour is understandable, considering the heterogeneity of the population experiencing PI.^{4 26 36}

For some, the fear of new dislocations and the following avoidance of activities and social life led to a feeling of hopelessness and low self-esteem, and they felt different, misunderstood and stigmatised. A few also felt that others did not take their knee-problem seriously and considered them as lazy. This is important for healthcare providers to be aware of in the management of patients with PI. Further, the lack of confidence in both the knee and in oneself was repeated in the participants' stories and underscores the importance of confidence building in these patients.

Postoperative fear of new dislocations has been reported in a recent systematic review examining return to sports after surgery.^{21 37} Our findings support this and shed further light on the extent of fear that remains after

surgery. Even though participants felt that the patella had become stable after surgery, many could not shake that feeling of fear and awareness. A goal of stabilising surgery is to improve function and reduce concerns regarding the knee. Interestingly, most participants experienced that a stable patella alone was not enough for the fear to disappear. Accordingly, our findings indicate that post-operative rehabilitation should address psychological as well as functional factors by involving gradual exposure to activities that were previously feared. This is in line with research on other knee injuries, where the psychological factors have gained increased attention in the last years³⁸ and further research should explore how to address psychological barriers after patellar stabilising surgery.

CONCLUSION

The participants in our study expressed that they struggled with an extensive fear of new patella dislocations and had developed a heightened awareness of the knee throughout the years living with PI. They also described that they had adapted their daily activities according to this fear, leading to social isolation and low self-esteem. A main finding was that the fear and avoidance behaviour were still present after surgery. This increases our understanding of how PI affects the patients' lives and facilitate the development of more targeted interventions that address each patient's needs and barriers for physical unfolding. Our study suggests that an increased attention towards interventions targeting unwanted psychological issues both before and after surgery is warranted.

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Patient consent for publication Not applicable.

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Semi-structured interview

Function in everyday life

- How has it been for you to live with an unstable kneecap?
- What expectations did you have to how your knee would function after surgery?
- What expectations did you have for function after surgery?
- How have you adapted your life to a knee with an unstable kneecap?
- How does your knee work at work/school?
- How does your knee function in activities of daily living?
 - o Do you have any examples?
- Do you avoid activities and why?
 - o What makes you unable to do that activity/movement?
- How has it affected you socially?
- Were your problems taken seriously and how?

Sports and leisure activities

- What are your wishes for activities and sports?
- What prevents you from doing the activity(s)/sport(s) you want?
- Do you have any examples of why you can't engage in that activity?
- Which activities and sports do you do today?
- How often are you physical active or engaging in sports during a normal week?
- Are there activities you avoid because of your knee problem? If so, please describe?
- How motivated are you to be able to do all the activities/sports you want?
- When did you feel ready to do activities beyond ADL activities after surgery?
- How has having an unstable kneecap affected your activity level?
- What will it take to get back into activity?
- How relevant is it for you to test whether you are ready to do sports and/or strenuous activities?
- What do you think of the tests, are they relevant for you and your problems?
- How did you experience the testing?
- Which other tests do you think is relevant?

Changes after surgery

- What have you done to regain knee function after the surgery?
- How was the rehabilitation with your physio?
- Is there anything you miss in the follow-up from your local physio or the hospital? Describe.
- Why did you end the rehabilitation?
- What changed after the surgery?
- Does the fear subside? And how?
- How has it affected you to live with an unstable kneecap?
- Has living with an unstable kneecap affected you as a person?
- What is the most important/biggest impact your knee problems have had on your life?
- Is there anything else you would like to add?

Patient and public involvement (first 4 interviews)

- What do you think about the questions we have asked you?
- Did you understand all the questions? If no, describe.
- Are there any topics or questions you miss?

- Are the questions relevant for your knee problems, and is there any we should remove?
- Do you think that this study is relevant for you and other persons with similar problems?
- Do you have any thoughts you would like to add?