



# PAINSTORIES – Exploring the Temporal Developments in the Challenges, Barriers, and Self-Management Needs of Adolescents with Longstanding Knee Pain: A Qualitative, Retrospective Interview Study with Young Adults Experiencing Knee Pain Since Adolescence

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**ABSTRACT:** Patient education is essential to enable rehabilitation and self-management of long-standing knee pain in adolescents. Currently, a lack of insights into the socio-cognitive processes governing adolescents' self-management remains an obstacle for enhancing treatment efficacy. This study developed a conceptual model for integrating adolescents' challenges and barriers into future treatments. We conducted semi-structured retrospective interviews with 14 young adults (age 21–25 years) with knee pain since adolescence (9 years mean duration). Temporal developments in participants' knee pain were captured through a memorization exercise. Data was analyzed via the General Inductive Approach. Themes were organized into a matrix, extracting a conceptual model, which was tested with eight new participants. The analysis identified seven themes. Further interpretation, via the matrix, organized these within a four-stage trajectory of; gaining awareness, knowledgeability, contextual application and reconceptualization, each with different challenges and dilemmas, participants had to overcome to progress their self-management. Testing the conceptual model, confirmed stages and highlighted acceptance as key to overcoming barriers. The study described adolescents' integration of self-management as proximal and inquiry-based, with acceptance, driving increasingly complex management behaviors. We hypothesize future interventions may benefit from exploring supporting adolescents' inquiries into their knee pain at different stages of the trajectory.

**Perspective:** This study presents a conceptual model and vocabulary for optimizing patient education concepts, to target the challenges, barriers and needs of adolescents with knee pain at different stages of their mastery journey. We believe our findings may inform reflections among clinicians and researchers, and development of more effective education interventions.

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**Key words:** Patient education, self-management, musculoskeletal pain, knee pain, youths, adolescents, rehabilitation.

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## Introduction

Musculoskeletal pain is a common risk to healthy living during adolescence and is associated with disability, loss of quality of life, psychological distress, and depressive symptoms.<sup>3,50</sup> Approximately one in three adolescents (age 12–19) will experience ongoing or recurring musculoskeletal pain and between 20 to 59% hereof will seek treatment for the condition from their general practitioner (GP).<sup>42,51,56</sup> The most common pain site is knee pain, which accounts for almost a third of all musculoskeletal pain complaints in this age group.<sup>49,50</sup> This makes knee pain the most common musculoskeletal disorder in adolescents and commonplace in general practice.

While knee pain has historically been attributed as a self-limiting condition, between 40-50% of adolescents will continue to experience pain after two to five years, and 70% will reduce their participation in sports and value activities as a result of their knee pain.<sup>45,50,47</sup> This is problematic since adolescence constitutes a period of transition both functionally, mentally, and socially,<sup>14,54</sup> with physical activity and participation in team sports being hailed as contributors towards developing and sustaining positive health behaviors into early adulthood.<sup>8,20,57,58</sup> Furthermore, pain and physical impairment may lead to withdrawal from formative- or performance corrective experiences, which could break a negative spiral with decreasing self- and social- efficacy beliefs.<sup>15,16,23</sup> Teaching adolescents to self-manage their knee pain in everyday situations is important to shorten the period with experienced physical limitation,<sup>23</sup> and guiding them down a positive trajectory that leads to increased mastery of their pain and the condition as a whole.<sup>4,29</sup>

Patient education can contribute to long-term improvements in patients with chronic conditions, by empowering them to manage their conditions autonomously in everyday situations. Adolescents in particular can be difficult to support<sup>55</sup> due to their increasing desires for independence,<sup>30</sup> and limited capacity for understanding and complying with general health instructions.<sup>7</sup> Interventions combining exercises with patient education have shown promise for improving prognosis of adolescent knee pain<sup>12,46</sup> but ensuring adherence remains a barrier in this patient population.<sup>49</sup>

Behavioral science show that patients' self-management of chronic illness is a complex, problem-based activity, driven by patients' beliefs in their ability to exercise everyday control of their condition.<sup>4,25,33</sup> Self-management programs which combine patient education modalities (decision-making support, peer-guidance, motivational- and cognitive support), have shown potentials for facilitating adolescents transition into self-management,<sup>18,31,53</sup> and the efficacy of the programs are generally higher when guided by social-cognitivist theory.<sup>53</sup> Still, the focus on enhancing patients' injury management<sup>53</sup> and absence of reflections on how adolescents experienced interventions in terms of necessity (timing, need, usefulness), influence on illness beliefs (timeline, efficacy beliefs, outcome expectancies)

and applicability in everyday situations<sup>4,27,38</sup> complicates the transferal of applied principles into new and revised patient education concepts, aimed at empowering adolescents to take control and master their knee pain.

Examining the day-to-day challenges of adolescents' with knee pain and how these inspired learning and coping, may yield valuable insights into patients' socio-cognitive processes governing their self-management and identify anchor-points for patient education designs. The aim of this study was to explore how the everyday challenges, barriers and self-management needs of adolescents with knee pain evolved over time, through retrospective interviews with young adults with knee pain since adolescence. This was used to develop a theoretical model to inform the design of future educational interventions for supporting self-management in this patient group.

## Methods

The study was designed as an open-scope qualitative inquiry, using semi-structured retrospective interviews with funnel method questioning,<sup>26</sup> goal-free data analysis,<sup>59</sup> and ongoing evaluation of emerging findings from experts in adolescent knee pain, general practitioners (GP's), and young adults with knee pain during adolescence. Transcendental phenomenology by Zahavi<sup>65</sup> was included to support our knowledge production, by guiding our reflections on where to bracket ourselves<sup>34</sup> and where to utilize phenomenological reduction through practice,<sup>13</sup> to gradually unveil the essential components of our participants shared experience.<sup>65</sup> The study was registered and data was stored at Aalborg University. A protocol was submitted to the Regional Committee on Health Science Ethics of Northern Jutland, who ruled that our lack of an intervention meant our study didn't meet national requirements for projects which should be reported.

## Interview Design

The interview setup was designed to create a safe space for participants to share their personal experiences, and engage in meaningful co-construction of knowledge with the interviewer. We used Kvale and Brinkman's<sup>26</sup> seven steps for planning research interviews, defined as; thematization, design, conducting interviews, transcription, verification and reporting findings, to structure our inquiry, based on a single-person semi-structured approach. The overall theme of our interviews was defined as the '*challenges, barriers and self-management needs*' of adolescents' with knee pain, to broaden the scope of our inquiry to encompass the decision-making, behaviors and rationales of our participants. To accommodate the complexity of the adolescent's experiences of living with- and learning to manage their knee pain, an interview guide and a memorization exercise was developed. This setup was designed to facilitate a two-step exploration of the phenomenon's temporal and salient aspects.

**Table 1. Overview of the nine open questions that formed the basis of our interview guide.**

1	Thinking back, how would you complete the sentence; Living with knee pain as an adolescent is like_____?
2	What did you experience as the greatest challenge related to living with knee pain as an adolescent?
3	From your experience, what is the most important thing (skill) an adolescent should learn to become better at managing his/her knee pain?
4	How did you balance the tasks of managing your condition in relation to living as a young person?
5	How was your participation in past-time activities influenced by your knee pain?
6	Please describe what role your family played in you learning to master your condition?
7	How do you feel that your GP (or other healthcare professionals) prepared you and your parents for the task of managing you knee pain?
8	In retrospect, how would you say your knee pain has contributed to how your life has developed until now?
9	Is there anything we have forgotten?

A complete, translated list of open and probing questions is attached as figure s1 in the supplementary appendix. All interviews were conducted in Danish, the native tongue of the participants.

### Designing the Interview Guide

The interview guide was developed in collaboration with experts in adolescent knee pain and GP's with experience in treating adolescent knee pain. It contained nine open ended- and several probing questions, centered on the themes: the experience of living with knee pain, common challenges, learning, self-management, the family's role, treatments and the overall impact of knee pain. The open-ended questions are outlined within Table 1. Themes were selected, based on insights gathered a priori by the project group members, based on their experiences with working with youths with this condition. The interview guides layout was designed to support funnel method questioning technique, to reduce risks of interpretive bias, and elicit vivid descriptions from the participants (supplementary appendix; Fig s1).

### The Memorization Exercises

The memorization exercise was designed to provide participants a platform for articulating- and organizing their experiences into a narrative form. Taking inspiration in patient user-journey maps<sup>35</sup> and the patient- lifeline exercise, used by GP's to map developments in patients with long standing conditions<sup>21</sup>, a modified version of the exercise was conceived and included prior to the interviews. This was done, to help participants reflect on-, identify, and capture the salient features of their experiences with their knee pain, and tie these together into a visual representation of their illness trajectory as exemplified in Fig 1. Participants could then refer to this, at any time, during the interviews. The participants' descriptions of their experiences with their knee pain were captured via audio recordings, to support further analysis and interpretation. The interview guide and memorization exercise were piloted during two test interviews with young adults, who experienced knee pain throughout adolescence. The piloting informed several adjustments to our interview procedure. This including expanding the scope of inquiry during memorization exercises to focus on general well-being, instead of knee pain, and capture the social aspects of participants health journeys. Furthermore, the formulation and sequence of interview questions

was revised, to enhance participant comprehensibility and flow during interviews.

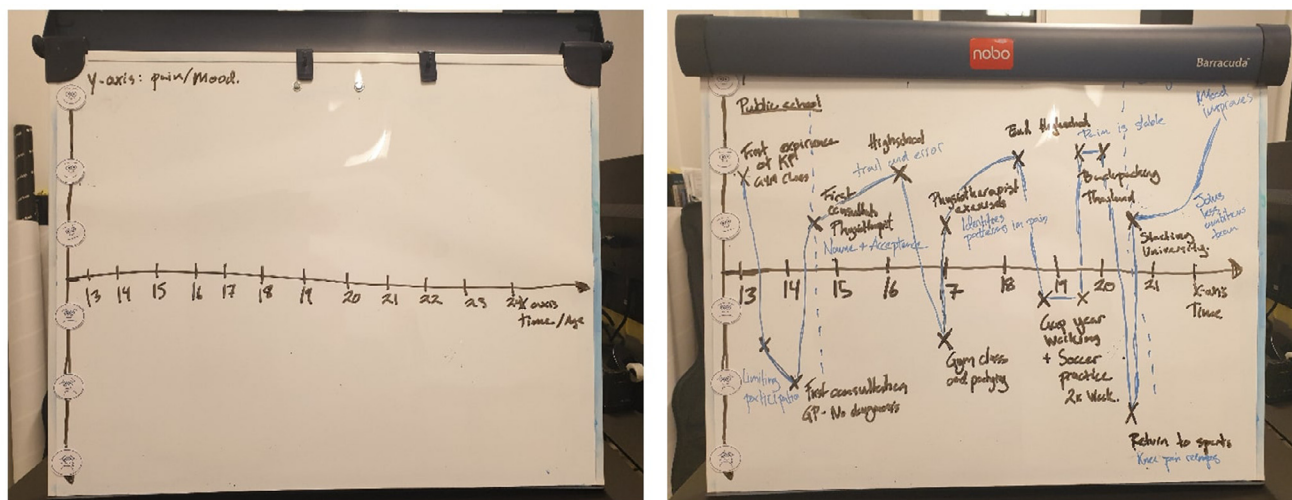
### Participant Selection

We included young adults (aged 21–25) from the APA2011 cohort<sup>50</sup> with a history of non-traumatic knee pain during adolescence, who reported pain at the five-year follow-up.<sup>47</sup> We anticipated that these patients could provide us insights into the common challenges faced by adolescents with knee pain, and how confronting everyday challenges influenced their journey towards mastery. The APA2011 cohort consisted of participants around age (12–19) from schools in low, middle and high socio-economic status areas.<sup>50</sup> Permission for cross project data sharing was obtained from 'The Danish Data Protection Agency' in April 2017, allowing for transferral of contact information (name, number, e-mail) of potential participants per consent. From this subset, participants were sampled purposely based on perceived information power. We excluded patients with:

- Other musculoskeletal conditions, non-related to their knee pain.
- Other pain/chronic conditions, self-reported psychological challenges.
- Use of prescription medicine, potentially affecting ability to recall pain or experiences (eg, Psych pharmaceuticals).
- Surgery on the previous painful knee.
- Inability to communicate in Danish.

These criteria were defined to facilitate generalizability and ensure participants could recall experiences specifically related to their knee pain.

Potentially eligible participants were contacted by text message between May and August 2017 and invited to participate. Participants providing a positive response were contacted via telephone and screened by a researcher, before being invited for a clinical examination with a physiotherapist, to determine if they still suffered from knee pain and use their anamnesis to ensure they didn't meet exclusion criteria. During interviews, the interviewers remained vigilant for signs of undisclosed competing conditions which could impede recall, like descriptions of eg, pain unrelated to knee pain,



**Figure 1.** A recreation of the memorization exercise. Participants would start by recalling salient experiences and placing them in relation to age (x axis) and mood/pain experience (y axis, wong-baker pain scale<sup>63</sup>). Finally, participants and researchers filled out gaps to visualize developments in participants' trajectories.

difficulties completing memorization exercises, consulting healthcare providers for issues unrelated to knee pain, use of prescription medicine for other than knee pain, gaps and vague answers.<sup>5</sup>

To validate the results obtained from the interviews, we included additional eight young adults (aged 21–27) with knee pain emerging between age 10 to 15. These participants were included through social media and patient networks of Center for General Practice (CAM-AAU). The inclusion was conducted by posting adverts in social media forums on knee pain and musculoskeletal pain in adolescents, which were shared by the members (patients & clinicians) for additional exposure. Participants who responded positively to social media posts, were forwarded participant information via e-mail, contacted, and screened via telephone before engaging in the tests of the conceptual model.

## Data Collection

The interviewer has a background in information science without any specific clinical or research experience to color his perception of the adolescent knee pain. All interviews were conducted in a general practice clinic due to the familiarity for the participants, and the high level of trust people in Denmark generally have with their GPs. The interviews were done out of normal working hours, which ensured a calm environment with no interruptions. Each interview session started with questions regarding age, height, weight, clinical characteristics, and other demographics. Afterwards, the memorization exercise was completed and lastly, the interviews were conducted. Interview questions would generally follow the sequence of the interview guide, with new themes being explored as they emerged. All interviews were audio recorded and transcribed verbatim by the interviewer (SKJ) and a student assistant. The interview guide was regularly updated to accommodate new themes emerging when engaging in dialogue with participants in an interview setting.

## Analysis & Testing

To structure the analysis of the data the 'General Inductive Approach (GIA) for analyzing qualitative evaluation data'<sup>59</sup> was included as a framework for systemizing the process of exploring participants experiences, identifying themes, and synthesizing insights into a shared narrative. The GIA was chosen for its orientation towards exploring underlying patterns within participants' descriptions through goal free, thematic analysis and identification of relationships across datasets.<sup>59</sup> Through this, a flexible yet rigorous method for extracting a proto-theory through analysis, induction, and testing with clinicians and patients.

## Analysis of Visualizations from Memorization Exercises

The visualizations were interpreted through the user-journey map method.<sup>35</sup> The aim was to extract a basic structure for outlining the temporal developments in the adolescents' perception of their knee pain. This was done by printing each model in an A4 format, reading through each document and marking the shifts, developments, and 'moments of changes' in the participants' descriptions of their knee pain. Marked areas were labelled thematically, and organized within a conceptual ontology, identifying the features and temporal sequence outlining the shared experience of participants (supplementary appendix; Fig S2). The identified features were named by noting the participants' descriptions within a matrix and condensing these into summary form.

## Analysis of Interview Data

We used the GIA for analyzing the data extracted during interviews with participants.<sup>59</sup> By taking point in 'challenges and barriers' as evaluative objectives for identifying themes, the analytical process was broken

**Table 2. Overview of the analytical steps applied during the analysis and interpretation of interview data.**

<i>ANALYTIC STEP</i>	<i>STEP 1: PREPARATION</i>	<i>STEP 2: FAMILIARIZATION</i>	<i>STEP 3: CODING</i>	<i>STEP 4: CONDENSATION &amp; REFINEMENT.</i>	<i>STEP 5: SYNTHESIS &amp; EVALUATION.</i>
Analytic process:	Preparation of 'raw data' for analysis.	Initial read-through, identification of point of interests.	Identification and organization of meaning units into main, generic, and sub-categories.	Selection, condensations of meaning units within themes. Stakeholder evaluation, renaming and redefining codes.	Synthesis of data and extraction of the conceptual model. Identifying themes for reporting data.
Analysis performed by:	Audio files were transcribed by SKJ and a student worker. Transcriptions were conducted to ensure meaning retention.	SKJ conducted in-depth read through of the texts to familiarize himself with the content and identifying points of interest.	In-text themes were identified, sorted, and coded into thematic categories by SKJ through several rounds of coding. Categories were, revised, renamed, and expanded as new insights emerged from the data.	Selected categories were condensed by SKJ into summaries. Thematic overlaps were eliminated, and categories were regrouped/ renamed as new understandings was archived.	A matrix was designed from memorization exercise findings. Summaries were organized within this by SKJ to inform extraction of analytical themes and a conceptual model.
Analytical tools:	Express Scribe*	By hand.	Nvivo 11**, mind map and code list.	Word***, mind map and code list.	Word***
Units of analysis:	None.	Identification of 12 preliminary categories.	4 super-type, 12 generic and 27 sub-categories.	17 categories and thematic relationships.	7 analytical themes, a conceptual model.
Evaluation:	None	None.	Testing of coding by student worker and researcher (JLT).	Condensations were discussed and peer- evaluated by researchers (MSR, SH, NP, JLT, SKJ)	Test and evaluation of conceptual model with (n = 8) patients.

This includes descriptions of; the analytical processes, units of analysis, inclusion of tools and steps applied to evaluate findings.

\*Express Scribe v. 7.01 (NCH software, Canberra, Australia).

\*\*Nvivo 11 v. 11.01.4.11 (QSR International Pty Ltd, Melbourne, Australia).

\*\*\*Microsoft Word for Office 365 MSO (Microsoft office, Richmond, USA).

down in a four-step sequence of; 1. Preparation, 2. Familiarization, 3. Coding, 4. Condensation, peer evaluation and refinement. To facilitate the synthesis with findings from the memorization exercise, a matrix analysis was introduced as a 5th analytical step, enabling us to organize insights from the interviews into a sequence and facilitate the extraction of a conceptual model. The individual steps of the analysis are described in detail in [Table 2](#).

### Testing the Conceptual Model

Testing of the conceptual model was conducted in a general practice setting, where interviews had taken place, in order to validate the contents and layout of the design. Each test session combined elements from qualitative interviews and a think aloud test<sup>22,26,39</sup> following the sequence of; 1. Collection of clinical characteristics, 2. Completion the memorization exercise, 3. Walkthrough of the conceptual model by the researcher in open terms, 4. The Participant and researcher (SKJ) identified divergences and overlaps between the model and participants visualizations, and 5. The participant evaluated the model and suggested changes. The tests were documented via audio recordings, notes, and photography. On completion of the test, the researcher (SKJ) would listen through the audio, take notes, add findings into a matrix and make adjustments to the model.

## Results

### Study Population

From the 139 young adults from the APA2011<sup>50</sup> who were contacted via text messages, 37 responded positively, and 35 were subsequently contacted and screened via telephone for participation. Among potential patients screened, four were eliminated due to knee surgery and eight declined to participate. The first inclusion provided 22 young adults with knee pain who agreed to participate in our interviews. Two of these participated in pilots as testers for the interview guide and model exercise. One participant failed to show up and two cancelled last minute, with 17 participants completing the interviews. Three participants were subsequently excluded, as the interviews revealed they fulfilled exclusion criteria, due to underlying psychological- or pain- pathologies which were undisclosed during screening. Thus, 14 participants were included in the final analysis.

Of the included interview participants, 10 (71%) were female and 4 (29%) were male. Patellofemoral pain (PFP) was the most common diagnosis identified during the interview prescreening. Participants reported how the average age for the emergence of knee pain was around age 15, how 7 (50%) experienced an insidious onset and how they lived 9 years on average with their knee pain. Common points of care were reported as: General Practice 12 (85%), Physiotherapy 11 (79%) with 4 (29%) reporting receiving physiotherapeutic

treatment from the APA2011 cohort.<sup>49</sup> These characteristics resembled those identified within the cohorts' population, relating to; gender distribution (72% female), onset age (14–15 years) and onset type (68% traumatic)<sup>47,48</sup> indicating only a small variation between the cohorts population and our sub-sample.

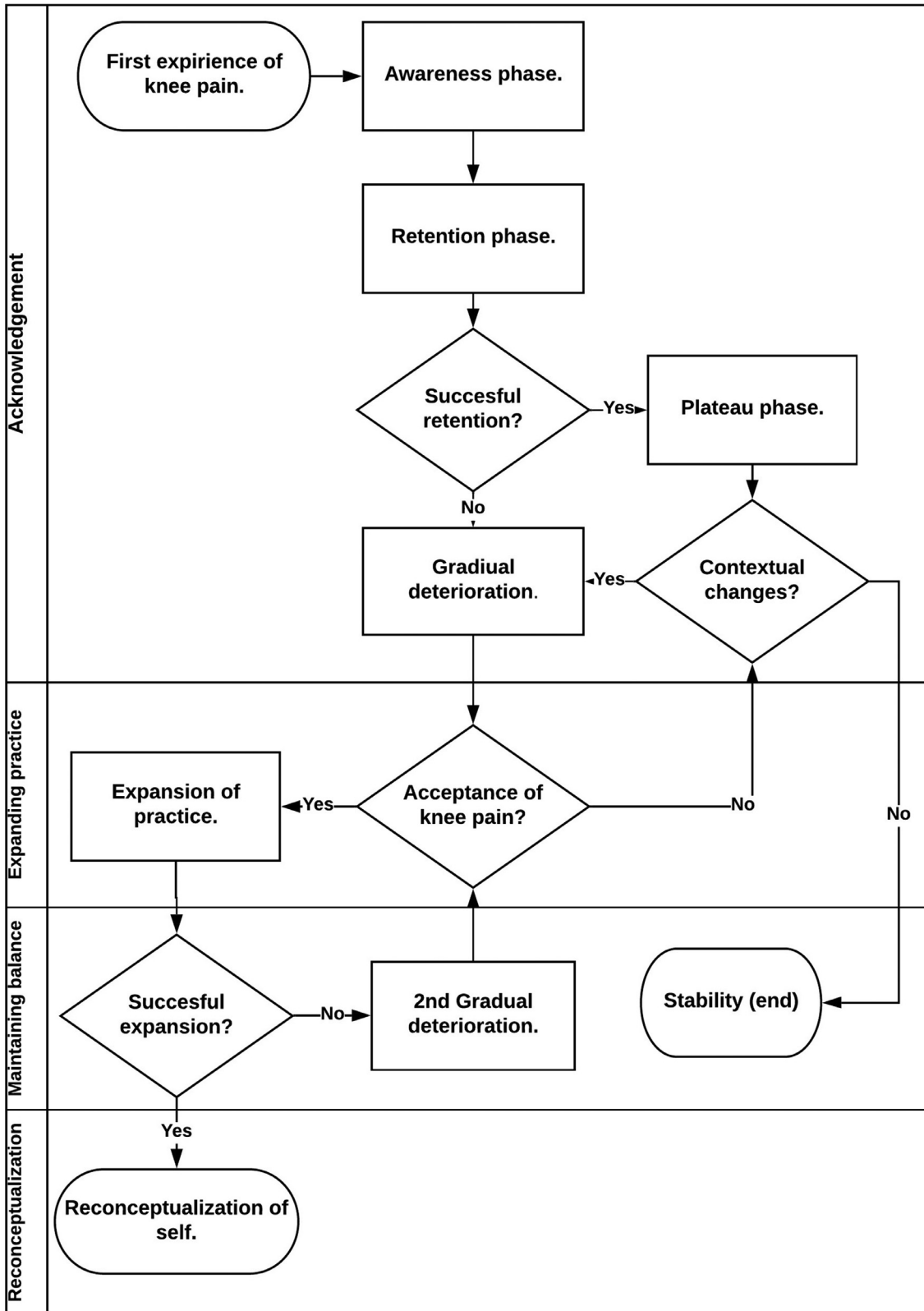
For subsequent testing of the model, nine potential candidates were screened via telephone, and one was eliminated due to competing conditions, which were deemed to impede recall. The clinical characteristics of tests participants differed from the interview participants in terms of distribution of gender (63% female) and reported onset types (88% insidious onset) and the fact that no test participants were part of the APA2011 cohort. Test participants were 12 years (mean age) when the knee pain emerged and had lived with knee pain for 10.1 years on average. The most common sources for treatments for the test participants were the GP 7 (88%) or physiotherapists 4 (50%).

### Findings from the Recall Exercises

From the 14 completed models 13 were submitted for interpretation. Breaking the patient's visualizations into segments and organizing them within a conceptual ontology informed the design of a flowchart, illustrated in [Fig 2](#). The interpretation outlined a complex temporal sequence, consisting of four main phases oriented towards i) acknowledgement, ii) expanding practice, iii) maintaining balance, iv) reconceptualization of self, and eight sub-processes representing how participants experienced, attributed, and acted on their knee pain across time. The sequence of sub-phases were organized as two individual loops, mediated by acceptance, with an overlap between phase 2 & 3 and phase 4 acting as the endpoint ([Fig 2](#)). Based upon the flowcharts layout and themes, we extrapolated how participants' initial efforts towards self-management were primarily oriented towards maintaining stability or control by either, halting the development of their knee pain or maintaining connection to sports and valued activities (supplementary appendix; [Fig S3](#)). Thus, we interpret that 'acceptance' was associated with participants adapting a more proactive approach towards self-management, and gradually expanding their self-management practices to maintain balance with the knee pain. These insights, and the identified phases and sub-processes are described in detail within the supplementary appendix [Fig s3](#), to illustrate how these insights provided anchor points for our interpretation of interview data.

### Thematic Coding Findings from the Interviews

Thematic coding revealed a complex model of four super-type, 12 generic and 27 sub-themes. The four super-type themes were labelled 'apprehension-', 'knowledge-', 'contextual-', and 'social/value-barriers'. Each super-type theme had unique clusters of themes and sub-themes with different challenges, processes, and behaviors as portrayed in [Fig 3](#). The model outlined



**Figure 2.** The flowchart model was defined by synthesizing insights from the memorization exercises. The model visualizes a four-stage sequence of reflective and social sub-processes, which participants negotiated to progress mastery, which was mediated by acceptance. Full version in supplementary appendix Fig s3.

how all four thematic clusters were embedded in a hierarchical relationship of increasing complexity, illustrated in the relationship (illustrated 1–4) between the subcategories within the learning and the behaviors category (Fig 3, supplementary appendix; Fig S4). We interpret that mastering one cluster allowed participants to take on more complex management challenges, with social challenges being the final domain of mastery. To explore this mechanism, 17 generic and sub-categories were selected for in-depth interpretation. The seven analytical themes resulting from this in-depth interpretation are outlined below.

### **Interpretation of the Seven Analytical Themes**

**Theme 1: Emergence of Knee Pain:** This theme explored how participants experienced their knee pain emerge (related to the first experience of knee pain category), and how they initially perceived the pain.

Twelve participants recalled and ten provided in-depth accounts of the first time they felt knee pain. Descriptions included activity and location like; *soccer practice, climbing stairs, horseback riding, gym class, and vacationing*. Those with a traumatic onset described how the traumatic injury made them immediately aware that something was wrong. Participant 7 described how his parent's reactions and hospital visit confirmed his belief that something was not right.

*P7: It was something I noticed right away, because I'm sure I cried because it was painful and I was convinced it wasn't a good thing, because they (P7's siblings) got a hold of some adults and then I ended up staying at a Norwegian hospital until late at night.*

On the other hand, participants with an insidious onset described differences in how their knee pain first emerged ranging from; *mild pain behind the kneecap, tingling, throbbing, a ball in the knee, flares, sharp pain during specific activities to a feeling that something was wrong*. Others described their knees 'quitting' on them during strenuous activities. Participants 4 and 10 described how their knee pain emerged differently below:

*P4: It started behind the kneecap, and almost felt like there was something in there that started complaining and telling me that it's wasn't comfortable anymore. Maybe it was due to me walking in a wrong way, or my shoes not being worn in or something like that.*

*P10: I was at school. During gym class. We were running a Cooper-test and we had been told that, as a woman, you should be able to run approximately 2 kilometers in 12 minutes. . . and I couldn't because I started to feel pain and I simply could not pick up the pace.*

Many participants initially attributed their symptoms as a momentary nuisance, limited to a specific activity. Several participants expressed initially feeling concerned, and some described an added uncertainty as they had no reference for how to respond to the experienced knee pain. Participant 1 described an initial worry that eventually subsided as she grew accustomed to the pain.

*P1: I was a huge question mark, because I had never tried anything like this before. So, my initial thought was that something was not right (with my knee). But since it just kind of stayed the same every day, I didn't think more of it and eventually I grew accustomed to it, because it was primarily when I was walking up the stairs, I felt it and not really anywhere else.*

Several participants described not perceiving emerging symptoms as concerning, as they did not consider it an injury. This prevented them from seeking advice or medical support. Participant 6 describes his perception of what being injured meant below:

*P06: At that time, I had a very rigorous conviction on what it meant to be injured or not injured. Being injured meant that I could not play handball. On the contrary, not being injured meant that I could play. That was the conviction I had at the given time.*

**Theme 2: The Double-Bind.** The double-bind theme was located between the 'retention' and 'gradual deterioration' phase and explored descriptions how knee pain participants them in dilemmas in social situations.

**Making Value Judgements.** Regardless of whether there was an initial plateau in pain, all participants eventually reached a threshold where it could not be ignored. Participants describe difficulties deciding in situations on whether to try to manage their knee pain, or maintain the social situation/activity. Many felt that acting on their knee pain made them vulnerable to being judged by others. Participant 10 described:

*P10: I didn't want to be the one of whom others would think "oh she is so annoying - that she is going to interfere with our performance" I didn't want to be her. And that was also how I felt back in school. When doing cross country running, I was definitely not going to be the one who slowed us down.*

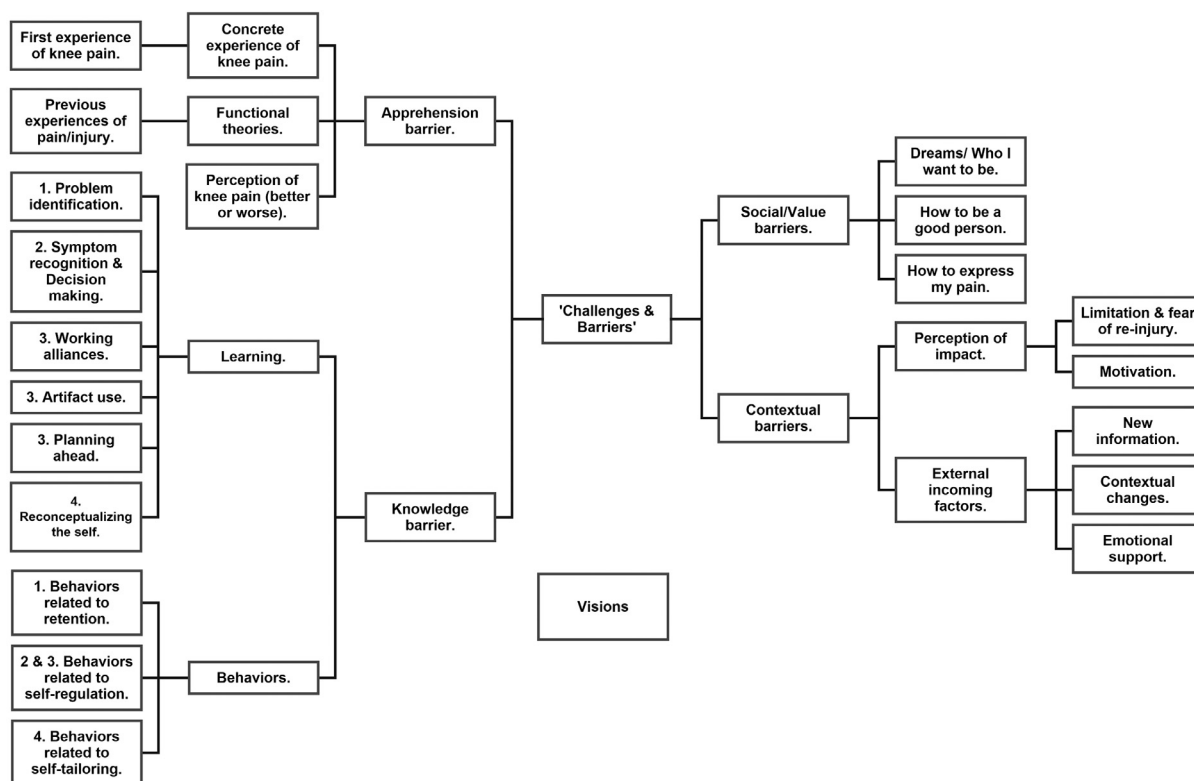
Twelve participants expressed fear of being branded as whiney, lazy, attention seeking or incompetent. Many were in doubt of whether the pain was 'normal' or severe enough to merit action. Participant 8 described playing through his pain to avoid social sanctions:

*P8: If you're in a match and then say "I need to take a break because my knees hurt" some will surely end up thinking "no, we shouldn't bring this guy back in" or "c'mon, we need you to..", and that will then make you think "oh, well that's the way it supposed to be". I've often played through all kinds of pain which I shouldn't have.*

While seven participants highlighted their frustration with knee pain, and how participating in sports gained a transactional dimension, providing momentary pay-offs like; *joy, pain relief, or worry reduction* if successful. Vice versa, failure to perform could result in frustration or feeling a loss of control or identity. Participants 5 and 14 described this below:

*P14: It didn't make me feel particularly good (..) I've always been an active person, so I reckon I felt that this was not something I was used to; it was unlike me. . . not to join in. Not to participate.*

*P5: During the start of the match I could have run faster, than I did at that time.. then you lose a dual or*



**Figure 3.** The coding revealed a system of four thematic clusters oriented towards; apprehension, knowledge, contextual and social and values, all with individual sub-themes. The coding identified a hierarchy between the learning and behavior clusters (illustrated 1–4). Full version in supplementary appendix Fig s4.

something and then you become frustrated. That makes you fight even harder for it, but it's not always physically possible (...) and that's yet another letdown.

**Theme 3: Functional Theories.** The theme explored how patients formed theories or beliefs which empowered them to cope with their knee pain.

Thirteen participants described developing personalized theories relating to different aspects of the bio-psycho-social model, on the origins and mechanics of their knee pain. The different theories identified are illustrated in Table 3, based on orientation towards the biological, psychological or social domain.

Five developed functional theories due to lack of knowledge. Other participants described how their theories were informed by previous experiences with injuries, observations of relatives /peers reacting to pain/ injuries or adopting their views. Participant 02 describes how her knowledge of her grandfather's pain, made her conclude that pain was part of adulthood.

P02: (...) I didn't see it (the knee pain) as something that didn't go along with being a thirteen-year-old girl. My grandfather had arthritis, so I thought that it (the knee pain) was just part of being human in some way or another.

These theories reduced worries and concerns and provided a path towards management. Making judgements and observing the outcomes of behavioral choices, solidified and gradually expanded their theories. Participant 6 described how his theories changed when his pain did not disappear as anticipated, leading him to explore different solutions.

P06: I had this idea that it (knee pain) got worse because I played handball... When that idea disappeared and it just continued to get worse, just because it got worse, I concluded that I probably had to do something active to avoid it worsening further. In this case, seeking treatment and finding some sort of solution.

**Theme 4: Getting a Name.** Located between 'gradual deterioration' and 'expansion of practice' category, this theme highlights how getting a name or diagnosis acted/was as a 'moment of change' which aided acceptance of knee pain.

Several participants described how the experience of pain persisting, worsening, or being physically limited worried them, and motivated them to seek external support. Several participants used the term getting a 'name' to describe, how receiving a diagnosis from their GP or PT validated them, removed doubts and made the condition more tangible.

P02: And then the GP tells him (a researcher) that she (P02) fits into our project because she could not have any other condition... And I just felt such a sense of relief, because it was like ok, so it wasn't me there was something wrong with.

Getting a name made the condition communicable to others and aided them and others to accept their condition.

P10: I think so, because it was put into words..by others (a physiotherapist). Whereas those who did not have knee pain, also heard what it was all about. Now you know that it was something that other people

knew about (...) and that made it easier for others to accept.

On the other side, seven participants described how not being recognized or getting a name, resulted in them retaining their doubts on the validity of their pain experience. While this heightened barriers for seeking treatment, four participants described how it also confirmed 'theories' on how the pain was nothing serious, why they returned to their sports.

*P08: And then you end up thinking "Well then it's probably not so bad; this thing I'm struggling with" and "Oh well then it must be all right to push through and play soccer until I can't anymore. (...) If you are told "well... there is nothing we can't do about it"... then there is also nothing I can do about it myself.*

**Theme 5: Establishing a Feedback Loop.** The category was located between the 'acceptance' and 'expanding practice' category and explored the connection between acceptance and learning in participants descriptions.

Some participants described, how getting a name made it acceptable to take actions towards managing their pain, and seven described that it provided them with an explanation, when not able to perform. Participant 1 described how her physiotherapists recognition, made it permissible to take brakes.

*P1: It had something to do with having a professional telling you; it's this kind of pain you're experiencing and knowing that she was a part of the domain of what I did as a past time activity ... this made it more ok for me to take timeouts (during sports). Then I could tell the others that it had been approved of, because it (the pain) was real.*

Several participants formed a reverse feedback loop, where their trial-and-error informed their functional theories. Six participants described, how they started to notice nuances in their knee pain and gradually learned to differentiate 'good pain from the bad', many eventually became adept at finding 'the limit' with the knee pain, which aided them in making judgements on when to change behaviors to alleviate their pain. Participant 8 described this decision-making below.

*P08: The longer I had it (knee pain) the more conscious I became about it, because the only way I could learn about it was "ok now it's starting to hurt, and now... Now I need to take a brake". So yes.. I gradually became better at making the right decisions or doing the right things. So, I could be ready to do the things I preferred spending my energy on.*

Several participants highlighted how this required willingness to lean into their pain, since 'you had to be in your knee, to learn how not to strain it' to find the limit. Others highlighted how pressing-on was important for challenging their functional theories and learning how to apply behaviors (e.g. *pacing, taking brakes, modifying behaviors*), to alleviate the pain. Participant 11 used the term trust to describe, the paradox of how pressing-on during sports, helped identify her boundary.

*P11: The limit (with knee pain) you'll find automatically, because as soon as you pass over it (the limit) you no longer have trust, because you might end up having*

**Table 3. Descriptions of the functional theories, participants formed to make sense of their knee pain, organized based on the statement's primary association with the bio-psycho-social model.**

FUNCTIONAL THEORIES\*

Biological	My knee pain is due to my knees being worn— therefore I cannot do anything about it. My knees hurt because I play handball – when I quit the pain will disappear. I am out of shape. My knee is broken. My knee pain only emerges during specific situations. I need to lose weight Maybe I am not strong enough. I need to strengthen my knee. If I run a little bit today, I can't run at all tomorrow.
Psychological	Maybe this is all in my imagination. Knee pain is like having hurt a finger. I cannot do anything to make the pain go away.
Social	Is this normal? You are injured when you cannot participate in sports. Others have it worse than I. Maybe I am just being whiney. I am too young to have knee pain. Having pain is part of being an adult.

\*Organized based on their primary association with the bio-psycho-social model.

*a pain for a week or so.. But when you figure out how "I can go to here.. I can take 55 kilos or something and that's my limit" then I can trust my knees until here.*

Four participants describing becoming able to identify contextual triggers and make short-term behavioral adjustments. Participant 12 described identifying triggers and take action on them.

*P12: It's connected to your previous experiences. Like thinking, this (activity) has been painful before (...), remembering this until the next time and then knowing;" okay, I've experienced this (activity) as a trigger previously, so it's probably still a trigger and then using this knowledge". If I'm doing something new, and I'm unsure whether it will trigger them (the knees) I'll jump into it, remember if it's a trigger and use this knowledge next time.*

**Theme 6: Contextual Application.** Located between the 'expansion' and 'reconceptualization' phase, the theme highlights how participants' experiences with their knee pain across multiple contexts empowered compromise and further acceptance of their knee pain.

Whereas several participants described reaching a point where they would sometimes forget their knee pain, either due to them becoming familiar with their pain or due to behavioral- or lifestyle changes, but also how life-changing events like; *returning to sports, gaining fulltime employment, entering high school, traveling or entering university* made the pain resurface. A

recurring theme was participants gaining the ability to view the pain in a broader perspective. Participant 8 described gradually becoming aware of a pattern in his knee pain and adapting to it in time.

*P08: It was like this (activity) hurts and this doesn't. This (activity) is what I can do instead, in order to not have knee pain" and slowly you'll get on top of it.. If I use my day in this way or I do this, then there are two different patterns in how my knees will behave... and I reckon you automatically adjust to this.*

**The Motivational Shift.** Another recurring theme was, how small successes with managing knee pain in different contexts accumulated over time. Four participants felt this provided them with a boost or hope for recovery, while others described how they started to view their knee pain as challenges rather than limitations in situ. Participant 13 describes this shift below:

*P13: But I would view a point of irritation as a limitation, because it's something that prevents you from doing what it is you want to do. Whereas an opportunity is.. well an opportunity, where you can decide in which direction you choose to take it.*

Motivation acted as a secondary feedback loop, and eleven participants highlighted drawing on external stimuli to maintain performance when the pain reemerged. While four participants described engaging with other youths with knee pain as beneficial, five described how being able to participate in sports or other value activities with other youths with or without knee pain, provided them with emotional support, companionship and inspired them to maintain performance.

*P10: Well I thought it was good to have someone else to talk to about it. (..)Being able to discuss things with each other like "how is it going with yours (knees), are you getting your exercises done and... also do you want to come along to the gym after class today". Having someone to do this with and talk to..*

Three participants highlighted that they reached a point where they needed more information on managing their knee pain, whereas several other participants emphasized that they sought emotional support/knowledge from health care professionals, relatives with pain or internet sources; they described how this information had a soothing or transformational effect and helped them identify new self-management approaches.

**Returning to Sports.** At they became more confident, nine participants decided to return to their previous sports, starting out fitness or seeking new challenges like; *running a marathon, trying a new sport, or travelling abroad*, and how this became a second moment of change. Several participants described making compromises to maintain their participation while balancing the knee pain. Participant 08 describes how moving to a less competitive team, meant he could still compete.

*P08: Maybe this is why I decided to play on a lower level, because then I would always be part of the better half (of the team). (..) Then I wouldn't as get annoyed at myself from not being able to perform at my very best.*

**Theme 7: Reconceptualization of Self.** The reconceptualization phase was the final step in the trajectory and describes how participants reimagined themselves

by integrating the knee pain into future plans and dreams.

From the seven participants in this theme, six described how certain experiences like pregnancy, travelling during a gap year, full time employment, entering university or entering adulthood acted as 'moments-of-change' making the participants contemplate the future impact of their knee pain and what they wanted from life.

*P04: It is only now, especially after being pregnant and having my son, because there are things, I really want to be able to do with him, as he grows older, and to do this I need a body that is in functioning order.*

A shared feature in participants' descriptions, was how value systems and visions for their future selves had changed and how this impacted their sports participation, self-expression, and dreams. Four participants described this as associated to making compromises earlier on. A recurring theme was how integrating the knee pain into their dreams, made it easier to retain a positive outlook and prioritize activities towards maintaining balance.

*P01: I've given this a lot of thought – not so much on education but rather, whether I should choose to become a gym teacher, since I heard it's physically demanding and whether my knee pain could take it. I've also contemplated whether it was stupid to walk around injured, during my gym classes. (..) And also about thinking forwards, when me and my partner will buy a house, and apartment or what we will end up with, because it cannot have to many steep stairways, because I can't do those either.*

Two participants described that they still felt drawn towards sports whereas four described how knowledge of their knee pain and ability to compromise made it easier to accept the limitation, prioritize and seek out alternatives. Only one participant described that knee pain no longer impacted her quality of life but four stated they had developed new life goals (eg, going abroad, settling down with a partner, and starting at the university) and this had made it easier to accept the pain and limitations.

## Synthesis into Conceptual Model

The findings from the analysis were illustrated in a conceptual model to visualize the challenges, barriers and needs participants encountered on their journeys towards mastery of their knee pain. Taking point in descriptions of the knee pain creating unknown situations and how participants made judgements to manage their pain/situations, a patient journey was defined as process with four embedded phases focusing on; *awareness, knowledge, contextual application and reconceptualization of self* and a 'moment-of-change' defined as 'acceptance'. All phases were illustrated as closed processes; except for phase 2 based on participants descriptions of the 'knowledge' and 'context phase' as intertwined or overlapping. To visualize the challenges and dilemmas participants navigated/balanced to transcend into the next phase, different

sub-processes constellations were defined, based on findings from interviews and matrix analysis.

### **Validating the Model**

The testing revealed a high level of recognition amongst participants, while informing small changes in models' layout. While all participants were able to recognize and confirm the general layout and wording of items, two participants felt their experiences matched the patient journey model perfectly. Four participants' experiences diverged in few instances, only to realign with the trajectory later, and two participants' experiences deviated in later phases due to either competing injuries or recovery. Six participants described, how their experiences with their knee pain generally followed the sequence outlined within the model. From the two participants whose experiences diverged from the sequence; one described how re injury digressed her back into the knowledge phase to relearn to manage her injury, while another participant described how efforts towards managing an emerging back injury, allowed him to bypass the knowledge- and move into the context phase, when his knee pain returned. All confirmed the layout of the apprehension phase and the double-bind, with four using terms like *'in limbo'* or *'balancing'* to confirm the layout. Furthermore, four described their personal functional theories when reviewing this phase. Seven participants confirmed getting a *'name'* or an explanation constituted a moment of change, and five confirmed how this led to acceptance. The one participant who did not receive a diagnosis, described how not being able to participate prompted her to accept the knee pain. The *'knowledge phase'* was confirmed by seven-, whereas six confirmed and one participant somewhat confirmed the context phase. Only two test participants reached the *'reconceptualization phase'*, one felt she was entering it, and two others confirmed its existence as plausible. Finally, our testing revealed the existence of a secondary *'acceptance'* between the context and reconceptualization phase, which was described as related to a re-injury, but also a transition into the fourth phase. This item was added to the final version of the model after the testing.

### **The Conceptual Model**

The insights extracted during the tests, informed the final iteration of the conceptual model (Fig 4, supplementary appendix; Fig s5) adding the *'acceptance of limitation'* as a point of transition between the *'context'* and the *'reconceptualization'* phase. Furthermore, participants' feedback solidified the premises communicated within the design illustrated within Fig 4, while informing descriptions of each phase, the challenges, barriers and self-management needs of participants initially identified during the analysis. A full version of the model with descriptions of phases is enclosed in supplementary appendix; figure s5.

The apprehension phase - was the period between when participants first experienced the knee pain and until they accepted the condition. It was characterized by the struggle to retain valued activities, cutting down on other activities, frustration, and doubt. Subthemes included the double-bind where participants risked frustration and negative emotions to maintain participation in sports/value activities. Functional theories and previous experiences were mechanisms for maintaining balance and coping with doubts and insecurities. Challenges were recognizing the extent of injury, asking for help, getting a name. Barriers were doubts on injury severity, fear of stigma and inability to recognize the knee pain.

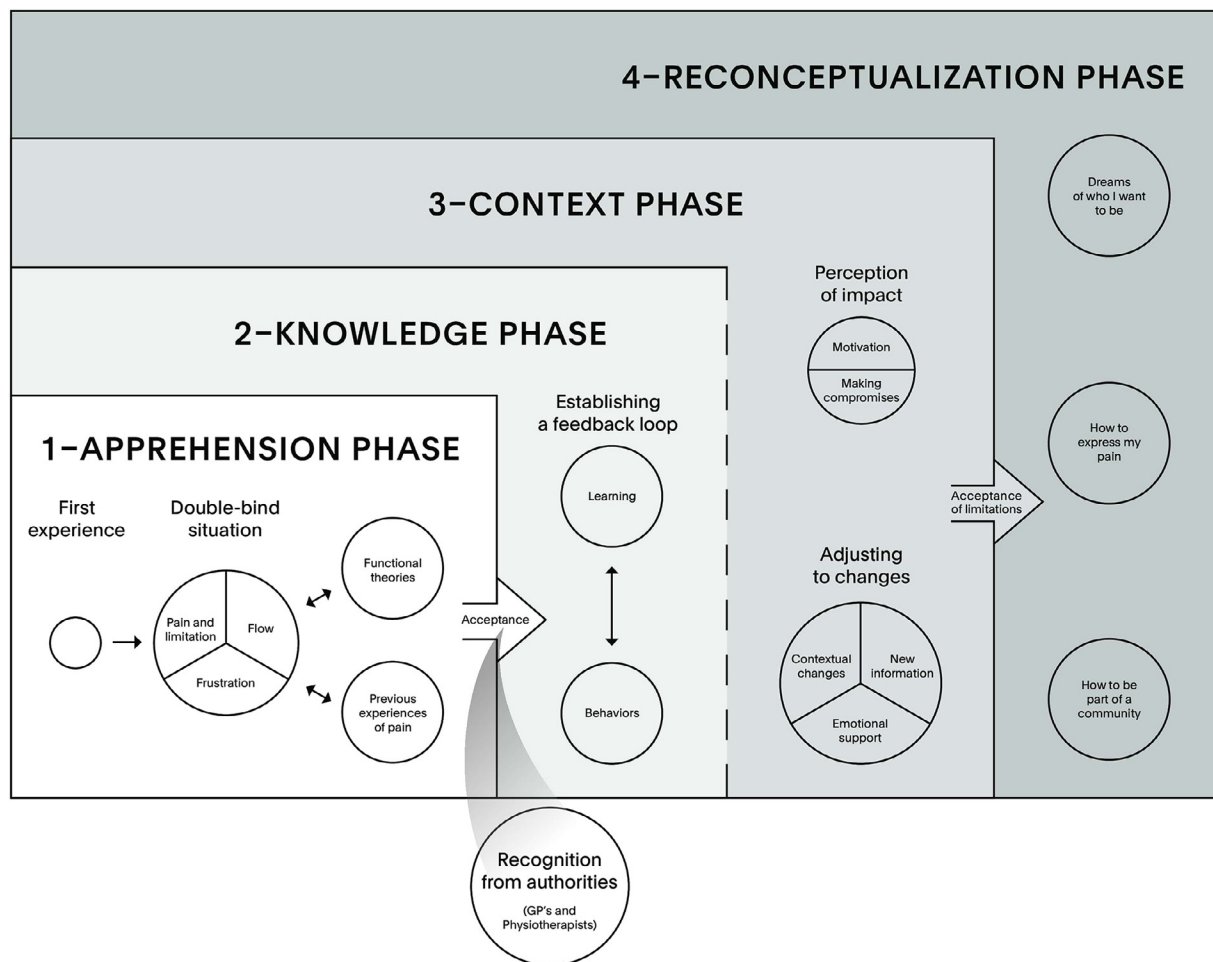
The knowledge phase – commenced after acceptance. Participants explore and gradually become more knowledgeable on managing the knee pain. Subthemes illustrated discovery of new nuances in symptoms informed a feedback-loop to behaviors and learned (expanded theories) from observing outcomes. Participants learned to alternate between leaning into the pain, finding the limit and alleviating the pain. Challenges were separating good pain from bad, finding the limit and pacing/alleviating the pain, while barriers were learning to lean into the pain.

The context phase - was characterized by participants attaining a broader perspective and making accurate predictions on future pain manifestations. Subthemes illustrated how contextual changes made the pain remerge and how participants drew on *'social support'* or *'new information'* from eg, healthcare providers to *'adjust to changes'*. *'Motivation'* was defined as a dual process influencing efficacy beliefs, with *'compromise'* as opposite to highlight how patients learned to compromise to engage in valued activities. Challenges were defined as; identifying activities which provoked or limited pain, planning and utilizing external support. Barriers was described as navigating the dilemma of motivation and compromising, resulting in an acceptance of limitation.

The reconceptualization phase - was defined as the final phase and characterized by participants integrating the knee pain into their future plans. Acceptance of limitations was the point of transition, driven by the ability to compromise. Different life changes (eg, pregnancy, entering university, travelling) prompted patients to rethink themselves. This facilitated a reconfiguration of participants' dreams or visions of future selves, their beliefs on how to be part of a community and expressions of their knee pain.

### **Discussion**

This study explores the socio-cognitive processes governing adolescents with knee pains' formation of self-management strategies. We identified that adolescents undergo several critical phases, to gradually acquire skills to tackle everyday management challenges. Certain experiences (eg, getting a name for their condition) may potentially accelerate this, while others provided setbacks (eg, developing maladaptive pain beliefs). Our



**Figure 4.** Final version of the conceptual model, visualizing the four phases of participants’ self-management, with sub-processes and challenges. Phases were depicted as embedded, illustrating how taking on more complex management tasks, was contingent on participants mastering previous phases and acceptance. See appendix 5 for model.

findings are presented within a conceptual model, which can be leveraged to inform the design of new patient education concepts. This is particularly relevant as patient education and self-management training constitutes core components of treating adolescent knee pain<sup>10,12,49,52</sup>.

**Explanation of Findings**

This study is the first to outline a conceptual model for understanding adolescents’ self-management of musculoskeletal pain, drawing upon in-depth interviews to explore how the adolescent knee pain manifests over time, leading to changes in their experienced barriers, challenges, and needs. By combining insights from the interviews and the memorization exercises, the analysis identified several processes, which participants highlighted as influencing their self-management practices.

**Self-Management as an Inquiry**

Participants described how their knee pain started out as a biomechanical phenomenon (eg, pain or

limitation), and transcended into different experiential domains (social, psychological) as the pain developed. Strauss and Corbin<sup>11</sup> describes a similar process in adults with chronic illness, driving the need for more complex management styles to cope with pain-, life- and autobiographical aspects of illness. Our participants describe how increasing pain added uncertainty to otherwise familiar situations. As conceptualized in Gannick’s<sup>17</sup> ‘field of disease action’, participants had to prioritize regulating symptoms or managing contextual aspects of the given situation. Our analysis indicated gaining acceptance altered the ‘uncertainty’, and allowed participants to explore the boundaries of their condition by observing outcomes of performance, as described within social-cognitive theory<sup>1,4</sup>. Participants described how external stimuli (eg, parents-, peer attitudes) influenced their pain beliefs, and how these beliefs were closer to theories which were ‘constructed’ as participants became more knowledgeable on the condition. These ‘functional theories’ influenced how participants coped with negative emotions related to increases in pain though sense-making and predictions, as described by Khanom<sup>24</sup> and in Bandura’s<sup>4</sup> outcome expectancies.

Studies with patients with low back pain highlight, how perceived pain threats lead to anxiety and activity avoidance<sup>28</sup>. Participants described initially using successful performance (eg, sports participation) to cull aversive emotions, acceptance allowed them to begin exploring how to take actions on their symptoms. While a recent study conceptualizes self-management as a combination of behaviors<sup>61</sup>, our findings indicated how some management behaviors like; *finding the limit*, *learning into knee pain* and *pacing/holding back* (alleviating pain) acted as the foundation for more complex self-management behaviors.

### **Establishing Balance**

Our findings revealed how participants managed different facets of their knee pain across their trajectories, indicating their self-management efforts served the purpose of creating order, in the wake of aversive developments pain (eg, aggravation of pain from sports or social activities)<sup>24,25</sup>. From this, we established that the participants' perceptions of how to reestablish equilibrium guided their self-management decisions. The memorization exercises illustrated how participants' management styles transitioned from reactive to proactive. While this transition was important for progressing participants' self-management, the exercises did not elucidate how this change occurred. Townsend<sup>60</sup> and Paterson<sup>43</sup> outline how experiencing increasing symptoms from chronic conditions can foster reactive behaviors (eg, avoidance or activity reductions), either to avoid compromising personal values (eg, not letting down teammates) or maintaining identity (eg, avoiding stigma). Our data confirm and expand upon this, by highlighting how trying-and-failing to manage the knee pain increased frustration and eventually prompted participants to expand their management practices by testing new behaviors (eg, consulting coaches, seeking treatments, compromising) to overcome external challenges.

### **Acceptance and Behavioral Change**

Our analysis revealed that our participants acquired self-management strategies in steps, and that frustration played an important role in driving their expansion of management practices. Still, a key insight related to how acceptance played a crucial role in empowering patients to psychologically adjust to external challenges and transcend cognitive barriers. This is reflected in several studies<sup>6,36,40,44,62</sup> describing acceptance as inversely correlated with anxiety, perceived severity, disability, and avoidance behaviors. Participants described getting a 'name' or diagnosis as a starting point for acceptance as described by Wiess<sup>62</sup> by removing the doubt and stigma as highlighted by Olsson<sup>40</sup>. This resulted in participants switching from focusing on pain reduction, towards gradually adapting an accommodative management approach, as documented by McCracken et al.<sup>36</sup>. Still our findings expanded upon these

observations, by highlighting how participants attained acceptance in a two-step process (accepting pain and accepting limitation) with the second step often coinciding with reemergence of knee pain. Based on this, we infer that whilst pain acceptance became a linchpin for behavioral change, this did not change held beliefs on pain mechanics as observed by Rankin et al.<sup>44</sup>, since participants trail-and-error adjusted their pain beliefs, dreams, and willingness to compromise before the second acceptance could be archived.

### **Learning and Knee Pain**

Our analysis revealed how our participants' efforts towards mastering their knee pain followed a four-phase trajectory of different reflective practices. While other studies have identified similar patterns in patients with chronic conditions acquisition of self-management<sup>2,11</sup>, what prompts patients to progress between self-management phases remains somewhat undefined. Our findings indicate adolescent's development of self-management of knee pain was inherently a proximal process<sup>9</sup>. Through this process, participants gradually became able to address more complex aspects of self-managing their knee pain, by combining experiential and constructive learning styles<sup>37</sup> as indicated by the phases and processes of the model. Participants expanded their self-management incrementally through everyday trial- and error, this learning empowered participants to maintain the balance within the boundary of the given phase. We interpret that constructive learning occurred when participants encountered a challenge or dilemma, they couldn't resolve without confronting fears or values (eg, disclosing knee pain, leaning into pain, compromising) and how participants drew on external information (eg, recognition, getting a name, treatments, formative experiences) to alleviate doubts and garner acceptance. Thus, our data indicated constructive learning changed adolescents' functional theories enabling them to engage in more complex management behaviors. Understanding how to empower participants to engage in both types of learning should be explored further in future qualitative studies.

### **Clinical Implications**

Our findings above indicate that a significant part of adolescents with knee pains formation of self-management strategies occurs by them experiencing and overcoming everyday challenges. This insight opens up new possibilities for developing patient education strategies and tools for progressing patients' self-management. We recommend expanding the scope from providing information on etiology and exercises, towards creating a space for empowering adolescents to conduct their own inquiry into their knee pain. Thus, educating adolescents should be an ongoing collaboration where clinicians provide reassurance, advice and practice corrections. Previous studies highlight the first clinical contact as a teachable moment<sup>32</sup>, a key insight

corroborated this, by highlighting how getting a 'name' from a healthcare provider alleviated our participants' doubts, and empowered them to transcend into the 'knowledge phase' and commence exploring the boundaries of their knee pain. Furthermore, adolescents' 'functional theories' can sometimes result in counter-productive behavioral choices and may need to be discussed with clinicians to aid their construction of knowledge and remove cognitive self-management barriers. Understanding how different components of patient education can support the adolescent's integration of self-management at different stages of the trajectory, could be valuable for addressing individual patient needs. Extracting a taxonomy of self-management behaviors should be explored, to develop patient-centered patient education practices.

### Strength and Limitations

The study has strengths and limitations, which should be considered when interpreting findings. Literature describes, how revisiting pain experiences is complicated by subjectivity<sup>34,41</sup>, emotive states and cognitive factors, like recall bias or saliency<sup>19</sup>. Additionally, stigma related to living with chronic conditions, may have led to say-do-issues or omissions during interviews<sup>41</sup>. Due to the heterogeneous presentations of knee pain, our strategy for inclusion constituted both a strength and limitation in itself. A strength was how interview participants were included from a population-based cohort study on adolescent knee pain<sup>50</sup>, ensuring all interviewees had lived experience, within the boundary of the phenomena of knee pain<sup>64</sup>. Furthermore, eliminating participants who reported competing musculoskeletal conditions or psychological issues requiring medication, provided clear descriptions of participants' experiences with knee pain. While we believe this strengthened the credibility of our conceptual model<sup>35</sup>, this focus may have limited the transferability of findings to the wider cohort of adolescents with knee pain and competing pain or psychological conditions<sup>3,50</sup>. Interventions received during the cohort, influenced some participants' trajectories<sup>49</sup>. How this influence manifested was deemed a point of interest, rather than a confounding factor. Secondly, steps were taken to reduce recall bias during interviews; incorporating a memorization exercise to help participants organize recalled experiences prior to interviews, and using funneling method questioning. Still, the effectiveness hereof was difficult to determine precisely. To compensate for how the majority of interviews and analysis was conducted by one researcher (SKJ), testing and evaluation from other researchers was conducted (SH, NP, JLT, MSR) to safeguard for tunneling and interpretive bias throughout the data analysis<sup>59</sup>. Furthermore, selecting 'barriers and challenges' as analytical objectives allowed for

identification of themes on how participants perceived, interpreted and internalized the knee pain. While this patient-centered outlook allowed us to focus on extracting the trajectory, the role of contextual or social phenomena like caregiver-, parental-, peer-support or additional treatments influence on participants coping were not addressed directly, but indirectly through how these external phenomena contributed to participants' management abilities as context stimuli<sup>4</sup>, which is a limitation. Still, testing demonstrated how participants included outside the cohort could recognize, navigate and relate visualizations to their personal experiences, indicating that the conceptual model had sufficiently captured essential components of participants' experience of living with knee pain.

### Conclusion

Our analysis revealed that adolescents' journey towards mastery of their knee pain occurred as a four-stage process, each with challenges and dilemmas which the adolescents had to navigate to progress their self-management. Participants described tackling increasingly complex self-management challenges to maintain balance with their knee pain, and how acceptance was key to overcoming barriers and ascending into the next stage in the process. Adolescents used self-management to explore the boundaries of their knee pain, and how 'pressing on', 'finding the limit' and 'pacing/holding back' acted as cornerstones for developing self-management strategies. Understanding how to create a space for adolescents to conduct their own inquiry into their knee pain through; diagnosis, ongoing collaboration and support, while adjusting functional theories should be explored to enhance the efficacy of future patient education concepts.

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### Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jpain.2021.10.006>.

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