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The experience of living with knee osteoarthritis: A systematic review of qualitative studies

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Abstract

Objectives: Systematically review the qualitative literature on living with knee osteoarthritis from patient and carer perspectives.

Design: Systematic review of qualitative studies. Five electronic databases (CINAHL, Embase, Medline, Psychinfo, SPORTDiscus) were searched from inception until October 2018. Data were synthesised using thematic and content analysis.

Participants: Studies exploring the experiences of people living with knee osteoarthritis, and their carers were included. Studies exploring experiences of patients having participated in specific interventions, including surgery, or their attitudes about the decision to proceed to knee replacement were excluded.

Results: Twenty-six articles reporting data from 21 studies about the patient (n=665) and carer (n=28) experience of living with knee osteoarthritis were included. Seven themes emerged: (1) Perceived causes of knee osteoarthritis are multifactorial and lead to structural damage to the knee and deterioration over time (n=13 studies); (2) Pain and how to manage it predominates the lived experience (n=19 studies); (3) Knee osteoarthritis impacts activity and participation (n=16 studies); (4) Knee osteoarthritis has a social impact (n=10 studies); (5) Knee osteoarthritis has an emotional impact (n=13 studies); (6) Interactions with health professionals can be positive or negative (n=11 studies); (7) Knee osteoarthritis leads to life adjustments (n=14 studies). A single study reporting the perspectives of carers reported similar themes. Psychosocial impact of knee osteoarthritis emerged as a key factor in the lived experience of people with knee osteoarthritis.

Conclusions: This review highlights the value of considering patient attitudes and experiences including psychosocial factors when planning and implementing management options for people with knee osteoarthritis. Trial registration: PROSPERO registration number CRD42018108962

Strengths and limitations of this study

- The systematic review was reported consistent with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) and registered prospectively with PROSPERO (registration number CRD42018108962).
- A comprehensive search strategy of qualitative studies about patient and carer perceptions about their lived experience with knee osteoarthritis was conducted.
- Comprehensive data synthesis was applied using thematic and content analysis leading to results that went beyond the summary of the selected studies.
- The findings of this review are limited to the experience of living with knee osteoarthritis, and not the experience of receiving specific interventions, including surgery.
- Exclusion of non-English language articles limits the generalizability as other cultures with other languages might have different perceptions of knee osteoarthritis.

Introduction

The experience of living with chronic pain associated with knee osteoarthritis is multidimensional comprising biological dimensions such as subchondral bone pathology and inflammation(1), and psychological and social dimensions such as pain catastrophizing, depression, avoidance of activities and social support(2-4). The current management of knee osteoarthritis is focussed on pain management to address the biological impairment of joint pathology, through joint-specific exercises, pharmacology and in advanced stages, joint replacement surgery(5, 6). However, levels of pain and disability reported by people with osteoarthritis are poorly correlated with radiographic evidence of disease severity(7). Further, knee replacement surgery, although common, does not always have a successful outcome(1).

The role of psychological and social dimensions in the management of knee osteoarthritis has received relatively little attention, in comparison with management of joint pathology(2). However, the role of psychological and social factors in chronic musculoskeletal pain conditions other than knee osteoarthritis has been studied extensively(8). In chronic low back pain, for example, psychological and social factors have been shown to play a role in the persistence of pain, and interventions designed to target these factors can improve pain, disability and quality of life in this population(9). Targeting the psychological and social dimensions of knee osteoarthritis in addition to the biological dimensions may optimise outcomes. In order to design targeted interventions, we must first have an understanding of the psychological and social dimensions of knee osteoarthritis from the perspectives of people affected by it.

Qualitative research provides insight into the lived experience of health and how individuals' make sense of their health symptoms. Rather than relying on the a priori assumptions of researchers or clinicians, qualitative research prioritises the voice of the 'expert' participant, thus shedding light on aspects of the lived experience that cannot be reached by quantitative

approaches(10). Two recent systematic reviews have synthesised qualitative research related to knee pain, including people living with osteoarthritis(11, 12). Wride et al(12) explored the feelings and experiences of people living with knee pain from seven studies, three of which included people with non-osteoarthritic related knee pain. This review found many people with knee pain struggle to adapt to normal living, and that their negative experiences were exacerbated by a lack of knowledge and available information to help them plan for the future. In another review, Smith et al(11) explored the perceptions of people diagnosed with hip and/or knee osteoarthritis from 32 studies (18 of which sampled people with knee osteoarthritis only) to determine their attitudes and perceptions towards living with their musculoskeletal condition. Participants in these studies reported a number of factors that contributed to their negative attitude and perception about their hip and/or knee osteoarthritis, such as their understanding of the pathology of osteoarthritis, the activity limitations they experienced, and their perceptions of other people's beliefs towards their condition.

The two previous systematic reviews synthesising qualitative data have limitations as the they did not consider the experience of knee osteoarthritis separately to the experience of hip osteoarthritis (e.g. Smith et al(11)), despite empirical evidence that these are distinct conditions that impact people in different ways(13). In addition, neither review(11, 12) looked at the perspectives of carers. Those in the immediate social environment may exert an influence on how an individual copes with their condition. In the case of knee osteoarthritis, family members and significant others often adopt the role of carer. By investigating the perceptions and experiences of both patients and carers, health professionals can gain a greater understanding of the role of the psychological and social dimensions of the knee osteoarthritis experience, which may lead to improved management of people with knee osteoarthritis.

Therefore, the aim of this study was to systematically review the qualitative literature on the experience of living with knee osteoarthritis from the perspectives of patients and carers.

Methods and analysis

Design

A systematic review of qualitative studies was conducted. The review was reported consistent with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ),(14). We did not involve patients or public in our work. A review protocol was registered prospectively with PROSPERO registration number CRD42018108962 https://www.crd.york.ac.uk/PROSPERO.

Search strategy

Five electronic data bases (CINAHL, Embase, Medline, Psychinfo, SPORTDiscus) were searched from inception until October 2018. The search strategy comprised two key concepts: knee osteoarthritis and qualitative research. For each concept, key words and MeSH terms were combined using the 'OR' operator and the results were combined using the AND operator (Appendix). The search results were downloaded into bibliographic software (Endnote version 18). Two reviewers independently reviewed the titles and abstracts according to the selection criteria (Table 1). If eligibility was uncertain based on title and abstract, the full-text of the study was obtained. Reference lists of included articles were manually searched for additional relevant articles, and citation tracking of included articles was completed using Google Scholar.

Eligibility criteria

Studies reporting the experiences of people living with knee osteoarthritis, and their carers were included. Studies that explored experiences of participation in specific interventions for knee osteoarthritis, including perioperative management and attitudes about the decision to

proceed to total knee replacement were excluded (Table 1). Since the aim of our review was to explore the experience of living with knee osteoarthritis, with a focus on the psychological and social dimensions, it was decided not to include studies that explored perceptions about biological interventions including surgery.

Table 1: Selection criteria

	Inclusion criteria	Exclusion criteria
Design and report	• Qualitative studies • Reports lived experience of knee osteoarthritis • Full text article published in peer-reviewed journal • Primary research	• Questionnaires/surveys • Non-English language • Single case studies • Secondary analysis of qualitative data such as a systematic review
Participants	• Knee osteoarthritis • Perceptions of people diagnosed with knee osteoarthritis, and their carers • May include other conditions providing perceptions about knee osteoarthritis are reported separately	• Participants not identified as having knee osteoarthritis (e.g. knee pain, anterior cruciate ligament injury)
Interventions	• No intervention • May include studies exploring perceptions about management, such as knee replacement, provided experiences about living with knee osteoarthritis are reported separately	• Explored experiences of patients having participated in interventions • Explored experiences about perioperative management of knee replacement • Explored attitudes about the decision to proceed to total knee replacement

Appendix: Search strategy in Medline

Search
1. knee osteoarthritis mp or Osteoarthritis, Knee/
2. knee/
3. Knee joint/
4. (knee adj3 osteoarthritis).mp
5. qualitative research.mp or Qualitative Research/
6. qualitative analysis.mp
7. qualitative evaluation.mp
8. qualitative study.mp
9. 1 or 2 or 3 or 4
10. 5 or 6 or 7 or 8
11. 9 and 10

/ denotes MeSH term; mp denotes keyword

Data collection process

Data were extracted from each study on participant age, sex, disease severity and body mass index, where available. Data were also extracted on the study design including sample size, data collection method (e.g. interview or focus group), and qualitative framework informing the analysis.

Methodological quality of the included studies

The Critical Appraisal Skills Programme (CASP) checklist was applied independently by two reviewers to assess methodological quality of the included studies(15). Discrepancies between reviewers were discussed until consensus was reached. The CASP checklist includes 10 questions in 3 sections about the validity of the results (questions 1-6), ethical considerations, trustworthiness and clarity of results (questions 7-9), and the value of the results (question 10). Each question was answered as "yes", "no" or "can't tell", and the checklist provided decision rules and instructions on how to interpret checklist criteria. The CASP checklist has been used in other qualitative systematic reviews in musculoskeletal research(16, 17).

Data analysis

The text used to describe themes and sub-themes in the included articles were assigned descriptive codes using an inductive process. The identified codes were then organised into themes and sub-themes in a process of thematic analysis. Consistent with content analysis methods, the number of studies that identified each theme was counted. This was initially completed by one researcher (NS) after which the identified themes were checked independently by two other researchers (JW, NT).

Results

Study selection

The search strategy yielded 720 articles. After screening the titles and abstracts of these articles, 42 underwent full text review. Sixteen articles were excluded after full text review resulting in a final library of 26 articles (Figure 1). The most common reasons for exclusion were that articles were abstracts, and the results of knee osteoarthritis were not reported separately from osteoarthritis at other joints. The 26 included articles reported data from 21 studies (Table 2) on the experience of living with knee osteoarthritis from the perspectives of people themselves (n=20) or their carers (n=1).

Methodological quality of included studies

All studies had a clear rationale for using qualitative methods, used appropriate qualitative designs, and included explicit statements of findings that were considered high value. Two studies did not report approval from an ethics committee(18, 19) and four studies reported insufficient details about data analysis reducing the trustworthiness of the results(18-21). Only two of the 21 studies adequately reported the relationship between the researcher and the participant(22, 23). A pre-existing relationship between the participant and researcher increases the risk of social desirability(24), whereby there is the tendency of the participants to answer questions in a manner that will be viewed favourably by the researchers (Table 3).

Study participant characteristics

The 21 studies included 665 people with knee osteoarthritis (71% women; mean age 65 years, age range 25 to 87) and 28 carers of people with knee osteoarthritis (46% women; mean age 48 years) (Table 2). The studies were conducted in Asia (n=6), North America (n=6), Europe (n=8) and New Zealand (n=1) and 15 of the 21 studies were published since 2011. Participants' comorbidities as described in 6 studies included diabetes,

depression/anxiety, polyarthritis, hypertension, heart disease, haemophilia, silicosis, vascular problems, cancer, gout, osteoarthritis in other joints and multiple knee surgeries. Participants in 9 studies self-assessed their pain severity at the time of their participation as mild to severe(19, 21, 25-31), and participants in 4 studies had severe osteoarthritis and were awaiting total knee replacement(23, 32-34). Thirteen studies provided details on participant employment status; the majority of participants were retired or not working, except for 3 studies(22, 29, 35) in which the majority of participants were employed at the time of the study.

Table 2: Characteristics of included studies of experiences of living with knee osteoarthritis

Study	Country	Population	Demographics (N, age, sex, BMI)	Method: Framework/analysis	Sampling	Data collection	Research questions
Alami *et al.,* 2011	France	Knee osteoarthritis	N=81 71% women,	Descriptive -Inductive	Purposive	Individual interviews -semi-structured	Explore views of patients about management of knee osteoarthritis
Ahmad *et al.,* 2018	Malaysia	Knee osteoarthritis	N=12 Mean age 67 yrs 67% women	Thematic analysis	Purposive	Individual interviews -in-depth	Explore perspectives of patients with knee OA mainly about pain experiences, its impact, effects of physiotherapy and their personal expectation
Al-Taiar *et al.,* 2013	Kuwait	Severe knee osteoarthritis -Kuwaiti women waitlisted for total knee replacement	N=39 Mean age 62 yrs 100% women	Thematic analysis	Convenience	Focus groups	Explore the pain experience and mobility limitation as well as the patient' s decision making process to undertake total knee replacement among women with knee pain in the waiting list for surgery
Carmona-Teres *et al*., 2017	Spain	Knee osteoarthritis -symptomatic	N=10 Mean age 70 yrs, 70% women	Content thematic analysis based on Lazarus stress model categories	Theoretical	Individual interviews -semi-structured	Understand experiences, perceptions, cognitive evaluation, values, emotions, beliefs and coping strategies of people with knee osteoarthritis
Chan and Chan, 2011	Hong Kong	Knee osteoarthritis -mild to very severe	N=20 Mean age 57 yrs, 65% women	Grounded theory	Convenience	Individual interviews -semi-structured	Evaluate influence of different pain patterns on quality of life Investigate coping strategies
Clarke *et al.*, 2014 Pouli *et al.*, 2014	UK	Knee osteoarthritis -symptomatic	N=24 Mean age 62 yrs, 71% women	Descriptive thematic analysis	Purposive	Individual interviews -semi-structured	Explore participant's experience of living with knee osteoarthritis and their beliefs about knee osteoarthritis and its treatment
Darlow *et al.,* 2018	NZ	Knee osteoarthritis	N=13 Age range 50-84 54% women	Interpretative description	Purposive	Individual interviews -semi-structured	Explore the beliefs of people with knee osteoarthritis about the disease, how these beliefs had formed and what impact these beliefs had on activity participation, health behaviour and self-management

Figaro *et al.,* 2004	US	Knee osteoarthritis -not actively seeking total knee replacement	N=94 Mean age 71yrs 84% women	Content analysis Constant comparative methods	Purposive Network, convenience and snowball sampling to extend the sample	Structured field interviews	Explore older urban Blacks with knee osteoarthritis to determine their preferences and expectations of total knee replacement
Hall *et al.,* 2008	Canada	Unilateral knee osteoarthritis -scheduled for total knee replacement	N=15 Mean age 67 yrs 40% women	Grounded theory	Purposive	Individual interviews -semi-structured	Explore views of total knee replacement and the role of physiotherapy
Hendry *et al.,* 2006	UK	Knee osteoarthritis -mild to severe symptoms	N=22 Age range 52-86 yrs 73% women	Conceptual Framework	Convenience	Individual interviews Focus Groups (N=6)	Explore the views of primary care patients with knee osteoarthritis towards exercise, and explore factors that determine acceptability and motivation to exercise, and barriers that limit its use
Hsu *et al.*, 2015	Taiwan	Family carers of people with knee osteoarthritis	N=28 Mean age 48 yrs, 46% women	Descriptive content analysis	Convenience	Individual interviews -semi-structured	Explore primary caregivers' perceptions of their older relatives' knee osteoarthritis pain and management
Keysor *et al.*, 1998	USA	Knee osteoarthritis -presence of functional limitations	N=4 Age range 25-43 yrs, 75% women	Van Kaam method of phenomenologic data analysis	Purposive	Individual interviews -semi structured (each participant interviewed twice)	Understand the experience of living with osteoarthritis as young and middle-aged adults
Kao and Tsai, 2012, 2013	Taiwan	Knee osteoarthritis -symptomatic	N=17 Mean age 50 yrs, 82% women	Constant comparison	Purposive	Individual interviews -semi structured	Understand the living and illness experiences of middle-aged adults with early knee osteoarthritis
MacKay *et al.*, 2016, 2014a, 2014b	Canada	Knee osteoarthritis -moderately symptomatic	N=51 Median age 49 yrs, 61% women	Constructivist grounded Theory/ constant comparative method	Purposive	Focus groups Individual interviews -semi-structured	Explore the meaning and perceived consequences of knee symptoms

Maly and Krupa, 2007	Canada	Knee osteoarthritis	N=3 Age range 62-87 yrs, 67% women	Descriptive phenomenology	Convenience	Individual interviews -semi structured	Understand the experience of living with knee osteoarthritis in older adults
Man *et al.*,2017	US	Knee osteoarthritis -waitlisted for total knee replacement	N=8 Age range 46-80 yrs 50% women	Thematic analysis	Purposive	Individual interviews -semi-structured	Explore the meaning and importance of occupational changes experienced by individuals during the pre- total knee replacement period
Morden *et al.* 2011, Ong *et al.* 2011	UK	Knee osteoarthritis -moderate to severe	N=22 Age range 50-75+ yrs, 59% women	Constant comparison	Purposive	Individual interviews -in-depth Diaries	Explore the meaning and enactment of self-management in everyday life
Nyvang *et al.,* 2016	Sweden	Knee osteoarthritis -scheduled for total knee replacement	N=12 Mean age 66 yrs 58% women	Thematic analysis	Purposive	Individual interviews -semi-structured	Explore patients' experiences of living with knee osteoarthritis when scheduled for total knee replacement and further their expectations for future life after surgery.
Tallon *et al.,* 2000	UK	Knee osteoarthritis -mild to moderate	N=7	Content analysis	Convenience	Focus group	Explore perception of treatment preferences
Victor *et al.,* 2004	UK	Knee osteoarthritis	N=170 Mean age 63 yrs, 73% women	Content analysis	Convenience	Individual interviews Group discussion Diaries	Explore meaning of osteoarthritis for those receiving health promotion
Xie *et al.*, 2006	Singapore	Knee osteoarthritis -symptomatic	N=41 Mean age 64 yrs, 66% women	Grounded theory/ Content analysis	Purposive	Focus groups	Determine health-related quality of life domains affected by knee osteoarthritis. and identify ethnic variations in the importance of these domains

Yrs = Years

Table 3: Critical Appraisal Skills Programme (CASP) assessment

Study name	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3.Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participant been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Alami *et al.,* 2011	Y	Y	Y	Y	N	N	Y	Y	Y	Y
Ahmed *et al.,* 2018	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Al-Taiar *et al.,* 2013	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Carmona-Teres *et al.,* 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Chan and Chan., 2011	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Clarke *et al.*, 2014 and Pouli *et al.,* 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Darlow *et al.,* 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Figaro *et al.,* 2004	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hall *et al.,* 2008	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Hendry *et al.,* 2006	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hsu *et al.,* 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Kao *et al.,* 2012, 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Keysor *et al.,* 1998	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mackay *et al.,* 2016, 2014a. 2014b	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Maly and Krupa, 2007	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Man *et al.*,2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Morden et al. 2011, Ong et al. 2011	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Nyvang et al. 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Tallon et al. 2000	Y	Y	Y	N	Y	N	N	N	Y	Y
Victor et al. 2004	Y	Y	Y	Y	Y	N	N	N	Y	Y
Xie et al. 2006	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Y = yes, N = no

Major themes reported by included studies

Seven major themes emerged from the data: (1) The perceived causes of knee osteoarthritis are multifactorial and lead to structural damage to the knee and deterioration over time; (2) Pain and how to manage it predominates the lived experience; (3) Knee osteoarthritis impacts activity and participation; (4) Knee osteoarthritis has a social impact; (5) Knee osteoarthritis has an emotional impact; (6) Interactions with health professionals can be positive or negative; and (7) Knee osteoarthritis leads to life adjustments.

(1) The perceived causes of knee osteoarthritis are multifactorial and lead to structural damage to the knee and deterioration over time

Thirteen studies reported what participants perceived the causes of knee osteoarthritis were(18-22, 26-29, 31, 32, 36, 37). Perceived cause of knee osteoarthritis included internal factors (such as being overweight, family history of osteoarthritis, ageing, working in occupations requiring heavy manual work such as extensive kneeling or lifting, past sporting activities, and menopause); and external factors (such as trauma and the weather). Participants perceived knee osteoarthritis as preventable or partially attributable to actions or incidents that were modifiable (e.g. pushing too far or knee injury) had they changed their behaviour earlier in life. Participants in 4 studies expressed strong beliefs and concerns about their knee osteoarthritis being caused by structural deterioration(19, 22, 27, 28) using language such as ‘bone on bone’ with the joint worn away by movement. Carers of people with knee osteoarthritis attributed the cause of their relative’s knee osteoarthritis to ageing, working too hard or to unknown causes (36).

The prognosis of knee osteoarthritis was discussed by participants in 6 studies(20, 22, 26-29). Participants believed their symptoms would get worse over time as knee osteoarthritis was ‘a progressive degenerative disease’ and could not be ‘cured’. However, participants in one

study(29) also felt they could halt or slow the progression of their symptoms through diet and exercise.

(2) Pain and how to manage it predominates the lived experience

The participants' experience of pain and its management emerged as a theme in 19 studies(19-23, 25-27, 29-39). Pain was described by participants as the predominant 'omnipresent' feature of knee osteoarthritis. Pain was perceived to interrupt and deter daily activities such as walking, to make people less confident in their bodies, and to slow people down. Participants in one study described two distinct patterns of pain: 'mechanical' pain described as 'sharp' pain related to discrete movements or activities, and 'inflammatory' pain described as a 'burning' pain which was more unpredictable and associated with the weather or prolonged activity(21). Pain was perceived as insurmountable when there was no foreseeable end to it and made some participants feel 'old'. Carers reported their relatives with knee osteoarthritis rarely mentioned pain until they needed help(36). Participants reported managing their pain with medication but that this was not always a satisfactory strategy due to feelings of dependence, undesirable side-effects, and only partial relief from symptoms. Other pain management strategies described were activity-related (including exercise, avoidance of certain activities, brief rest, pacing, and physiotherapy), psychological-related (having a positive life philosophy, humour, continuing to engage in pleasurable activities), passive treatment modalities (including ice, heat, massage, Chinese traditional medicine) and weight loss. Some believed joint replacement was inevitable and the only real solution for their pain(19, 22). Similarly, carers of relatives with knee osteoarthritis believed the most promising method to reduce pain was a knee replacement, and often persuaded their relatives to see a doctor about having surgery(36). In contrast, participants from one study preferred a natural solution only as they had a negative perception of surgery and saw it as a last resort(37).

(3) Knee osteoarthritis impacts activity and participation

Participants in 16 studies reported functional limitations due to their knee osteoarthritis particularly mobility restrictions(19-23, 25, 26, 29-36, 39). Participants predominantly reported limitations in movements involving weight-bearing such as standing, stair climbing, squatting, carrying, lifting, kneeling, bending; limitations in self-care activities such as dressing, toileting, sleeping, cooking; limitations in leisure pursuits such as walking, gardening, sport, and other forms of exercise, and a fear of falling. Living with knee osteoarthritis was reported by participants to reduce their physical activity and exercise, and to become sedentary. Participants described the impact on physical activities was associated with the severity of their knee osteoarthritis. The combined consequences of pain and functional limitations was an inability for some participants to participate in paid employment, or a reduction in work hours affecting household income, or other impacts on work such as requiring modifications, tiring easily, or being less efficient. For others, living with knee osteoarthritis meant a loss of independence, and a loss of sleep(22).

(4) Knee osteoarthritis has a social impact

Participants in 10 studies felt their knee osteoarthritis had a substantial social impact(21, 23, 28-30, 32-35, 39). It limited their ability to stay socially connected because of reduced participation in leisure activities and because of difficulties with taking public transport. For some participants, the inability to take part in socially-based physical activity, such as walking with friends or playing sport was the most difficult aspect of this condition. Participants described social isolation marked by doing fewer activities outside of home. Participants felt mobility limitations made it conspicuous to others that they had poor health. Living with knee osteoarthritis reduced their enjoyment of activities, particularly when travelling. Others described a change in their social relationships conveying that they related more to older individuals with health problems. Participants also described the repercussions

of knee osteoarthritis on family life, reporting difficulties taking care of the family including looking after grandchildren and playing with their children.

(5) Knee osteoarthritis has an emotional impact

Thirteen studies reported data on the emotional impact participants said they experienced as a result of having knee osteoarthritis(19-23, 25, 26, 29, 30, 34-36, 39). Living with knee osteoarthritis was described as being 'difficult' and often described as having a negative impact on the participant's mood, resulting in feelings of loss, anxiety, inadequacy, frustration, irritability, emotional distress, depression, embarrassment, fear for the future and uncertainty of the outcomes of knee pain. Carers reported their relatives with knee osteoarthritis could lose their temper easily when experiencing severe pain(36). Some participants reported their mobility limitations in particular devalued their sense of self-worth because mobility was integral to their identity. Living with knee osteoarthritis made them feel like 'a partial person', 'less valuable' and losing their identity, since they had to give up something that was part of their normal life. Other participants talked of a reduced sense of control or of being 'lost' after being 'told' to eliminate athletic activities and change their lifestyles. Other participants reported grieving for activities they could no longer take part in, or their vision of ageing. Participants in one study(21) felt the unpredictability and uncertainty of living with knee osteoarthritis caused the most stress. While participants in another study(34) said they dreamed of regaining their previous level of physical activity, their knee was a major barrier to achieving their dreams.

(6) Interactions with health professionals can be positive or negative

Eleven studies explored the interactions people with knee osteoarthritis described having with health professionals(18, 19, 25-27, 29, 35, 37-40). Participants said the impact of their diagnosis was a positive step towards successful management; although for people with low

expectations of treatment, the impact of their diagnosis resulted in limited contact with health professionals. Participants who had positive interactions with health professionals described being listened to, being offered hope for the future, and being provided with recommendations for managing knee osteoarthritis including weight loss and exercise. Participants who had negative experiences interacting with health professionals described their dissatisfaction with receiving limited information about their condition and the management options available including ways to avoid aggravating their condition, a sense of not being listened to, not being given sufficient attention or not understanding the information provided to them. For example, in one study(29) participants recounted how their symptoms were viewed by health professionals as something that could not be changed, which they 'just had to live with' or were dismissed as an inevitable part of ageing.

(7) Knee osteoarthritis leads to life adjustments

Fourteen studies(19, 21-23, 25, 26, 28, 29, 31, 33-36, 39) reported participants' descriptions of adjusting to having knee osteoarthritis in terms of role changes or modifications, ownership of their health management, awareness of their condition and developing coping strategies. Participants described taking measures to alleviate their symptoms and protect their knee joint including lifestyle adjustments by keeping active and controlling their weight, adapting their work, modifying activities or postures to manage everyday routines (e.g. climbing stair less frequently and looking for escalators, not carrying heavy things, planning ahead, looking for places to sit, avoiding situations whereby pain would be intolerable and avoiding public transport) and seeking out health-related information. In one study(22), participants described living with knee osteoarthritis as a balancing act recognising the health benefits from being physically active as well as beliefs about further joint deterioration and pain. Two studies(23, 33) described a 'tipping point' whereby participants arrived at the point

where they were giving up all their enjoyable activities with an extensive feeling of loss, and felt their best option was a knee replacement.

Discussion

This systematic review provides insights into the experience of living with knee osteoarthritis as described by the seven emergent themes. While the experience of persistent pain and disability were the main features of everyday living with knee osteoarthritis, psychological and social factors such as emotional distress, loss of social contact, and fear for the future were commonly expressed concerns of the participants. Other common views were the perceptions of knee osteoarthritis as an inevitable part of ageing, attributing their osteoarthritic knee to 'wear and tear', and finding ways to adjust their lives until they reach the 'tipping point' characterised by a perceived need for a knee replacement. A theme highlighted was unsatisfying relationships between people with knee osteoarthritis and healthcare professionals if there was limited information about the knee osteoarthritis and effective management options. Importantly, patient and health professional interactions were also perceived to provide a positive step towards effective management for people with knee osteoarthritis.

The psychological and social impact of knee osteoarthritis emerged as the key factor in the lived experience of people with knee osteoarthritis. Previous systematic review analyses have not focussed on the psychological and social impact of living with knee osteoarthritis(11, 12). The anxiety, depression and feeling of hopelessness that emerged as a theme in our review only recently received attention in published clinical practice guidelines. For example, clinical practice guidelines for management of knee and hip osteoarthritis(41, 42) emphasise the importance of a holistic assessment to ascertain the impact of osteoarthritis on the whole person. This included specific recommendations for a psychosocial evaluation to identify unique factors that may affect a person's quality of life and participation in usual activities,

and to embed patient-centred care principles in the management of patients with knee osteoarthritis. Patient-centred care encourages patient participation in decision making and communication with patients about their management options. Hence, for some patients, offering a psychological intervention such as cognitive behavioural therapy may be important to improve the lived experience and self-management of osteoarthritis.

Psychological and social factors such as emotional distress, concerns about disability and learning to live with pain have been identified among people living with other chronic musculoskeletal pain conditions(43, 44). Some of the experiences of living with knee osteoarthritis we identified, such as the perception among the participants in the included studies that their condition was an inevitable part of ageing, the perceived poor prognosis due to the 'progressive degenerative disease', and the pre-occupation with the existing damage to their joint and their perceived need for surgery have also been recognised in people with low back pain(45, 46). An explanation for the perception of 'damage' for people with knee osteoarthritis is likely to have been influenced by the results of imaging as well as the messages people receive from their health professionals(47). This highlights the importance that health professionals not only focus on reducing joint-related pain and improving function, but to also include strategies to address misconceptions about knee osteoarthritis, such as education that osteoarthritis does not necessarily worsen with ageing and that people can remain healthy and active with osteoarthritis,(27, 48) as well as help patients participate in decisions about their management.

Our overall findings highlight the importance of equipping patients with information and self-management strategies to reduce the impact of knee osteoarthritis on their lives, particularly their psychosocial wellbeing, by reducing pain, maintaining function, increasing social and physical activity participation, helping patients to remain in employment, and achieve optimal mental health. For example, one option to address patients' harmful beliefs and

attitudes towards pain and damage is to address the negative or mistaken language and beliefs about their knee through education. Emphasising facts such as 'hurt does not equal harm' and 'exercise is safe'(49) and dismissing myths such as 'exercise is damaging' may be fundamental to alter people's negative attitudes and may be best combined with interventions such as exercise programs to potentially improve patients' overall perception of their knee. Beliefs about a health condition are formed not only from personal experiences, but also from observing others and external sources of information such as the media. Thus, negative beliefs about knee osteoarthritis can predate the onset of the condition(50). Therefore, there may be a role for public health campaigns to dispel myths about knee osteoarthritis across society more broadly.

The main limitation of this systematic review was the exclusion of studies exploring patients' perceptions of interventions they received such as exercise or perioperative management for knee osteoarthritis. These experiences in response to biological interventions would be expected to be different from the experience of living with knee osteoarthritis and should be the subject of further study. Only one study reported carer perceptions about living with knee osteoarthritis. Although the themes identified in this single study converged with 5 of the 7 themes, further enquiry may be required to confirm their perceptions. Further, given the pattern of recurring themes we identified, it is unlikely that the inclusion of subsequent studies would have substantially added to the themes we described in this review. Finally, exclusion of non-English language articles limits the generalizability as other cultures with other languages might have different perceptions of knee osteoarthritis.

Conclusion

This review highlighted the value of taking patient attitudes and experiences into account, consistent with patient-centred care, when planning and implementing management options for people with knee osteoarthritis. These findings could inform clinical practice guidelines,

to help clinicians better understand the lived experience of knee osteoarthritis, optimise the patient-clinician interaction, and provide insights into how patient education may be conducted. These findings could also lead to new research questions to address patients lived experience with knee osteoarthritis and interventions to target modifiable psychological and social factors.

Author contributions

JAW: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript. NFT: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript. SB: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript. NS: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript.

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Competing interest statement

All authors declare that they do not have any potential conflicts of interest.

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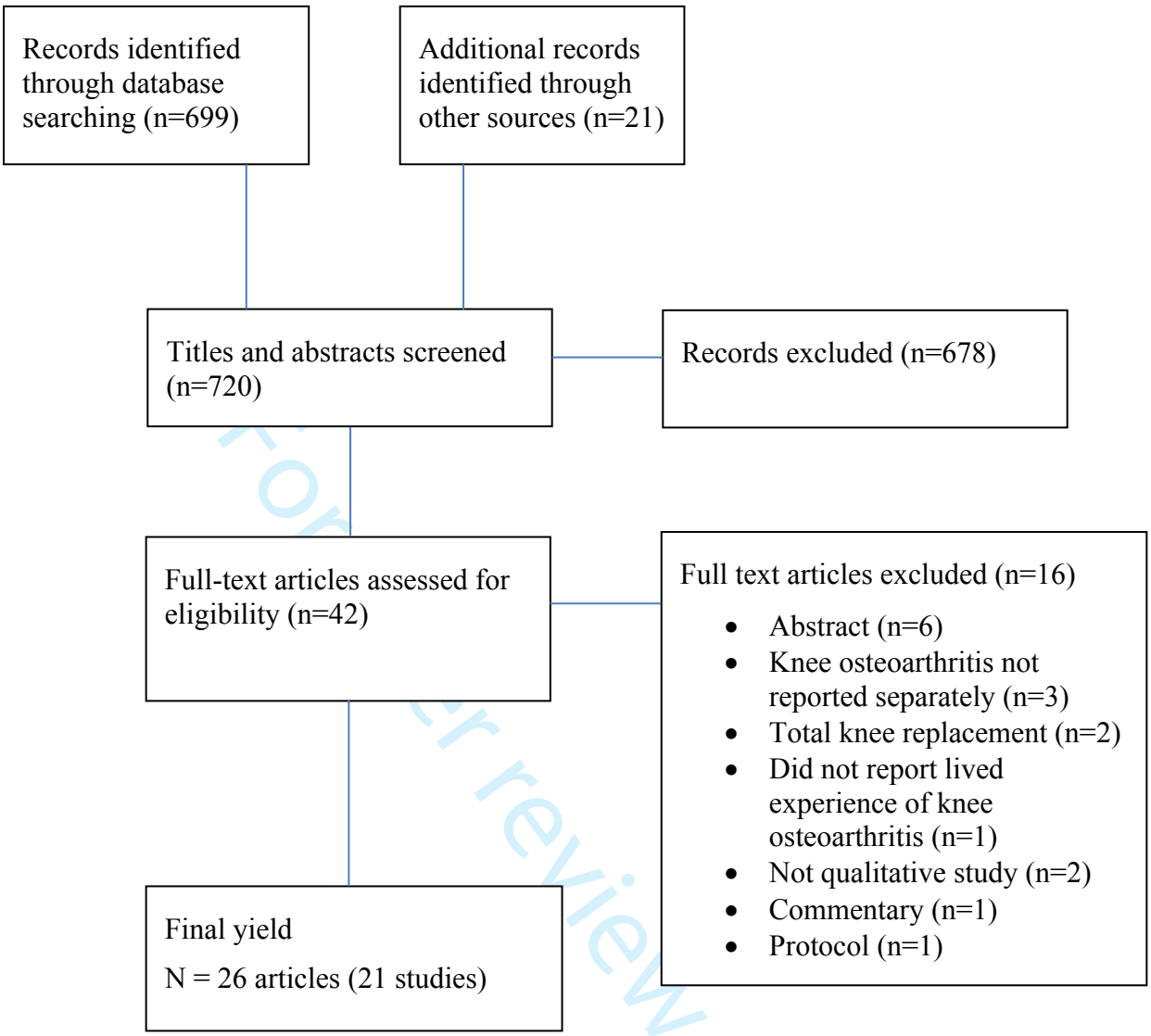

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Systematic review

1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

The experience of living with knee osteoarthritis: a systematic review

2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.
12/10/2018

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.
19/12/2018

5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

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Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Jason Wallis

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Dr Wallis

7. * Named contact email.

Give the electronic mail address of the named contact.

jason.wallis@easternhealth.org.au

8. Named contact address

Give the full postal address for the named contact.

Allied Health Clinical Research Office, level 2/5 Arnold Street, Box Hill, Victoria, Australia, 3128

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

61 3 9895 3715

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Eastern Health

Organisation web address:

www.easternhealth.org.au

11. * Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Dr Jason Wallis. La Trobe University, Eastern Health
Professor Nicholas Taylor. La Trobe University, Eastern Health
Dr Samantha Bunzli. The University of Melbourne
Professor Nora Shields. La Trobe University

12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

None

13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

What are the experiences of living with knee osteoarthritis from the perspectives of patients and their caregivers?

16. * Searches.

Give details of the sources to be searched, search dates (from and to), and any restrictions (e.g. language or publication period). The full search strategy is not required, but may be supplied as a link or attachment.

Five electronic databases (CINAHL, Embase, MEDLINE, PsycINFO, SPORTDiscus) will be searched from inception until October 2018. English language articles will be included.

Manually checking reference lists of included studies and citation tracking of included studies using Google Scholar will be used to identify additional relevant studies.

17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

https://www.crd.york.ac.uk/PROSPEROFILES/108962_STRATEGY_20181206.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Knee osteoarthritis is a common chronic disease affecting adults and older adults. The main symptom associated with knee osteoarthritis is pain, with or without stiffness and swelling around the joint. People with knee osteoarthritis often have difficulty with mobility and other everyday activities, which in turn can affect participation in work and leisure activities.

The experience of chronic pain associated with knee osteoarthritis is multidimensional comprising of biological, psychological and social dimensions. The experience and construct of pain associated with knee osteoarthritis may be best explored with qualitative analysis. Qualitative analysis can also play an important complementary role to quantitative methods in knee osteoarthritis research.

19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

People diagnosed with knee osteoarthritis and their caregivers will be included. Participants not identified as having knee osteoarthritis (e.g. knee pain, ACL injury) will be excluded.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

No interventions are included in this review.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

No control groups are included in this review.

22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

Full text articles published in a peer review journal that used qualitative methods will be included in this review. Questionnaires, surveys, single case studies and systematic reviews of qualitative research will be excluded from this review.

23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

In results we will report the country of origin, and participant details including age, sex, disease severity, and body mass index. Note these settings and characteristics will not be included in the selection criteria.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

A descriptive analysis, based on a content analysis approach, will be used to identify and discuss themes related to the experiences of living with knee osteoarthritis from patients with knee osteoarthritis and their caregivers.

Timing and effect measures

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None..

Timing and effect measures

26. * Data extraction (selection and coding).

Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.

Two reviewers will independently review the titles and abstracts yielded according to the selection criteria. Any discrepancies will be resolved through discussion between the two reviewers. A third reviewer will be used to achieve consensus, if required.

Data to be extracted from each study will include: country of origin, participant demographics (e.g. number of participants, severity of osteoarthritis, age, sex, and body mass index), qualitative design of the individual studies including data collection method (interviews or focus groups) and qualitative frameworks informing the analyses.

27. * Risk of bias (quality) assessment.

State whether and how risk of bias will be assessed (including the number of researchers involved and how discrepancies will be resolved), how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.

The Critical Appraisal Skills Programme (CASP) checklist will be used for qualitative study results. The CASP checklist provides decision rules and instructions on how to interpret checklist criteria.Two reviewers will independently apply the CASP checklist with any discrepancies will be resolved through discussion between the two reviewers. A third reviewer will be used to achieve consensus, if required. Results of the quality assessment may influence and inform the interpretation of results and planned synthesis.

28. * Strategy for data synthesis.

Give the planned general approach to synthesis, e.g. whether aggregate or individual participant data will be used and whether a quantitative or narrative (descriptive) synthesis is planned. It is acceptable to state that a

quantitative synthesis will be used if the included studies are sufficiently homogenous.

A descriptive synthesis, including a content analysis approach is planned. The number of studies supporting an identified theme will be noted.

29. * Analysis of subgroups or subsets.

Give details of any plans for the separate presentation, exploration or analysis of different types of participants (e.g. by age, disease status, ethnicity, socioeconomic status, presence or absence or co-morbidities); different types of intervention (e.g. drug dose, presence or absence of particular components of intervention); different settings (e.g. country, acute or primary care sector, professional or family care); or different types of study (e.g. randomised or non-randomised).

We plan to analyse the experiences of caregivers separately from patients with knee osteoarthritis.

30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Meta-analysis
No

Methodology
No

Narrative synthesis
Yes

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
Yes

Systematic review

Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal
Yes

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care

No
Perioperative care
No
Physiotherapy
No
Pregnancy and childbirth
No
Public health (including social determinants of health)
No
Rehabilitation
No
Respiratory disorders
No
Service delivery
No
Skin disorders
No
Social care
No
Surgery
No
Tropical Medicine
No
Urological
No
Wounds, injuries and accidents
No
Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.
Australia

33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

No I do not make this file publicly available until the review is complete

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Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

We plan to publish this review in a peer-reviewed journal

Do you intend to publish the review on completion?

Yes

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Knee Osteoarthritis; Qualitative

37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.

Checklist: Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ)

	Item	Guide and description	Evidence in manuscript
1	Aim	State the research question the synthesis addresses.	Research question included in introduction on page 5..
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	The theoretical framework was a thematic analysis and content analysis included in the methods section of manuscript on page 9 lines 158-63. The rationale using this inductive approach to address the limitations in quantitative research was included in the introduction on page 4.
3	Approach to searching	Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved)*.	A pre-planned search was applied and registered on Prospero - registration number CRD42018108962 https://www.crd.york.ac.uk/PROSPERO. Page 6.
4	Inclusion criteria	Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type).*	Eligibility criteria included in methods section, pages 6-7.
5	Data sources	Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources.	The search strategy and rationale is included in methods section of manuscript on page 6.
6	Electronic Search strategy	Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)*.	The search strategy was included in methods section of manuscript on page 6, lines 119-29. An example of the strategy using Medline was included (appendix, page 8).
7	Study screening methods	Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).*	This screening process was included in the search strategy in methods section of manuscript on page 6.

	Item	Guide and description	Evidence in manuscript
8	Study characteristics	Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*	The study characteristics were included in Table 2 (pages 12-14).
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).*	Study selection results were included in results section of the manuscript on page 10 and Figure 1.
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).*	We used a checklist (CASP) that is commonly applied in qualitative reviews in musculoskeletal research. This is included in the methods section on page 9..
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope*[25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*	The CASP checklist assesses the validity of the results, ethics, trustworthiness, clarity and value of results. This is included in the methods section on page 9..
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	The CASP appraisal was applied independently by two reviewers, included in methods section of manuscript on page 9.
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	The results of the appraisal were included in results section of manuscript on page 10, lines 174-81, and Table 3.
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).*	The text used to describe themes and sub-themes in the primary studies were assigned descriptive codes using an inductive process. - Included in methods section of manuscript on page 9.
15	Software	State the computer software used, if any.	The search results were downloaded into bibliographic software (Endnote Version 18), included in the methods, section of the manuscript

	Item	Guide and description	Evidence in manuscript
			on page 6..
16	Number of reviewers	Identify who was involved in coding and analysis.	Included the data analysis section of the methods on page 9..
17	Coding	Describe the process for coding of data *(e.g. line by line coding to search for concepts).*	The coding process was included the data analysis section of the methods on page 9.
18	Study comparison	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).*	A content analysis approach enabled comparison within and across studies, included in the data analysis section of the methods on page 9..
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	An inductive process was used and reported in the data analysis section in the methods, page 9..
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations of the author's interpretation.	Included in the results section of the manuscript. An example of a quotation included for theme one was 'a progressive degenerative disease' on page 17..
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).*	Included in the discussion section of the manuscript e.g. "The psychosocial impact of knee osteoarthritis emerged as the key factor in the lived experience of people with knee osteoarthritis." Previous systematic review analyses have not focused on the psychological and social impact of living with knee osteoarthritis.

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The experience of living with knee osteoarthritis: A systematic review of qualitative studies

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The experience of living with knee osteoarthritis: A systematic review of qualitative studies

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ABSTRACT

Objectives: Systematically review the qualitative literature on living with knee osteoarthritis from patient and carer perspectives.

Design: Systematic review of qualitative studies. Five electronic databases (CINAHL, Embase, Medline, Psychinfo, SPORTDiscus) were searched from inception until October 2018. Data were synthesised using thematic and content analysis.

Participants: Studies exploring the experiences of people living with knee osteoarthritis, and their carers were included. Studies exploring experiences of patients having participated in specific interventions, including surgery, or their attitudes about the decision to proceed to knee replacement were excluded.

Results: Twenty-six articles reporting data from 21 studies about the patient (n=665) and carer (n=28) experience of living with knee osteoarthritis were included. Seven themes emerged: (1) Perceived causes of knee osteoarthritis are multifactorial and lead to structural damage to the knee and deterioration over time (n=13 studies); (2) Pain and how to manage it predominates the lived experience (n=19 studies); (3) Knee osteoarthritis impacts activity and participation (n=16 studies); (4) Knee osteoarthritis has a social impact (n=10 studies); (5) Knee osteoarthritis has an emotional impact (n=13 studies); (6) Interactions with health professionals can be positive or negative (n=11 studies); (7) Knee osteoarthritis leads to life adjustments (n=14 studies). A single study reporting the perspectives of carers reported similar themes. Psychosocial impact of knee osteoarthritis emerged as a key factor in the lived experience of people with knee osteoarthritis.

Conclusions: This review highlights the value of considering patient attitudes and experiences including psychosocial factors when planning and implementing management options for people with knee osteoarthritis. Trial registration: PROSPERO registration number CRD42018108962

Strengths and limitations of this study

- The systematic review was reported consistent with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) and registered prospectively with PROSPERO (registration number CRD42018108962).
- A comprehensive search strategy of qualitative studies about patient and carer perceptions about their lived experience with knee osteoarthritis was conducted.
- Comprehensive data synthesis was applied using thematic and content analysis leading to results that went beyond the summary of the selected studies.
- The findings of this review are limited to the experience of living with knee osteoarthritis, and not the experience of receiving specific interventions, including surgery.
- Exclusion of non-English language articles limits the generalizability as other cultures with other languages might have different perceptions of knee osteoarthritis.

Introduction

The experience of living with chronic pain associated with knee osteoarthritis is multidimensional comprising biological dimensions such as subchondral bone pathology and inflammation(1), and psychological and social dimensions such as pain catastrophizing, depression, avoidance of activities and social support(2-4). The current management of knee osteoarthritis is focussed on pain management to address biological dimensions (joint pathology), through joint-specific exercises, pharmacology and in advanced stages, joint replacement surgery(5, 6). However, levels of pain and disability reported by people with osteoarthritis are poorly correlated with radiographic severity of joint pathology, suggesting other factors apart from biological dimensions can affect the experience of living with knee osteoarthritis(7). Further, knee replacement surgery to address joint pathology, does not always have a successful outcome. Only about 40% of patients report being pain free two years after surgery(8), and about 20% were not satisfied with surgical outcome one year after surgery(9).

The role of psychological and social dimensions in the management of knee osteoarthritis has received relatively little attention in comparison with management of joint pathology(2). In other chronic musculoskeletal conditions, the role of psychological and social dimensions has been studied extensively(10). For example, in chronic low back pain, psychological and social factors have been shown to play a role in the persistence of pain, and interventions designed to target these factors can improve pain, disability and quality of life in this population(11, 12). Targeting the psychological and social dimensions of knee osteoarthritis in addition to the biological dimensions, consistent with a biopsychosocial approach, may optimise outcomes. There is preliminary evidence from a systematic review and meta-analysis of 12 randomised controlled trials showing psychological interventions, such as cognitive behavioural therapy, are associated with short-term reductions in pain for people

with knee osteoarthritis(13). Further, there is preliminary evidence from a randomised controlled trial that combining physiotherapist-delivered pain coping skills training, combined with exercise therapy, can lead to greater improvements in function compared to either treatment alone(14). In order to design targeted interventions consistent with a biopsychosocial approach, we must first understand the psychological and social dimensions of knee osteoarthritis from the perspectives of people living with the condition.

Qualitative research provides insight into the lived experience of health and how individuals' make sense of their health symptoms. Rather than relying on the a priori assumptions of researchers or clinicians, qualitative research prioritises the voice of the 'expert' participant, thus shedding light on aspects of the lived experience that cannot be reached by quantitative approaches(15). Two recent systematic reviews have synthesised qualitative research related to knee pain, including people living with osteoarthritis(16, 17). Wride et al(17) explored the feelings and experiences of people living with knee pain from nine studies, three of which included people with non-osteoarthritic related knee pain. This review found many people with knee pain struggle to adapt to normal living, and that their negative experiences were exacerbated by a lack of knowledge and available information to help them plan for the future. In another review, Smith et al(16) explored the perceptions of people diagnosed with hip and/or knee osteoarthritis from 32 studies (18 of which sampled people with knee osteoarthritis only) to determine their attitudes and perceptions towards living with their musculoskeletal condition. Participants in these studies reported a number of factors that contributed to their negative attitude and perception about their hip and/or knee osteoarthritis, such as their understanding of the pathology of osteoarthritis, the activity limitations they experienced, and their perceptions of other people's beliefs towards their condition.

The two previous systematic reviews synthesising qualitative data have limitations as they did not consider the experience of knee osteoarthritis separately to the experience of non-

osteoarthritic related conditions (e.g. Wride et al(17)), and to the experience of hip osteoarthritis (e.g. Smith et al(16)). Empirical evidence suggests hip and knee osteoarthritis are distinct conditions that impact people in different ways(18). In addition, neither review(16, 17) looked at the perspectives of carers. Those in the immediate social environment may exert an influence on how an individual copes with their condition. In the case of knee osteoarthritis, family members and significant others often adopt the role of carer. By investigating the perceptions and experiences of both patients and carers, health professionals can gain a greater understanding of how living with knee osteoarthritis effects their lives, which may lead to improved management of people with knee osteoarthritis.

Therefore, the aim of this study was to systematically review the qualitative literature on the experience of living with knee osteoarthritis from the perspectives of patients and carers.

Methods and analysis

Design

A systematic review of qualitative studies was conducted. The review was reported consistent with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ),(19). A review protocol was registered prospectively with PROSPERO registration number CRD42018108962 https://www.crd.york.ac.uk/PROSPERO.

Patient and public involvement

Patients and public were not involved in the development of the research question, outcome measures or research design.

Search strategy

Five electronic data bases (CINAHL, Embase, Medline, Psychinfo, SPORTDiscus) were searched from inception until October 2018. The search strategy comprised two key concepts: knee osteoarthritis and qualitative research. For each concept, key words and

MeSH terms were combined using the 'OR' operator and the results were combined using the AND operator (Appendix). The search results were downloaded into bibliographic software (Endnote version 18). Two reviewers independently reviewed the titles and abstracts according to the selection criteria (Table 1). If eligibility was uncertain based on title and abstract, the full-text of the study was obtained. Reference lists of included articles were manually searched for additional relevant articles, and citation tracking of included articles was completed using Google Scholar.

Eligibility criteria

Studies reporting the experiences of people living with knee osteoarthritis, and their carers were included. Studies that explored experiences of participation in specific interventions for knee osteoarthritis, including perioperative management and attitudes about the decision to proceed to total knee replacement were excluded as the focus of the review was on the lived experience of knee osteoarthritis, and not about the response to treatment from receiving a specific intervention (Table 1). Since the aim of our review was to explore the experience of living with knee osteoarthritis, with a focus on the psychological and social dimensions, it was decided not to include studies that explored perceptions about biological interventions including surgery.

Table 1: Selection criteria

	Inclusion criteria	Exclusion criteria
Design and report	• Qualitative studies • Reports lived experience of knee osteoarthritis • Full text article published in peer-reviewed journal • Primary research	• Questionnaires/surveys • Non-English language • Single case studies • Secondary analysis of qualitative data such as a systematic review
Participants	• Knee osteoarthritis • Perceptions of people diagnosed with knee osteoarthritis, and their carers • May include other conditions providing perceptions about knee osteoarthritis are reported separately	• Participants not identified as having knee osteoarthritis (e.g. knee pain, anterior cruciate ligament injury)
Interventions	• No intervention • May include studies exploring perceptions about management, such as knee replacement, provided experiences about living with knee osteoarthritis are reported separately	• Explored experiences of patients having participated in interventions • Explored experiences about perioperative management of knee replacement • Explored attitudes about the decision to proceed to total knee replacement

Methodological quality of the included studies

The Critical Appraisal Skills Programme (CASP) checklist was used to assess methodological quality of the included studies(20). The CASP checklist includes 10 questions in 3 sections about the validity of the results (questions 1-6), ethical considerations, trustworthiness and clarity of results (questions 7-9), and the value of the results (question 10). Two reviewers (JW, SB) independently answered each question as "yes", "no" or "can't tell", by reading the decision rules and instructions on how to interpret checklist criteria. Discrepancies between reviewers were discussed with a third reviewer (NT) until consensus was reached with the overall judgment scored as yes or no. The CASP checklist has been used in other qualitative systematic reviews in musculoskeletal research(21, 22).

Data collection process

Data were extracted from each study on participant age, sex, disease severity and body mass index, where available. Data were also extracted on the study design including sample size, data collection method (e.g. interview or focus group), and qualitative framework informing the analysis. From the results section of each included paper, we extracted the main themes and subthemes as outlined below.

Data analysis

Data were analysed using a three-stage approach adapted from Sandelowski and Barroso(23). In stage one, the results sections of each paper including direct quotations were read and re-read so the authors familiarised themselves with the content, prior to extracting main themes and subthemes. Themes and subthemes were then extracted and assigned descriptive codes using an inductive process. In stage two, the identified codes were then reviewed and codes were grouped together according to their topical similarity. In stage three, these groupings of codes were subsequently organised into themes and sub-themes in a process of thematic

analysis. To help understand the relative importance of the emergent themes and subthemes relative to each other, and consistent with content analysis methods, the number of studies that identified each theme was counted. The process of data extraction, initial coding, grouping of codes, and identification of emergent themes and subthemes was completed by one researcher (NS). The data analysis process was subsequently checked independently by two other researchers (JW, NT) before the final themes and subthemes were confirmed by the research team.

Results

Study selection

The search strategy yielded 720 articles. After screening the titles and abstracts of these articles, 42 underwent full text review. Sixteen articles were excluded after full text review resulting in a final library of 26 articles (Figure 1). The most common reasons for exclusion were that articles were abstracts, and the results of knee osteoarthritis were not reported separately from osteoarthritis at other joints. The 26 included articles reported data from 21 studies (Table 2) on the experience of living with knee osteoarthritis from the perspectives of people themselves (n=20) or their carers (n=1).

Methodological quality of included studies

All studies had a clear rationale for using qualitative methods, used appropriate qualitative designs, and included explicit statements of findings that were considered high value. Two studies did not report approval from an ethics committee(24, 25) and four studies reported insufficient details about data analysis reducing the trustworthiness of the results(24-27). Only two of the 21 studies adequately reported the relationship between the researcher and the participant(28, 29). A pre-existing relationship between the participant and researcher

increases the risk of social desirability(30), whereby there is the tendency of the participants to answer questions in a manner that will be viewed favourably by the researchers (Table 3).

Study participant characteristics

The 21 studies included 665 people with knee osteoarthritis (71% women; mean age 65 years, age range 25 to 87) and 28 carers of people with knee osteoarthritis (46% women; mean age 48 years) (Table 2). The studies were conducted in Asia (n=6), North America (n=6), Europe (n=8) and New Zealand (n=1) and 15 of the 21 studies were published since 2011. Participants' comorbidities as described in 6 studies included diabetes, depression/anxiety, polyarthritis, hypertension, heart disease, haemophilia, silicosis, vascular problems, cancer, gout, osteoarthritis in other joints and multiple knee surgeries. Participants in 9 studies self-assessed their pain severity at the time of their participation as mild to severe(25, 27, 31-37), and participants in 4 studies had severe osteoarthritis and were awaiting total knee replacement(29, 38-40). Thirteen studies provided details on participant employment status; the majority of participants were retired or not working, except for 3 studies(28, 35, 41) in which the majority of participants were employed at the time of the study.

Table 2: Characteristics of included studies of experiences of living with knee osteoarthritis

Study	Country	Population	Demographics (N, age, sex, BMI)	Method: Framework/analysis	Sampling	Data collection	Research questions
Alami *et al.,* 2011	France	Knee osteoarthritis	N=81 71% women,	Descriptive -Inductive	Purposive	Individual interviews -semi-structured	Explore views of patients about management of knee osteoarthritis
Ahmad *et al.,* 2018	Malaysia	Knee osteoarthritis	N=12 Mean age 67 yrs 67% women	Thematic analysis	Purposive	Individual interviews -in-depth	Explore perspectives of patients with knee OA mainly about pain experiences, its impact, effects of physiotherapy and their personal expectation
Al-Taiar *et al.,* 2013	Kuwait	Severe knee osteoarthritis -Kuwaiti women waitlisted for total knee replacement	N=39 Mean age 62 yrs 100% women	Thematic analysis	Convenience	Focus groups	Explore the pain experience and mobility limitation as well as the patient' s decision making process to undertake total knee replacement among women with knee pain in the waiting list for surgery
Carmona-Teres *et al*., 2017	Spain	Knee osteoarthritis -symptomatic	N=10 Mean age 70 yrs, 70% women	Content thematic analysis based on Lazarus stress model categories	Theoretical	Individual interviews -semi-structured	Understand experiences, perceptions, cognitive evaluation, values, emotions, beliefs and coping strategies of people with knee osteoarthritis
Chan and Chan, 2011	Hong Kong	Knee osteoarthritis -mild to very severe	N=20 Mean age 57 yrs, 65% women	Grounded theory	Convenience	Individual interviews -semi-structured	Evaluate influence of different pain patterns on quality of life Investigate coping strategies
Clarke *et al.*, 2014 Pouli *et al.*, 2014	UK	Knee osteoarthritis -symptomatic	N=24 Mean age 62 yrs, 71% women	Descriptive thematic analysis	Purposive	Individual interviews -semi-structured	Explore participant's experience of living with knee osteoarthritis and their beliefs about knee osteoarthritis and its treatment
Darlow *et al.,* 2018	NZ	Knee osteoarthritis	N=13 Age range 50-84 54% women	Interpretative description	Purposive	Individual interviews -semi-structured	Explore the beliefs of people with knee osteoarthritis about the disease, how these beliefs had formed and what impact these beliefs had on activity participation, health behaviour and self-management

Figaro *et al.,* 2004	US	Knee osteoarthritis -not actively seeking total knee replacement	N=94 Mean age 71yrs 84% women	Content analysis Constant comparative methods	Purposive Network, convenience and snowball sampling to extend the sample	Structured field interviews	Explore older urban Blacks with knee osteoarthritis to determine their preferences and expectations of total knee replacement
Hall *et al.,* 2008	Canada	Unilateral knee osteoarthritis -scheduled for total knee replacement	N=15 Mean age 67 yrs 40% women	Grounded theory	Purposive	Individual interviews -semi-structured	Explore views of total knee replacement and the role of physiotherapy
Hendry *et al.,* 2006	UK	Knee osteoarthritis -mild to severe symptoms	N=22 Age range 52-86 yrs 73% women	Conceptual Framework	Convenience	Individual interviews Focus Groups (N=6)	Explore the views of primary care patients with knee osteoarthritis towards exercise, and explore factors that determine acceptability and motivation to exercise, and barriers that limit its use
Hsu *et al.*, 2015	Taiwan	Family carers of people with knee osteoarthritis	N=28 Mean age 48 yrs, 46% women	Descriptive content analysis	Convenience	Individual interviews -semi-structured	Explore primary caregivers' perceptions of their older relatives' knee osteoarthritis pain and management
Keysor *et al.*, 1998	USA	Knee osteoarthritis -presence of functional limitations	N=4 Age range 25-43 yrs, 75% women	Van Kaam method of phenomenologic data analysis	Purposive	Individual interviews -semi structured (each participant interviewed twice)	Understand the experience of living with osteoarthritis as young and middle-aged adults
Kao and Tsai, 2012, 2013	Taiwan	Knee osteoarthritis -symptomatic	N=17 Mean age 50 yrs, 82% women	Constant comparison	Purposive	Individual interviews -semi structured	Understand the living and illness experiences of middle-aged adults with early knee osteoarthritis
MacKay *et al.*, 2016, 2014a, 2014b	Canada	Knee osteoarthritis -moderately symptomatic	N=51 Median age 49 yrs, 61% women	Constructivist grounded Theory/ constant comparative method	Purposive	Focus groups Individual interviews -semi-structured	Explore the meaning and perceived consequences of knee symptoms

Maly and Krupa, 2007	Canada	Knee osteoarthritis	N=3 Age range 62-87 yrs, 67% women	Descriptive phenomenology	Convenience	Individual interviews -semi structured	Understand the experience of living with knee osteoarthritis in older adults
Man *et al.*,2017	US	Knee osteoarthritis -waitlisted for total knee replacement	N=8 Age range 46-80 yrs 50% women	Thematic analysis	Purposive	Individual interviews -semi-structured	Explore the meaning and importance of occupational changes experienced by individuals during the pre- total knee replacement period
Morden *et al.* 2011, Ong *et al.* 2011	UK	Knee osteoarthritis -moderate to severe	N=22 Age range 50-75+ yrs, 59% women	Constant comparison	Purposive	Individual interviews -in-depth Diaries	Explore the meaning and enactment of self-management in everyday life
Nyvang *et al.,* 2016	Sweden	Knee osteoarthritis -scheduled for total knee replacement	N=12 Mean age 66 yrs 58% women	Thematic analysis	Purposive	Individual interviews -semi-structured	Explore patients' experiences of living with knee osteoarthritis when scheduled for total knee replacement and further their expectations for future life after surgery.
Tallon *et al.,* 2000	UK	Knee osteoarthritis -mild to moderate	N=7	Content analysis	Convenience	Focus group	Explore perception of treatment preferences
Victor *et al.,* 2004	UK	Knee osteoarthritis	N=170 Mean age 63 yrs, 73% women	Content analysis	Convenience	Individual interviews Group discussion Diaries	Explore meaning of osteoarthritis for those receiving health promotion
Xie *et al.*, 2006	Singapore	Knee osteoarthritis -symptomatic	N=41 Mean age 64 yrs, 66% women	Grounded theory/ Content analysis	Purposive	Focus groups	Determine health-related quality of life domains affected by knee osteoarthritis. and identify ethnic variations in the importance of these domains

Yrs = Years

Table 3: Critical Appraisal Skills Programme (CASP) assessment

Study name	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participant been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Alami *et al.,* 2011	Y	Y	Y	Y	N	N	Y	Y	Y	Y
Ahmed *et al.,* 2018	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Al-Taiar *et al.,* 2013	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Carmona-Teres *et al.,* 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Chan and Chan., 2011	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Clarke *et al.*, 2014 and Pouli *et al.,* 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Darlow *et al.,* 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Figaro *et al.,* 2004	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hall *et al.,* 2008	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Hendry *et al.,* 2006	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hsu *et al.,* 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Kao *et al.,* 2012, 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Keysor *et al.,* 1998	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mackay *et al.,* 2016, 2014a. 2014b	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Maly and Krupa, 2007	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Man *et al.,*2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Morden et al. 2011, Ong et al. 2011	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Nyvang et al. 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Tallon et al. 2000	Y	Y	Y	N	Y	N	N	N	Y	Y
Victor et al. 2004	Y	Y	Y	Y	Y	N	N	N	Y	Y
Xie et al. 2006	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Y = yes, N = no

Major themes reported by included studies

Seven major themes emerged from the data: (1) The perceived causes of knee osteoarthritis are multifactorial and lead to structural damage to the knee and deterioration over time; (2) Pain and how to manage it predominates the lived experience; (3) Knee osteoarthritis impacts activity and participation; (4) Knee osteoarthritis has a social impact; (5) Knee osteoarthritis has an emotional impact; (6) Interactions with health professionals can be positive or negative; and (7) Knee osteoarthritis leads to life adjustments. Themes were consistent between studies that included people with severe osteoarthritis and mild to moderate osteoarthritis. The study including caregivers (family members of the participants from one trial), captured 6 of the 7 major themes, with no new themes identified by caregivers.

(1) The perceived causes of knee osteoarthritis are multifactorial and lead to structural damage to the knee and deterioration over time

Thirteen studies reported what participants perceived the causes of knee osteoarthritis were(24-28, 32-35, 37, 38, 42, 43). Perceived cause of knee osteoarthritis included internal factors (such as being overweight, family history of osteoarthritis, ageing, working in occupations requiring heavy manual work such as extensive kneeling or lifting, past sporting activities, and menopause); and external factors (such as trauma and the weather). Participants perceived knee osteoarthritis as preventable or partially attributable to actions or incidents that were modifiable (e.g. pushing too far or knee injury) had they changed their behaviour earlier in life. Participants in 4 studies expressed strong beliefs and concerns about their knee osteoarthritis being caused by structural deterioration(25, 28, 33, 34) using language such as ‘bone on bone’ with the joint worn away by movement. Carers of people with knee osteoarthritis attributed the cause of their relative’s knee osteoarthritis to ageing, working too hard or to unknown causes (42).

The prognosis of knee osteoarthritis was discussed by participants in 6 studies(26, 28, 32-35). Participants believed their symptoms would get worse over time as knee osteoarthritis was 'a progressive degenerative disease' and could not be 'cured'. However, participants in one study(35) also felt they could halt or slow the progression of their symptoms through diet and exercise.

(2) Pain and how to manage it predominates the lived experience

The participants' experience of pain and its management emerged as a theme in 19 studies(25-29, 31-33, 35-45). Pain was described by participants as the predominant 'omnipresent' feature of knee osteoarthritis. Pain was perceived to interrupt and deter daily activities such as walking, to make people less confident in their bodies, and to slow people down. Participants in one study described two distinct patterns of pain: 'mechanical' pain described as 'sharp' pain related to discrete movements or activities, and 'inflammatory' pain described as a 'burning' pain which was more unpredictable and associated with the weather or prolonged activity(27). Pain was perceived as insurmountable when there was no foreseeable end to it and made some participants feel 'old'. Carers reported their relatives with knee osteoarthritis rarely mentioned pain until they needed help(42). Participants reported managing their pain with medication but that this was not always a satisfactory strategy due to feelings of dependence, undesirable side-effects, and only partial relief from symptoms. Other pain management strategies described were activity-related (including exercise, avoidance of certain activities, brief rest, pacing, and physiotherapy), psychological-related (having a positive life philosophy, humour, continuing to engage in pleasurable activities), passive treatment modalities (including ice, heat, massage, Chinese traditional medicine) and weight loss. Some believed joint replacement was inevitable and the only real solution for their pain(25, 28). Similarly, carers of relatives with knee osteoarthritis believed the most promising method to reduce pain was a knee replacement, and often persuaded their

relatives to see a doctor about having surgery(42). In contrast, participants from one study preferred a natural solution only as they had a negative perception of surgery and saw it as a last resort(43).

(3) Knee osteoarthritis impacts activity and participation

Participants in 16 studies reported functional limitations due to their knee osteoarthritis particularly mobility restrictions(25-29, 31, 32, 35-42, 45). Participants predominantly reported limitations in movements involving weight-bearing such as standing, stair climbing, squatting, carrying, lifting, kneeling, bending; limitations in self-care activities such as dressing, toileting, sleeping, cooking; limitations in leisure pursuits such as walking, gardening, sport, and other forms of exercise, and a fear of falling. Living with knee osteoarthritis was reported by participants to reduce their physical activity and exercise, and to become sedentary. Participants described the impact on physical activities was associated with the severity of their knee osteoarthritis. The combined consequences of pain and functional limitations was an inability for some participants to participate in paid employment, or a reduction in work hours affecting household income, or other impacts on work such as requiring modifications, tiring easily, or being less efficient. For others, living with knee osteoarthritis meant a loss of independence, and a loss of sleep(28).

(4) Knee osteoarthritis has a social impact

Participants in 10 studies felt their knee osteoarthritis had a substantial social impact(27, 29, 34-36, 38-41, 45). It limited their ability to stay socially connected because of reduced participation in leisure activities and because of difficulties with taking public transport. For some participants, the inability to take part in socially-based physical activity, such as walking with friends or playing sport was the most difficult aspect of this condition. Participants described social isolation marked by doing fewer activities outside of home.

Participants felt mobility limitations made it conspicuous to others that they had poor health. Living with knee osteoarthritis reduced their enjoyment of activities, particularly when travelling. Others described a change in their social relationships conveying that they related more to older individuals with health problems. Participants also described the repercussions of knee osteoarthritis on family life, reporting difficulties taking care of the family including looking after grandchildren and playing with their children.

(5) Knee osteoarthritis has an emotional impact

Thirteen studies reported data on the emotional impact participants said they experienced as a result of having knee osteoarthritis(25-29, 31, 32, 35, 36, 40-42, 45). Living with knee osteoarthritis was described as being 'difficult' and often described as having a negative impact on the participant's mood, resulting in feelings of loss, anxiety, inadequacy, frustration, irritability, emotional distress, depression, embarrassment, fear for the future and uncertainty of the outcomes of knee pain. Carers reported their relatives with knee osteoarthritis could lose their temper easily when experiencing severe pain(42). Some participants reported their mobility limitations in particular devalued their sense of self-worth because mobility was integral to their identity. Living with knee osteoarthritis made them feel like 'a partial person', 'less valuable' and losing their identity, since they had to give up something that was part of their normal life. Other participants talked of a reduced sense of control or of being 'lost' after being 'told' to eliminate athletic activities and change their lifestyles. Other participants reported grieving for activities they could no longer take part in, or their vision of ageing. Participants in one study(27) felt the unpredictability and uncertainty of living with knee osteoarthritis caused the most stress. While participants in another study(40) said they dreamed of regaining their previous level of physical activity, their knee was a major barrier to achieving their dreams.

(6) Interactions with health professionals can be positive or negative

Eleven studies explored the interactions people with knee osteoarthritis described having with health professionals(24, 25, 31-33, 35, 41, 43-46). Participants said the impact of their diagnosis was a positive step towards successful management; although for people with low expectations of treatment, the impact of their diagnosis resulted in limited contact with health professionals. Participants who had positive interactions with health professionals described being listened to, being offered hope for the future, and being provided with recommendations for managing knee osteoarthritis including weight loss and exercise. Participants who had negative experiences interacting with health professionals described their dissatisfaction with receiving limited information about their condition and the management options available including ways to avoid aggravating their condition, a sense of not being listened to, not being given sufficient attention or not understanding the information provided to them. For example, in one study(35) participants recounted how their symptoms were viewed by health professionals as something that could not be changed, which they 'just had to live with' or were dismissed as an inevitable part of ageing.

(7) Knee osteoarthritis leads to life adjustments

Fourteen studies(25, 27-29, 31, 32, 34, 35, 37, 39-42, 45) reported participants' descriptions of adjusting to having knee osteoarthritis in terms of role changes or modifications, ownership of their health management, awareness of their condition and developing coping strategies. Participants described taking measures to alleviate their symptoms and protect their knee joint including lifestyle adjustments by keeping active and controlling their weight, adapting their work, modifying activities or postures to manage everyday routines (e.g. climbing stair less frequently and looking for escalators, not carrying heavy things, planning ahead, looking for places to sit, avoiding situations whereby pain would be intolerable and avoiding public transport) and seeking out health-related information. In one study(28),

participants described living with knee osteoarthritis as a balancing act recognising the health benefits from being physically active as well as beliefs about further joint deterioration and pain. Two studies(29, 39) described a 'tipping point' whereby participants arrived at the point where they were giving up all their enjoyable activities with an extensive feeling of loss, and felt their best option was a knee replacement.

Discussion

This systematic review provides insights into the experience of living with knee osteoarthritis as described by the seven emergent themes. While the experience of persistent pain and disability were the main features of everyday living with knee osteoarthritis, psychological and social factors such as emotional distress, loss of social contact, and fear for the future were commonly expressed concerns of the participants. Other common views were the perceptions of knee osteoarthritis as an inevitable part of ageing, attributing their osteoarthritic knee to 'wear and tear', and finding ways to adjust their lives until they reach the 'tipping point' characterised by a perceived need for a knee replacement. A theme highlighted was unsatisfying relationships between people with knee osteoarthritis and healthcare professionals if there was limited information about the knee osteoarthritis and effective management options. Importantly, patient and health professional interactions were also perceived to provide a positive step towards effective management, particularly when health professionals listen to their patients, convey hope for the future, and provide recommendations for managing knee osteoarthritis.

This review, comprising data from 21 studies involving 665 people with knee osteoarthritis and 28 carers, adds to the literature by highlighting the magnitude of the psychosocial impact of living with knee osteoarthritis that permeates all aspects of life. A previous systematic review of the experience of hip and knee osteoarthritis focussed on the functional impacts of osteoarthritis, as well as people's lack of understanding and the stigma of their disease(16).

One small previous review of 9 studies focussed on the lived experience of knee pain, but did not limit this to osteoarthritis(17). While the assessment of the lived experience of a health condition should be disease-specific(47), the finding by Wride et al. that 'knee pain affects every aspect of life, redefining what people are able to do, who they do it with and how they do it' complements our findings among people with knee osteoarthritis.

The anxiety, depression and feeling of hopelessness that we identified in our review only recently received attention in published clinical practice guidelines. For example, clinical practice guidelines for management of knee and hip osteoarthritis(48, 49) emphasise the importance of a holistic assessment to ascertain the impact of osteoarthritis on the whole person. This includes specific recommendations for a psychosocial evaluation to identify unique factors that may affect a person's quality of life and participation in usual activities, and to embed patient-centred care principles in the management of patients with knee osteoarthritis. Patient-centred care encourages patient participation in decision making and communication with patients about their management options. Hence, offering a psychological intervention such as cognitive behavioural therapy(13) may be important to improve the lived experience and self-management of osteoarthritis. Recent Australian clinical practice guidelines conditionally recommend offering cognitive behavioural interventions (e.g. pain coping skills training) delivered by trained health professionals to people with knee osteoarthritis presenting with psychological impairments(48). Combined with exercise, the guidelines suggest these interventions may improve pain, self-efficacy, pain coping, depression, and anxiety(48).

Psychological and social factors such as emotional distress, concerns about disability and learning to live with pain have been identified among people living with other chronic musculoskeletal pain conditions(50, 51). Some of the experiences of living with knee osteoarthritis we identified, such as the perception among the participants in the included

studies that their condition was an inevitable part of ageing, the perceived poor prognosis due to the 'progressive degenerative disease', and the pre-occupation with the existing damage to their joint and their perceived need for surgery have also been recognised in people with low back pain(52, 53). An explanation for the perception of 'damage' for people with knee osteoarthritis is likely to have been influenced by the results of imaging as well as the messages people receive from their health professionals(54). This highlights the importance that health professionals not only focus on reducing joint-related pain and improving function, but to also include strategies to dispel patient misconceptions about knee osteoarthritis(55). Strategies may include providing education that osteoarthritis is not a 'wear and tear' disease, that it does not necessarily worsen with ageing and that people can remain healthy and active with osteoarthritis(33, 56). One strategy could be to apply audit and feedback which has been used to change clinician behaviour in the management of other clinical groups(57). Audit and feedback to health professionals could be applied to improve the education and language used to describe osteoarthritis, to overcome and dispel patient misconceptions as well as help patients participate in decisions about their management(58). It may also be important that carers are invited to be involved in conversations and education sessions with health professionals. This approach could potentially dispel carer misconceptions about the causes of osteoarthritis and its management, may be empowering for family members(59), and may lead to improved patient adherence to treatment and better outcomes.

The overall findings highlight the importance of equipping patients and carers with information and self-management strategies to reduce the impact of knee osteoarthritis on their lives, beyond simply providing information about osteoarthritis. In particular to improve their psychosocial wellbeing, by reducing pain, maintaining function, increasing social and physical activity participation, helping patients to remain in employment, and achieve

optimal mental health. For example, one option to address patients' harmful beliefs and attitudes towards pain and damage is to address the negative or mistaken language and beliefs about their knee through education. Emphasising facts such as 'hurt does not equal harm' and 'exercise is safe'(60) and dismissing myths such as 'exercise is damaging'(55) may be fundamental to alter people's negative attitudes and may be best combined with interventions such as exercise programs to potentially improve patients' overall perception of their knee. Beliefs about a health condition are formed not only from personal experiences, but also from observing others and external sources of information such as the media. Thus, negative beliefs about knee osteoarthritis can predate the onset of the condition(61). Therefore, there may be a role for public health campaigns to dispel myths about knee osteoarthritis across society more broadly.

The main limitation of this systematic review was the exclusion of studies exploring patients' perceptions of interventions they received such as exercise or perioperative management for knee osteoarthritis. This was excluded because experiences in response to biological interventions would be expected to be different from the daily experience of living with knee osteoarthritis (the focus of this review), and should be the subject of further study. Only one study reported carer perceptions about living with knee osteoarthritis. Although the themes identified in this single study converged with 6 of the 7 themes, further enquiry may be required to confirm their perceptions. Further, given the pattern of recurring themes we identified, it is unlikely that the inclusion of subsequent studies would have substantially added to the themes we described in this review. Finally, exclusion of non-English language articles limits the generalizability as other cultures with other languages might have different perceptions of knee osteoarthritis.

Conclusion

This review highlighted the value of taking patient attitudes and experiences into account, consistent with patient-centred care, when planning and implementing management options for people with knee osteoarthritis. These findings could inform clinical practice guidelines, to help clinicians better understand the lived experience of knee osteoarthritis, optimise the patient-clinician interaction, and provide insights into how patient education may be conducted. These findings could also lead to new research questions to address patients lived experience with knee osteoarthritis and interventions to target modifiable psychological and social factors.

Contributors

JW: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript. NT: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript. SB: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript. NS: contributed to the conception and design of the review, acquisition of data, analysis and interpretation of data, contributed to the writing of the paper by revising it critically for important intellectual content and read and approved the manuscript. Patients and public were not involved in this review.

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Data sharing statement

All data relevant to the study are included in the article or uploaded as supplementary information.

Competing interest statement

All authors declare that they do not have any potential conflicts of interest.

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Figure legend

Figure 1: Yield of studies

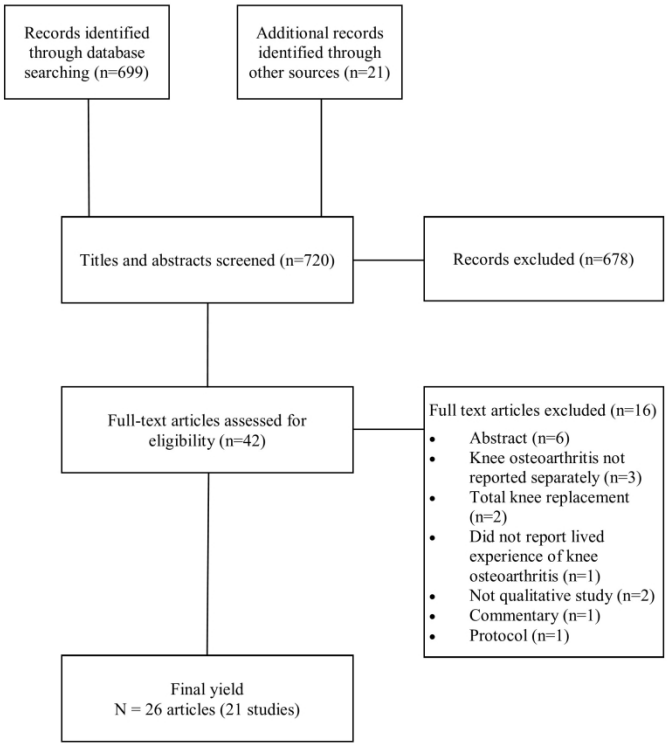

Figure1: Yield of studies

209x297mm (300 x 300 DPI)

Appendix: Search strategy in Medline

Search
1. knee osteoarthritis mp or Osteoarthritis, Knee/
2. knee/
3. Knee joint/
4. (knee adj3 osteoarthritis).mp
5. qualitative research.mp or Qualitative Research/
6. qualitative analysis.mp
7. qualitative evaluation.mp
8. qualitative study.mp
9. 1 or 2 or 3 or 4
10. 5 or 6 or 7 or 8
11. 9 and 10

/ denotes MeSH term; mp denotes keyword

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	6
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	6
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6,7 Table 1
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	9
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	9
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	9

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	10 Fig. 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	10-14 Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	15-16 Table 3
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	17
Synthesis of results	21	Present the main results of the review. If meta-analysis are done, include for each, confidence intervals and measures of consistency.	17-22
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	22
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	24
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	24
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	25

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

PRISMA 2009 Checklist

Checklist: Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ)

	Item	Guide and description	Evidence in manuscript
1	Aim	State the research question the synthesis addresses.	Research question included in introduction on page 5..
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology *(e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).*	The theoretical framework was a thematic analysis and content analysis included in the methods section of manuscript on page 9 lines 158-63. The rationale using this inductive approach to address the limitations in quantitative research was included in the introduction on page 4.
3	Approach to searching	Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved)*.	A pre-planned search was applied and registered on Prospero - registration number CRD42018108962 https://www.crd.york.ac.uk/PROSPERO. Page 6.
4	Inclusion criteria	Specify the inclusion/exclusion criteria *(e.g. in terms of population, language, year limits, type of publication, study type).*	Eligibility criteria included in methods section, pages 6-7.
5	Data sources	Describe the information sources used (e.g. *electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists)* and when the searches conducted; provide the rationale for using the data sources.	The search strategy and rationale is included in methods section of manuscript on page 6.
6	Electronic Search strategy	Describe the literature search *(e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits)*.	The search strategy was included in methods section of manuscript on page 6, lines 119-29. An example of the strategy using Medline was included (appendix, page 8).
7	Study screening methods	Describe the process of study screening and sifting *(e.g. title, abstract and full text review, number of independent reviewers who screened studies).*	This screening process was included in the search strategy in methods section of manuscript on page 6.

	Item	Guide and description	Evidence in manuscript
8	Study characteristics	Present the characteristics of the included studies *(e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).*	The study characteristics were included in Table 2 (pages 12-14).
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion *(e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).*	Study selection results were included in results section of the manuscript on page 10 and Figure 1.
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings *(e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).*	We used a checklist (CASP) that is commonly applied in qualitative reviews in musculoskeletal research. This is included in the methods section on page 9..
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings *(e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope*[25]*; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).*	The CASP checklist assesses the validity of the results, ethics, trustworthiness, clarity and value of results. This is included in the methods section on page 9..
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	The CASP appraisal was applied independently by two reviewers, included in methods section of manuscript on page 9.
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	The results of the appraisal were included in results section of manuscript on page 10, lines 174-81, and Table 3.
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).*	The text used to describe themes and sub-themes in the primary studies were assigned descriptive codes using an inductive process. - Included in methods section of manuscript on page 9.
15	Software	State the computer software used, if any.	The search results were downloaded into bibliographic software (Endnote Version 18), included in the methods, section of the manuscript

	Item	Guide and description	Evidence in manuscript
			on page 6..
16	Number of reviewers	Identify who was involved in coding and analysis.	Included the data analysis section of the methods on page 9..
17	Coding	Describe the process for coding of data *(e.g. line by line coding to search for concepts).*	The coding process was included the data analysis section of the methods on page 9.
18	Study comparison	Describe how were comparisons made within and across studies *(e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).*	A content analysis approach enabled comparison within and across studies, included in the data analysis section of the methods on page 9..
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	An inductive process was used and reported in the data analysis section in the methods, page 9..
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations of the author's interpretation.	Included in the results section of the manuscript. An example of a quotation included for theme one was 'a progressive degenerative disease' on page 17..
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. *new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).*	Included in the discussion section of the manuscript e.g. "The psychosocial impact of knee osteoarthritis emerged as the key factor in the lived experience of people with knee osteoarthritis." Previous systematic review analyses have not focused on the psychological and social impact of living with knee osteoarthritis.