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Wride, J

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**‘If you can’t help me, so help me God I will cut it off myself...’ The experience of living with knee pain: A qualitative meta-synthesis.**

**Authors:**

James M Wride <sup>a,b</sup> [jwride@nhs.net](mailto:jwride@nhs.net)

Katrina Bannigan <sup>a</sup> [katrina.bannigan@plymouth.ac.uk](mailto:katrina.bannigan@plymouth.ac.uk)

**Affiliations**

a: School of Health Professions, Plymouth University, Peninsula Allied Health Centre, Derriford Rd, Derriford, Plymouth, Devon, PL6 8BH UK

b: Royal Devon & Exeter NHS Foundation Trust, Barrack Road, Exeter, EX2 5DW, UK

**Corresponding Author:**

James M Wride: [jwride@nhs.net](mailto:jwride@nhs.net)

MSK Physiotherapy Department

Poltimore Building

Exeter Community Hospital

Hospital Lane

Exeter

EX1 3RB

01392 465 610

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## **ABSTRACT**

### **Objective**

To identify and explore the feelings and experiences of people living with knee pain as a precursor to exploring how this might contribute to improved care in the future.

### **Design**

The qualitative meta-synthesis was undertaken in three parts 1) a systematic search of the literature, 2) a critical appraisal of the relevant studies and 3) meta-aggregation of the findings from the selected studies. A qualitative meta-synthesis is a process that enables researchers to answer a specific research question by combining and summarising a variety of qualitative sources. This was undertaken using a contextualist approach which acknowledges different realities exist but tries to determine an underlying 'truth'.

### **Setting**

The participants from the selected studies were from a range of settings and ethnic groups, and cultural backgrounds.

### **Participants**

There were nine articles included in the meta-synthesis. Articles focused on the experiences of surgery, return to sport, or other aspects of care were excluded.

### **Results**

No articles were excluded following critical appraisal. Eleven categories were identified from 55 findings which resulted in two synthesised findings being identified: Knee pain affects every aspect of life and Searching for the best way forward.

## **Limitations**

Articles were largely limited to older adults living with osteoarthritis. Many of the findings did not report demographic data. Only English language studies were included.

## **Conclusion**

Many people living with knee pain struggle to adapt to living with knee pain and this is often exacerbated by a lack of knowledge and available information to help them plan for the future.

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## **CONTRIBUTION OF THE PAPER**

- **This is the first meta synthesis exploring the lived experience of people with knee pain.**
- **This review emphasises the wide-ranging effect of knee pain on peoples' lives.**
- **This study suggests the need for effective and appropriate education to better support people living with knee pain.**

**Key Words:** Knee pain; Qualitative; Osteoarthritis; Experience; Synthesis; Psychosocial.

## ConQual Summary of findings

Review Title: 'If you can't help me, so help me God I will cut it off myself...' The experience of living with knee pain: A qualitative meta-synthesis.

Population: People living with knee pain

Phenomena of interest: The lived experience of knee pain

Context: Any person from across the world living with knee pain.

Synthesised Finding	Type of Research	Dependability	Credibility	ConQual Score
Knee pain affects every aspect of life	Qualitative	Downgrade 2 levels *	Downgrade 1 level **	Very Low
Searching for the best way forward	Qualitative	Downgrade 2 levels *	Downgrade 1 level **	Very Low

\* Downgraded two levels due to across the included primary studies (None of the studies had a statement locating the researcher, no acknowledgement of their influence on the research. Most of the studies did not identify a research methodology).

\*\* Downgraded one level due to a mix of unequivocal and credible findings.

## 1 INTRODUCTION

2 Knee pain is estimated to affect 25% of the adult population on a frequent basis, with  
3 osteoarthritis being the most common cause in people over 50 [1]. This has placed  
4 increasing strain on all sectors of healthcare as people with knee pain present in  
5 ever increasing numbers. In the USA the number of total knee replacements  
6 performed increased by 134% between 1999 and 2008 costing over \$9 billion [2]. It  
7 has been estimated that, even prior to this increase in volume costs of caring for  
8 people with osteoarthritis, this accounted for 1- 2.5% of gross national product in the  
9 western world [3]. In addition to the financial costs, osteoarthritis has been shown to  
10 have a marked effect on Quality of Life (QoL), with QoL decreasing with increasing  
11 pain and decreasing physical function [4]. This is often related to reduced levels of  
12 mobility and ability to perform Activities of Daily Living [4].

13 Over the last 10 years there have been numerous high profile evidence-based  
14 programmes to manage knee pain more effectively [5]. Despite these efforts, and the  
15 increasing evidence base developing for many knee conditions (Osteoarthritis[6],  
16 Patellofemoral pain[7,8], Anterior cruciate rehabilitation[9]), there are patients who do  
17 not improve despite receiving the current best practice.

18 Evidence based practice as defined by Sackett [10], and refined by Howick [11],  
19 emphasises the importance of patients own beliefs and experiences in the  
20 application of evidence base. Awareness of this has led to improved care in low back  
21 pain. An increasing awareness of the psychosocial effects of the condition has  
22 helped to drive effective management of other musculoskeletal conditions [12,13].  
23 Approaches, such as stratification of patients based on psychological assessment  
24 [14], have shown improved management across both primary and secondary care

25 for people with low back pain [13,14]. There are tools in development exploring  
26 whether this approach can be replicated for other conditions [15]. The psychosocial  
27 aspect of care has yet to be fully explored in people living with knee pain. It may be  
28 that a greater awareness of the lived experience of knee pain may result in better  
29 treatment outcomes. In order to determine this, it is first necessary to identify  
30 people's experience and feelings of living with knee pain.

31 The aim of this paper was to explore the feelings and experiences of people living  
32 with knee pain as a precursor to exploring how this knowledge might contribute to  
33 improved care in the future.

#### 34 **METHODS**

35 As there was pre-existing literature the first step was to draw this together, to  
36 establish what is currently known about the topic. No existing systematic review was  
37 identified that had been completed or was underway. This study adopted systematic  
38 review methodology and, as the topic was about the lived experience, the research  
39 was essentially qualitative in nature so a meta-synthesis was undertaken using a  
40 contextualist approach. This approach acknowledges that multiple realities may be  
41 experienced, but it is still possible to identify a common underlying truth [16]. These  
42 realities are dependent on the context in which the person experiencing them is  
43 currently living and may change depending on their situation and experiences. A key  
44 aspect of this approach is an understanding of the researchers own background and  
45 biases. The primary author of the study is an experienced musculoskeletal  
46 physiotherapist who has experienced long-term knee problems. This creates a clear  
47 empathy with the participants in the various studies [16] The second author is a

48 health professional, with a long term interest in mental health, and so interested in  
49 psychosocial aspects of experiences.

50 The meta-synthesis was undertaken in three parts 1) a systematic search of the  
51 literature, 2) a critical appraisal of the relevant studies and 3) a meta-aggregation of  
52 the findings from the selected studies [17]. The findings of the study are reported in  
53 line with the ENTREQ guidelines [18].

54

## 55 **SEARCH STRATEGY**

56 In order to perform a comprehensive pre-planned literature search the SPIDER  
57 approach [19] was used to produce a number of search terms from the study  
58 question (Table 1). The search was limited to publications between January 2006  
59 and November 2016 and written in the English Language. The following databases  
60 were searched: CINAHL, AMED, Medline, Embase, PsycInfo and Web of Science.  
61 MeSH searches were also completed on CINAHL and Medline but these did not  
62 identify any additional papers. Citation searching of the selected studies identified no  
63 additional studies.

64 The searches identified a total of 358 papers. Once duplicates had been excluded,  
65 90 papers remained; their titles were examined to check for relevance. Papers were  
66 excluded if they did not clearly meet the criteria in the SPIDER (Table 1). The main  
67 reasons for exclusion were studies that focussed on patients' experiences, or  
68 perceptions, of surgery, of returning to sport, or attitudes to other aspects of care  
69 (medication, exercises, self-management). The number of relevant papers was 39  
70 (Figure 1). The abstracts were read in detail and a further 25 papers excluded as  
71 they did not meet the criteria set out in Table 1. The full text of the remaining papers



72 (n=14) were read and five further papers excluded as they focussed on attitudes  
73 towards surgery rather than the experience of living with knee pain. Nine papers met  
74 the full inclusion criteria and were deemed relevant for this study so were included in  
75 the review [20–28].

76

## 77 **QUALITY ASSESSMENT**

78 Each of the selected papers was reviewed independently by JW and KB using the  
79 Joanna Briggs Institute Qualitative Assessment and Review Instrument (QARI)  
80 checklist [17]; where disagreements occurred these were discussed. Recourse to a  
81 third reviewer was available but not needed. The appraisal scores are displayed in  
82 Table 2. It was agreed *a priori* that all papers would be included within the meta-  
83 synthesis. Quality assessment in qualitative research is a relatively new in  
84 healthcare [29], as such many older papers may fail to adhere to more recent  
85 guidelines. Since we are looking for the lived experience of people, this may be well  
86 presented despite methodological flaws. Overall the quality of the studies was poor,  
87 with none of the studies scoring yes for more than four out of the ten items on QARI.

88 The studies used a variety of qualitative methodologies to explore the experiences of  
89 people living with knee pain. Whilst all of these were appropriate there was a lack of  
90 clear definition regarding the research methodology in most of the studies (the  
91 exception being the two papers by Mackay et al [24,25]). The lack of a clear  
92 theoretical standpoint creates difficulties when trying to interpret the findings of these  
93 studies [30]. The methods of data collection also varied. Most of the included studies  
94 used interviews, as would be expected to learn about the lived experience, but a  
95 survey, diaries and focus groups were also used (Table 4). The methods of data

96 analysis varied across the studies with narrative analysis [22,23,28], content analysis  
97 [24–26] and grounded theory [27] all being used. Particular concerns were raised  
98 over the recruitment strategies of a number of studies this is because participants  
99 were recruited from orthopaedic clinics whilst awaiting surgical procedures  
100 [21,26,27]; participants may have felt obliged to participate.

### 101 **Meta-Aggregation Process**

102 In order to gain a true reflection of the researchers findings across the included  
103 studies a meta-aggregation process was used [17]. This approach seeks to reduce  
104 the subjective nature of thematic synthesis, since all themes identified must be  
105 clearly supported by the original text [31]. This approach aims to provide common or  
106 “universal” findings which can then be used to guide policy and decision making [31].  
107 This approach also seeks to reduce any biases which exist within the researchers.  
108 Each of the papers was initially reviewed and themes extracted from the findings (or  
109 results) section of each study by JW. Each theme was reported and supported  
110 (where able) with a reference from the original text. Themes were then classified as  
111 Unequivocal, Credible or Unsupported [17,31]. These were then reviewed by the  
112 second author (KB) and discussed to identify categories which were supported by at  
113 least two sources. This provided the basis for creating synthesised findings from  
114 across the different studies (Table 3).

### 115 **Synthesis of Findings**

116 The included studies primarily focussed on the experiences of living with knee  
117 osteoarthritis; one paper explored the long-term experience of living with Anterior  
118 Cruciate Reconstruction [20] and two others looked at self-reported knee pain  
119 [24,25]. The majority of the studies concerned themselves with people in the older

120 age range, which is expected with osteoarthritis, however three papers did engage  
121 with younger participants [20,24,25]. The studies were multinational in origin, with  
122 studies from the UK (n=3) [22,23,28], Canada (n=3) [24,25,27], Australia [20],  
123 Sweden [21], and Taiwan [26]. The characteristics of the studies are shown in Table  
124 4; it is noted that the studies by MacKay et al [24,25] and Ong & Jinks [22,23,28]  
125 used the same data sets for each of the studies with a different emphasis in the  
126 analysis of each study.

### 127 **Thematic Synthesis**

128 The initial meta-aggregation process identified 55 findings across the nine papers. Of  
129 these findings 33 were considered to be unequivocal, 15 credible and seven  
130 unsupported. These findings were aggregated into ten categories, which produced  
131 two synthesised findings. The two synthesised findings were knee pain affects every  
132 aspect of life, and the search for the best way forward (Figure 2). The two  
133 synthesised findings were then assessed using the CONQUAL system [32] and were  
134 rated of very low quality.

### 135 **Knee Pain Affects Every Aspect of Life**

136 Seven categories—emotional distress, change in relationships, lack of trust,  
137 increased awareness, coping strategies, loss of physical ability, regret and  
138 reflections—indicated that knee pain affects every aspect of life (Table 3). This  
139 finding is synthesised as: ‘Knee pain redefines what people are able to do, who they  
140 do it with and how they do it. Pain, fear and anxiety about the knees’ ability to  
141 function leads to reduced and/or adapted activity, and contemplation about lost  
142 ability and the emotional distress this can cause.’

143 In terms of what people are able to do participants reported their emotional distress  
144 as a feeling of depression, the loss of joy gained, and anger felt, at not being able to  
145 do things, and the overwhelming concern over what may happen in the future.

146 Equally the impact of who they can do things with was captured in the category  
147 change in relationships, which identified the loss of social relationships due to knee  
148 pain stopping their normal activities; some reported that this led to social isolation  
149 and changes in their friends to those they felt better understood their condition.

150 The category coping strategies captured how they were able to do things. People  
151 reported difficulties in finding ways to manage their knee pain; this included  
152 discussions on returning to sport or finding alternative options to this. They also  
153 discussed the length of time it took to adapt to this new reality and the role  
154 medication played in this.

155 The pain, fear and anxiety felt by many respondents was identified across two  
156 categories: lack of trust in the knee and an increased awareness of the knee. The  
157 lack of trust led to the need to moderate activities and situations because  
158 participants did not feel their knee could be trusted not to fail on them. The increased  
159 awareness was reported as a feeling of wariness related to its ability to function  
160 correctly. This led to the reduced and adapted activity which was often identified as a  
161 loss of physical ability. Many reflected on the loss of function and their need to rely  
162 upon others to help with tasks which had once been simple. They also identified that  
163 many tasks were now considered impossible or needed to be adapted to continue.

164 The reflection of, and contemplation on, these changes was summarised in the final  
165 category: regret and reflections. People identified how their knee pain changed how  
166 they viewed themselves and their self-image, they reflected on how choices made in

167 earlier life may have influenced their pain and what they might have done differently  
168 given the chance

### 169 **Searching for the Best Way Forward**

170 Four categories—gaining knowledge from friends, gaining knowledge from  
171 professionals, causes of knee pain, and pain and its' management—identified that  
172 many participants spent time searching for the best way forward (Table 3). This  
173 finding was synthesised as: 'People use a variety of traditional and non-traditional  
174 sources to find out about their pain and how to manage it. But often rely on their own  
175 judgement and knowledge to decide what is best for them'.

176 In terms of the traditional sources of knowledge people reported gaining knowledge  
177 from a variety of healthcare professionals, primarily this involved doctors and  
178 pharmacists. However a number identified their reluctance to access professional  
179 advice as they did not feel there was anything which could be done. As a result  
180 many turned to non-traditional sources of information with many seeking knowledge  
181 and management strategies from friends and acquaintances as well as the internet  
182 and written sources.

183 Many also sought to understand the causes of their knee pain with a wide variety of  
184 reasons identified such as overuse, injuries, diet and genetic makeup. They also  
185 sought information about pain and its' management. People discussed how they  
186 tried to manage their knee pain, what they felt affected it and how they were  
187 constantly looking for better ways to manage their pain. Some also discussed their  
188 reluctance to take traditional pain relief or to follow advice from professionals.

### 189 **Discussion**

190 To the best of our knowledge, based on extensive searching and consulting experts  
191 in the field, this is the first review to bring together the existing qualitative literature  
192 that explores the experience of living with knee pain. The critical appraisal in the  
193 quality assessment identified considerable limitations within the methodological  
194 rigour of the studies; this is reinforced by the very low CONQUAL scores. The poor  
195 methodological quality of these studies highlighted the need for quality evidence in  
196 this area.

### 197 **Living with Knee Pain**

198 This review has clearly identified the considerable effects knee pain has on every  
199 aspect of peoples' lives. This did not seem to vary according to the age of the  
200 participants; all groups reported disruption to all aspects of their life. Whilst some  
201 participants accepted this as a part of normal aging, many struggled to accept this  
202 change in their lifestyle. The disconnect between the societal expectations of  
203 remaining active as you enter advanced years was difficult for many participants to  
204 reconcile with the reality they were experiencing. This change in self-awareness  
205 whilst peers continued on 'a normal path' has been shown to have further negative  
206 impacts on self-perception [33]; several participants reported feeling isolated from  
207 previous friendship groups due to changes in their physical ability. In other  
208 conditions, i.e. Chronic Obstructive Pulmonary Disease, decreased physical activity  
209 has been shown to be progressive and associated with increased disease severity  
210 [34]. If this phenomenon is observed with knee pain, the reduction in social  
211 interaction with peers could have dramatic effect on overall health and wellbeing  
212 [35], and, combined with the emotional and physical impacts reported by the  
213 participants, presents a bleak picture of life living with knee pain.

## 214 **Searching for the Best Way Forward**

215 A common thread throughout most of the studies was the participants' search for  
216 information about their condition. This included information about causes, disease  
217 progression, treatment and self-management. Many preferred to seek information  
218 from friends, family and online resources. Whilst this is a growing trend [36], many  
219 participants still turned to professionals for a confirmatory diagnosis or when  
220 symptoms became unbearable. This pattern is reported across all of the studies and  
221 does not seem to be dependent on context from the perspective of geographical  
222 location or healthcare system. A concerning observation was the view that the only  
223 option that could be offered was that of surgery, with no worthwhile treatment options  
224 available. This contradicts the current evidence base for knee osteoarthritis.  
225 Physiotherapy has been shown to be effective in terms of cost, pain relief and quality  
226 of life improvements [6]. The ESCAPE-pain programme in the UK has pioneered the  
227 use of combined education and exercise in the management of knee osteoarthritis  
228 [5]; this approach has shown excellent results both clinically and in patients'  
229 understanding of their condition [37]. Whilst this approach is now firmly embedded in  
230 physiotherapy practice, there is a suggestion that the key role of exercise and  
231 education is still not universal among primary care providers [38]. As primary care is  
232 generally the first point of contact for people with knee pain this may suggest a  
233 widespread lack of patient education provided throughout primary care irrespective  
234 of location.

## 235 **Implications for research**

236 In terms of future research, methodological rigour is an important consideration. The  
237 studies in this study scored poorly on the QARI scoring. There were particular

238 concerns over the methodological rigour and theoretical underpinnings of the  
239 studies. Although most of the included studies used a variety of data collection  
240 methods were used. This, combined, with the lack of methodological rigour show the  
241 nascent state of qualitative research in physiotherapy. This emphasises the  
242 importance of all researchers undertaking qualitative research documenting the  
243 theory underpinning and methodology used in their study. This would increase the  
244 transferability and credibility of the studies. Future research studies should focus on  
245 whether psychosocial interventions improve outcomes, and what constitutes  
246 effective information provision, for people with knee pain.

#### 247 **Limitations**

248 Whilst the meta-aggregation process ensured the researchers' assumptions did not  
249 influence the analysis it may have led to some unique findings being lost as they  
250 were only identified in a single instance. The findings may not be generalisable to all  
251 types of knee pain and age ranges due to the predominance of osteoarthritis within  
252 the studies. Only English language studies were included which may have limited the  
253 transferability of the results.

254

#### 255 **Conclusion**

256 People living with knee pain often struggle to adapt to the new reality of their  
257 condition. They report a variety of ways in which they do, or do not, cope with this  
258 new aspect of their life. Many also report a difficulty fully understanding their new  
259 reality and a lack of clear and concise information available to help with this.

#### 260 **Acknowledgements**



261 None.

262 **Ethical Approval**

263 Ethical approval was not sought for this study because it is secondary research.

264 **Funding**

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266 commercial, or not-for-profit sectors. JW is funded by the NIHR as part of the NIHR  
267 Clinical Academic Pathway.

268 **Conflicts of Interest**

269 None.

270 **Systematic review registration number:** CRD42017070227

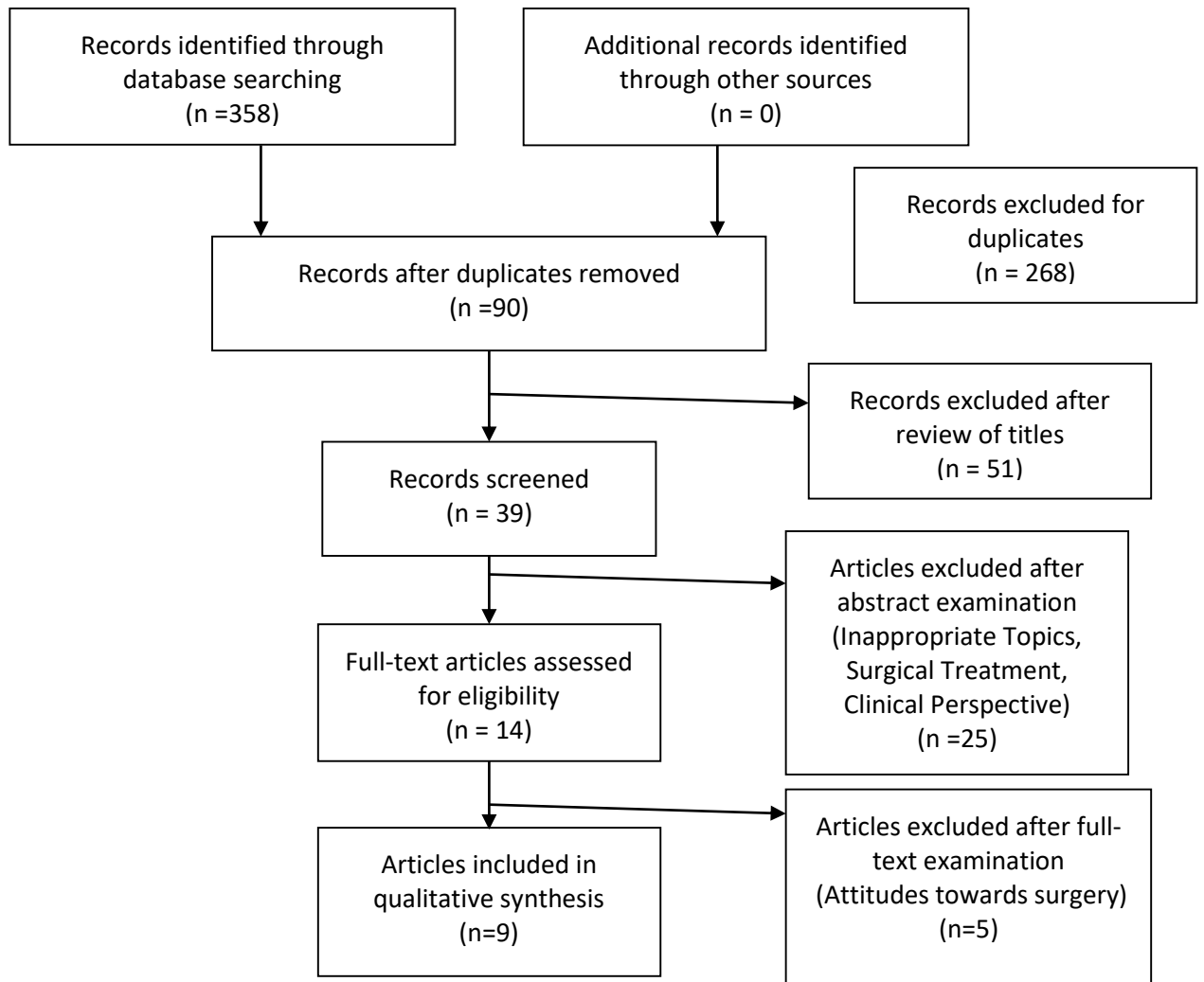
271

272 *Table 1: SPIDER outlining search terms and inclusion criteria*

S (Sample)	PI (Phenomenon of Interest)	D (Design)	E (Evaluation)	R (Research type)
Knee Pain	Experience	Interview		Qualitative
Anterior cruciate	Feeling	Focus group		
ACL	Perception			
Patellofemoral	Response			
Tibiofemoral				

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277

278 *Figure 1: PRISMA[39] flow chart of Review process.*

280 Table 2: Summary of QARI scoring (Y= Yes, N = No, U = Unclear) for included studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total Score
Fibay et al (2016) [20]	N	N	N	U	U	N	Y	Y	Y	Y	4/10
Hall et al (2008) [27]	N	N	N	N	N	N	N	Y	Y	N	2/10
Nyvang et al (2016) [21]	N	N	N	N	U	N	N	Y	Y	Y	3/10
Kao & Tsai (2012) [26]	N	N	N	N	N	N	N	Y	Y	Y	3/10
Jinks et al (2007) [22]	N	N	U	U	U	N	N	Y	Y	U	2/10
Mackay et al (2016) [24]	Y	Y	N	Y	U	N	N	U	Y	Y	5/10
Mackay et al (2014) [25]	Y	Y	N	Y	U	N	N	U	Y	Y	5/10
Ong et al (2011) [23]	N	N	N	N	N	N	N	Y	Y	U	2/10
Ong & Jinks (2006) [28]	U	N	N	N	N	N	N	N	Y	N	1/10
Question Total	20%	20%	0%	20%	0%	0%	10%	60%	100%	50%	

Q1 = Is there congruity between the stated philosophical perspective and the research methodology?; Q2 = Is there congruity between the research methodology and the research question or objectives?; Q3 = Is there congruity between the research methodology and the methods used to collect data?; Q4 = Is there congruity between the research methodology and the representation and analysis of data?; Q5 = Is there congruity between the research methodology and the interpretation of results?; Q6 = Is there a statement locating the researcher culturally or theoretically?; Q7 = Is the influence of the researcher on the research, and vice-versa, addressed?; Q8 = Are participants, and their voices, adequately represented?; Q9 = Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?; Q10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Table 3: Synthesised findings from the included studies

Synthesised Findings	Categories	Author	Finding	Supporting quote	Page No:	Plausibility
<p><b>Knee pain affects every aspect of life.</b> It redefines what people are able to do, who they do it with and how they do it. Pain, fear and anxiety about the knees ability to function leads to reduced and/or adapted activity,</p>	Emotional Distress	Hall et al (2008)	Emotional well-being	Depressed. Depressed. Very depressed. I mean, there have been times when I've sat down and had a good cry"	175	Unequivocal
		Nyvang (2016)	Change from their earlier lives - Emotional distress	The pain takes away the joy of doing things. Because you don't get done what you imagined because it hurts too much, and then, (it) takes over and I get angry, and that doesn't help	4	Unequivocal
		MacKay (2014)	Emotional disruption	I got quite depressed. Suddenly I was overwhelmed with this feeling of I'm only 60- whatever-I-was at the time. We're very long-lived in my family, oh my god, is this the beginning of the next 30 years? (Jean, age 65, focus group 1)	5	Unequivocal

and contemplation about lost ability and the emotional distress this can cause.	Change in relationships	Hall et al (2008)	Leisure/social activities.	Because of the loss of leisure activity, the participants reported a loss in social contact that had accompanied the activity (Orbell et al, 1998). “It wasn’t so much the dancing, it was a real social experience... so, I kind of miss that	175	Unequivocal
		MacKay (2014)	Social disruption	“I have a couple of girlfriends, who were walking regularly, and then I really hurt my knee bad and then I couldn’t join them. I am socially isolated because of it”	4	Unequivocal
		MacKay (2016)	Experience with symptoms	their symptoms made them feel older was through shifts in their social relationships. Some participants conveyed that they related more to older individuals with health problems. For example, one participant said, “I’ve had a couple of really good friends that have been there for me. And, I mean, they’re older people, so they have	345	credible

				their own health issues, so they understand a bit better		
Lack of trust in Knee	Filbay et al (2016)	Fear of re-injury: Fear avoidance	At the moment, pretty much, nothing. I'm always a bit cagey still. I'm always, it's always in the back of my mind, watch your knee, watch your knee.	108	Unequivocal	
	MacKay (2014)	Lack of trust in knee	"I have that feeling too. If I was coming home and it was dark and somebody was following me down the street, could I peel out of here...? Could I trust my knees to do that?"	7	Unequivocal	
Increased Awareness	Filbay et al (2016)	Fear of re-injury: Fear avoidance	At the moment, pretty much, nothing. I'm always a bit cagey still. I'm always, it's always in the back of my mind, watch your knee, watch your knee.	108	Unequivocal	

		MacKay (2014)	A new awareness	Some participants reported that their knee seemed to always be on their mind. One woman recounted: "It's just that I am constantly aware, thinking twice with very activity... Everything now has now a new think to it"	7	Unequivocal
	Coping strategies	Filbay et al (2016)	Physical activity preferences - strong preference for participation in competitive sports	I do love netball. I hate the gym. Absolutely hate it. It makes it pretty hard when you can't play the sports that you love, which I don't consider to really be exercise, and you've got to find alternatives to exercise which I can't stand	105	Unequivocal



		Filbay et al (2016)	Physical activity preferences - preferred, enjoyed or were satisfied taking part in noncompetitive recreational exercise	Oh look I probably could have played, but to me that was a fairly major injury that had me off for a long time from doing exercise, and the exercise that I like doing (recreational exercise), and I said I didn't want to risk doing it a second time.	105	Unequivocal
		Filbay et al (2016)	Early adaptation	I was quite happy to give up netball and touch football because I just was not going to go through that again and didn't want to do it again, and switched to cycling and running.	107	Unequivocal

		Filbay et al (2016)	Delayed adaptation	I was about 90 kilos, I was very, very overweight, and like I'm 53 kg now. I just started exercising again, and eating well. Since I lost weight, my knee has never locked again. I just decided one day that that was enough and I just started exercising. I've gone from what I feel like 10% quality of life, to 100% quality of life, for me, being active is everything.	107	credible
		Nyvang (2016)	Coping with knee problems - Alleviating pain	No, I don't think it's any fun if I'm going out to play golf and I have to take painkillers and you don't have a proper focus either. No, that's also why I want to get rid of the painkillers. I don't take many pills, I only do it when nothing else works anymore	5	credible
Loss of physical ability		Hall et al (2008)	Loss of functional mobility and	"I'm lucky to have a husband, you know, who's mostly retired. He can help with beds and all those kinds of things...he does a lot more of the shopping and, of course, this all comes with the	174	Unequivocal

			the need for assistance	retirement too ... he drives me to the hairdresser sometimes and so on.” (F 80)		
		Nyvang (2016)	Change from their earlier lives - Struggling through everyday life.	You always have to plan what you do now, I never had to do that before. If I wanted to go biking, wanted to go skiing, or wanted to do something else, I could do it whenever I wanted to, but I can't do that now.	4	credible
		Nyvang (2016)	Coping with knee problems - Physical coping strategies.	I can't take long walks when I'm out walking, for example, because then I know that I will get pain, and especially if I walk in town where there's asphalt. That also affects (the knee), and it depends on what type of shoes I have on. Strangely enough, it's easier to walk in the woods, even though it's uneven, but it's soft. Otherwise, I	5	credible

				can't dance and sometimes I have to take the elevator instead of stairs.		
		MacKay (2014)	Physical disruption	"I ran almost seven days a week for a good ten years, pretty much 5k a day every day. And there's nothing more in the world that I like more than doing that... And to have it cut off like that..."	4	Unequivocal
	Regret and reflections	MacKay (2014)	Altered sense of self	Men, in particular, recounted that they once felt 'strong' and 'capable', but knee symptoms made them feel less capable. For instance, Peter (age 57, focus group 1) stated: "All of sudden you start thinking, I can't do this anymore, and you extrapolate from the physical to the other things... You start to think that ... you're not as good as you used to be	6	Unequivocal

		MacKay (2016)	Prevention of symptoms	"What should I have done done different? I think I would have stopped jogging. I would have gone more on a bike...It was nice at that time, but there is payback"	345	Unequivocal
		Filbay et al (2016)	negative knee-related lifestyle modifications	You know, I'm disappointed that I didn't go back, and I'm disappointed that I swapped the lifestyle instead of keeping up with the sporting lifestyle. I went to a social lifestyle, and started putting the weight on, because now I'm at the stage where I've got too much weight. I've got worse knee issues. I'm not helping it by being overweight. It certainly made me change my lifestyle.	106	Unequivocal
<b>Searching for the best way forward.</b> People use a variety of traditional and	Gaining knowledge from friends	Hall et al (2008)	Lay sources of knowledge: Acquaintances and friends.	<i>"My friend's mother has had it done, and...yes, she can do everything she used to do, she has no pain, and, no, she doesn't have a limp. And she doesn't have to walk with a stick either. She had hers just over a year, eighteen months about. So</i>	176	Unequivocal

non-traditional sources to find out about their pain and how to manage it. But often rely on their own judgement and knowledge to decide what is best for them.				<i>it's very helpful to talk to somebody who's had it done." (F 63)</i>		
		Kao and Tsai (2012)	Acquisition of strategies - Opinions of neighbours, relatives, and friends	Actually, before I visited the doctor, my friends and relatives told me that elders had to maintain bone health. So they ate "Viartril-s" (a kind of glucosamine hydrochloride) to maintain their own bone health. I thought that everybody took it so I bought it. I wanted to maintain my own bone health.	1831	Unequivocal
		Kao and Tsai (2012)	<i>Acquisition of strategies - Illness information</i>	I looked for a lot of information. Seven years ago, we did not have the Internet, I bought some books to read and learned how to protect my joints.	1831	Unequivocal
	Gaining knowledge from professionals	Hall et al (2008)	Sources of knowledge: Physicians.	Part: "I just know that they take out my knee and put in the metal Teflon replacement." Int: "Is that the information that [DOCTOR] gave you?"	176	credible

				<p>Part: "Well, he showed me the actual joint."  Int: "The actual joint? Okay. And did he go through sort of the process of how it's going to be?"  Part: "No."</p>		
		Kao and Tsai (2012)	<p><i>Acquisition of strategies - Advice of primary care providers</i></p>	<p>I asked the pharmacist, and he proposed that I must eat food that is good for my cartilage. If I was in pain, I went to the clinic near my home to get an injection. The clinical doctor said that the fascia was inflamed. Sometimes he prescribed the antibiotic and analgesic medicine that reduced the pain</p>	1831	Unequivocal
		Kao and Tsai (2012)	<p><i>Search for confirmative diagnosis - Confirming diagnosis at</i></p>	<p>when I couldn't bear the pain any longer, my family members told me to go see a doctor. I visited the doctor in the neighboring public health center. The director explained to me that this condition starts at a time earlier than old age. You</p>	1832	credible

			<i>orthopedic clinics</i>	must go to the hospital to have the diagnosis confirmed. Then I registered as an orthopedic outpatient at a hospital. Only then did I know, after an X-ray examination, that this is degenerative arthritis.		
		Jinks et al (2007)	<i>Health care use</i>	"I haven't been to the doctors about it because I can't see any point, they can't operate and all they'll say is we'll give you ...I mean, we've got some fine doctors, so no, there's a limit to what they can do. Well, I mean, ...I don't even go to the hospital now. I mean, it's just, ...I take it that there's nothing you can do about it. I ...all I go to see him is ...well, I don't really go for anything bar my ... six monthly check-up. No, I never say anything. As I say, there's not a lot of point. All he could do is give me another painkiller and that's it	6	Unequivocal



	Causes of knee pain	Kao and Tsai (2012)	<i>Causes - Excessive knee joint loading</i>	I worked in the service industry and at a hotel counter, I often climbed up and down stairs and walked back and forth. Sometimes I had to stand for a long time. Therefore the knee could be very painful, I thought possibly that was what increased the knee pain now	1830	Unequivocal
		Kao and Tsai (2012)	<i>Causes - Injury or other disease</i>	I had high-level uric acid and gout for many years. Sometimes my feet hurt when I walked. So I supposed the causes of the knee discomfort were gout and high level uric acid that affected the knee joint	1830	Unequivocal
		Kao and Tsai (2012)	<i>Causes - Unhealthy dietary habits</i>	I drank latte coffee every day. It was black coffee, but I always added fresh milk. I thought that this small amount was okay. But this combination created the calcareous loss and the initiation of osteoporosis like this	1831	Unequivocal

		Kao and Tsai (2012)	<i>Causes - Family genetic disease</i>	many people in my family had rheumatitis, including my father. Many of these rheumatic people couldn't walk. I thought that my own symptoms looked very much like my father's rheumatitis and that my knee joint ache was caused by rheumatitis	1831	Unequivocal
		MacKay (2016)	Cause of symptoms	"What has happened is in some ways when you abuse or overuse it, there is a wear . . . in my case, I overused it more than a normal function which the body was supposed to do"	344	Unequivocal
	Pain and its management	Kao and Tsai (2012)	<i>Acquisition of strategies - Traditional medical help</i>	When I was uncomfortable I went to ask the traditional Chinese doctor for massage. If this region had pain he would massage it. He used his hands to massage the same lumbar vertebrae and both sides of the pelvis	1831	Unequivocal

		Jinks et al (2007)	<i>Medicine use</i>	<p>So she put me on a stronger Ibuprofen type of slow release which ...seems to help. She wanted me to have two a day, one in the morning and one at night, but I won't. I only have one in the morning. Sometimes I don't even have that cos like I say, I don't want to be stuck with tablets. I'm wary of side effects [...] You hear of the Ibuprofen type of thing can give you stomach bleed or anything. I don't want that, you know, or indigestions." (Shirley) The level of discussion with the GP or other health professionals about the pros and cons of taking NSAIDs did not appear to be high, and in the interviews people said that they tended to make their own decisions about dosage. This reflected findings from other studies that people try to take as little medication as possible.</p>	7	Unequivocal
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		Jinks (2007)	<i>Patterns and descriptions of need</i>	<p>Most people talked about knee pain in relation to specific activities such as being still in one position for some time, going up and down stairs or walking. The qualitative data, therefore, underpins the survey results. "I mean, if I sit too long, that doesn't help either. But the worst part is if I'm asleep and my legs are bent and I haven't woke up, the pain, I can't tell you what it is like. I can not move it...and what I do is I grip both hands round the knee and try to force my leg straight and I break out in a hot sweat. All I can say is that it is a bony pain. I could shout out with the pain."</p> <p>(Heather) The level of pain ranged from what was described above as discomfort, to severe pain that stopped people from undertaking many of their normal daily activities.</p>	4	Unequivocal
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		Jinks et al (2007)	<i>Self care and home remedies</i>	<i>Everything that comes on the telly, I say...Oh, I'll try those, I'll try one of those, you know see how it works. Nothing really cures it but it does ease the pain."</i>	8	credible
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Table 4: Study Characteristics

Authors Year of Publication	Aim	Methodology and Methods	Participants	Main themes and recommendations
Filbay et al [20]  2016	1)How do people with knee symptoms describe their quality of life and experiences 5 to 20 years after ACLR?  2) What factors affect quality of life in people with knee symptoms 5 to 20 years following ACLR?	Methodology:  Not Stated  Methods:  Semi-structured Interviews	<u>Number of Participants:</u>  17 (7 male, 10 female)  <u>Recruitment source:</u>  Previous cross-sectional study  <u>Sampling Method:</u>  Purposive  <u>Age:</u>  Mean = 36 (range 25-50)  <u>Country:</u>  Australia	<ul style="list-style-type: none"> <li>• Lifestyle Modification</li> <li>• Adaptation and acceptance</li> <li>• Fear of re-injury</li> </ul> <b>Recommendations:</b>  None
Hall et al [27]  2008	To examine individuals' experiences living with OA of the knee and what their expectations	Methodology:  Not Stated	<u>Number of Participants:</u>  15 (9 male, 6 female)	<ul style="list-style-type: none"> <li>• 'Breakpoint'</li> <li>• Seeking knowledge</li> <li>• Expectations / goals</li> </ul>

	are of arthroplasty and physiotherapy.	Methods: Semi-structured interviews	<u>Recruitment source:</u> Orthopaedic clinic  <u>Sampling Method:</u> Purposive/convenience  <u>Age:</u> Mean = 67 (range 52-80)  <u>Country:</u> Canada	<ul style="list-style-type: none"> <li>• Perceptions of post-operative physiotherapy</li> </ul> <p><b>Recommendations:</b></p> Post-operative education, use of local support groups to prevent social isolation, Implementation of preoperative exercise program.
Jinks et al [22] 2007	To examine knee pain and disability as reported by individuals participating in a population survey.	Methodology: Mixed-methods  Methods:	<u>Number of Participants:</u> 22 (for qualitative interviews), (12 males, 10 female)  10 diaries  <u>Recruitment source:</u>	<ul style="list-style-type: none"> <li>• Health care use</li> <li>• Medicine use</li> <li>• Selfcare and home remedies</li> </ul>

	To investigate subsequent health seeking-behaviour in order to understand the rationale behind peoples' decisions to seek or not seek health	Survey and Semi-structured interviews and diaries	GP database <u>Sampling Method:</u> Purposive sampling <u>Age:</u> Mean = 68 (range 53-85) <u>Country:</u> United Kingdom	<b>Recommendations:</b> None
Kao & Tsai [26] 2012	To explore the lived experiences of middle-aged adults with early knee OA in prediagnostic phase	<u>Methodology:</u> Not stated  <u>Methods:</u> Semi-structured interviews	<u>Number of Participants:</u> 17 (3 male, 14 female)  <u>Recruitment source:</u> Orthopaedic clinics  <u>Sampling Method:</u> Purposive  <u>Age:</u>	<ul style="list-style-type: none"> <li>• Awareness</li> <li>• Surmise of causes</li> <li>• Acquisition of strategies</li> <li>• Searching for confirmative diagnosis</li> </ul> <b>Recommendations:</b> Improved education for patients, including lifestyle, activity, and self-management activities.



			<p>Mean = 49.6 (range 43-55)</p> <p><u>Country:</u></p> <p>Taiwan</p>	
Mackay et al [25] 2014	To explore the perceived consequences of knee symptoms on the lives of people aged 35–65 years who had diagnosed osteoarthritis (OA) or OA-like symptoms.	<p>Methodology: Unclear</p> <p>Methods: Focus Groups and Interviews</p>	<p><u>Number of Participants:</u> 51 (20 male, 31 female)</p> <p><u>Recruitment source:</u> Advertisements in press and various locations.</p> <p><u>Sampling Method:</u> Purposive</p> <p><u>Age:</u> Median = 49 (range 37-65)</p>	<ul style="list-style-type: none"> <li>• Disrupted physical, social and emotional life</li> <li>• Altered way of thinking about body and self</li> </ul> <p><b>Recommendations:</b> Interventions are needed to help keep active. Greater awareness of emotional effects.</p>

			<u>Country:</u> Canada	
Mackay et al [24] 2016	To explore the meaning of knee symptoms to people ages 35–65 years, focusing on how people understood or perceived their knee symptoms.	Methodology: Constructivist grounded theory  Methods: Focus groups and Interviews	<u>Number of Participants:</u> 51 (20 male, 31 female)  <u>Recruitment source:</u> Advertisements in press and various locations.  <u>Sampling Method:</u> Purposive  <u>Age:</u> Median = 49 (range 37-65)  <u>Country:</u> Canada	<ul style="list-style-type: none"> <li>• Knee symptoms are preventable</li> <li>• Explanation of knee symptoms</li> <li>• Experience with symptoms</li> </ul> <b>Recommendations:</b> Research needed into preventative interventions.

<p>Nyvang et al [21] 2016</p>	<p>To describe patients' experiences of living with knee OA when scheduled for surgery and further their expectations for future life after surgery.</p>	<p>Methodology: Qualitative descriptive design</p> <p>Methods: Semi-structured interviews</p>	<p><u>Number of Participants:</u> 12 (5 males, 7 females)</p> <p><u>Recruitment source:</u> Awaiting knee arthroplasty</p> <p><u>Sampling Method:</u> Convenience</p> <p><u>Age:</u> Median = 65.7 (range 47-77)</p> <p><u>Country:</u> Sweden</p>	<ul style="list-style-type: none"> <li>• It's not just a knee, but a whole life</li> <li>• Change from earlier lives</li> <li>• Coping with knee problems</li> <li>• Ultimate decision to undergo surgery</li> </ul> <p><b>Recommendations:</b> Individualised approach to treatment and patients involved in decision making process.</p>
<p>Ong &amp; Jinks [28] 2006</p>	<p>To describe older people's everyday experience and context of living with knee pain and disability, and to explore the</p>	<p>Methodology: Not stated</p> <p>Methods: Diary analysis</p>	<p><u>Number of Participants:</u> 10</p> <p><u>Recruitment source:</u> Recruited from Jinks et al.</p> <p><u>Sampling Method:</u></p>	<ul style="list-style-type: none"> <li>• The cause of pain and its meaning</li> <li>• Knee pain in the context of co-morbidity</li> <li>• Consulting for knee pain</li> </ul>

	potential of open-format diaries in accessing these experiences.		Unclear <u>Age:</u> Not reported <u>Country:</u> United Kingdom	<b>Recommendations:</b> None
Ong et al [23] 2011	To explore the meaning and enactment of self-management in everyday life and the hard work associated with devising and maintaining routine adaptive strategies	Methodology: Not stated  Methods: Semi-structured interviews and diaries	<u>Number of Participants:</u> 22 (9 male, 13 female) <u>Recruitment source:</u> Participants in larger study <u>Sampling Method:</u> Unclear <u>Age:</u> Not reported (only age categories) <u>Country:</u> United Kingdom	<ul style="list-style-type: none"> <li>• Change and continuity: organic responses to the impact of pain</li> <li>• Reflection and evaluation: self-management as planning work</li> </ul> <b>Recommendations:</b> None

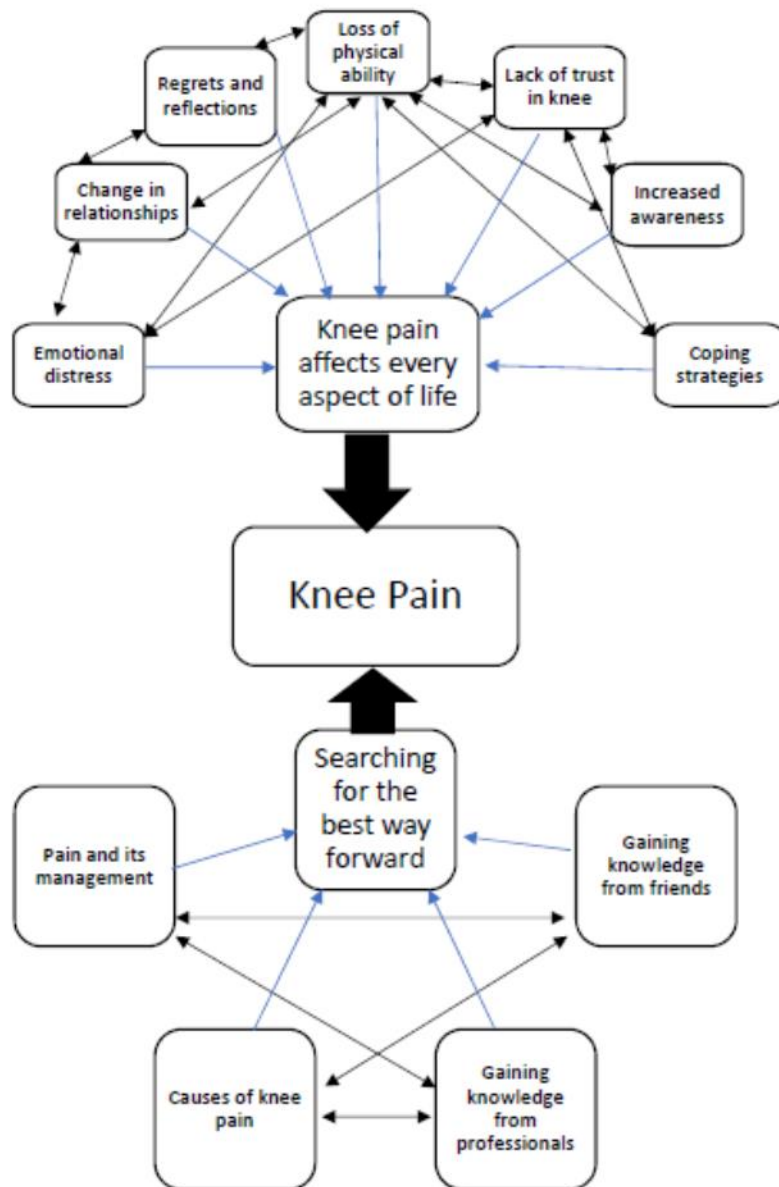


Figure 2: Mind-map showing interaction between categories: Bi-directional black lines show interaction between categories. Uni-directional lines show the development of synthesised findings

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