PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	The experience of living with knee osteoarthritis: A systematic review of qualitative studies
AUTHORS	Wallis, Jason; Taylor, Nicholas; Bunzli, Samantha; Shields, Nora

VERSION 1 – REVIEW

REVIEWER	Crystal MacKay West Park Healthcare Centre, Canada
REVIEW RETURNED	27-Mar-2019

GENERAL COMMENTS	Thank you for the opportunity to review this well-written manuscript. The authors have conducted a systematic review of the qualitative literature on living with knee osteoarthritis from the perspective of patients and carers. Please find below my comments on the manuscript: Introduction 1) Line 10: whilst the comment on lack of correlation between pain and radiographic findings is established, it's relevance in the introduction to this paper was not clear to me. 2) Line 14: I wonder if you could give the reader the stats on unsuccessful outcomes (e.g. 20% of knees still have pain, 9% of hips following TJR) 3) While I appreciate the number of studies may be small, it would be useful to incorporate OA specific studies that include psychosocial interventions. I believe there has been a systematic review on psychological interventions for OA (Zhang et al 2018) and I am aware of some individual studies using cognitive behavior interventions and pain coping skills training that may warrant consideration in the intro or discussion. Methods 4) For data collection, were data on "results" like quotes extracted from papers? 5) Data analysis: Please provide more clarity and details on the analytic approach, including the process for conducting the thematic analysis and content analysis (e.g. what "text" was assigned codes, process for grouping codes into themes…). Discussion 6) 2nd paragraph "psychological and social impact of knee osteoarthritis emerged as the key factor…". It seems there was a specific intent to understand the psychological and social impact – if so, it may not be surprising this emerged as a key finding. Suggest the wording of the sentence be revised to indicate that this was not a finding in prior reviews but there is evidence of impact based on your analysis. 7) Page 25, paragraph 1: As per #3, could integrate what we already know about psychological interventions in OA.

	8) Page 25, line 38. As you mention, health professionals are sometimes perpetuating the perceptions of OA as part of aging or “wear and tear”. How do we overcome this to dispel patient misconceptions? 9) Can you comment further on similarities and differences between your findings and prior systematic reviews? What has this study added to the literature? 10) Were there any patterns in the findings related to patient characteristics or stage of disease across studies?

REVIEWER	Jesper Knoop Vrije Universiteit Amsterdam, Netherlands
REVIEW RETURNED	06-May-2019

GENERAL COMMENTS	This is a very well written manuscript in which the available qualitative studies on patient's and caregiver's experiences on their disease and their treatment have been summarized. I have only some suggestions for minor improvement and clarification of the manuscript. 1. The authors conducted this study for the following reason: "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." With this in mind, I would say that the authors could provide more of their thoughts on how their study findings have provided new insights into the 'role of the psychological and social dimensions of the knee osteoarthritis experience' and how this could optimize current treatment options. 2. In addition to this first suggestion, I would be very interesting if the authors could further elaborate on the differneces between patients and caregivers in their experiences hat have been identified in the included studies, and if these differences could play a role in the current suboptimal OA management. 3. Can the authors explain how they made the decisions for yes vs no in the Critical Appraisal Skills Programme (CASP) assessment? 4. The authors state that "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." For me it is unclear why the authors decided to exclude such studies. Please provide your rationale for this in the Methods and the Discussion.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
Reviewer Name: Crystal MacKay

Introduction
Comment 1, Line 10: Whilst the comment on lack of correlation between pain and radiographic findings is established, it's relevance in the introduction to this paper was not clear to me.
Response: We agree the introduction needed to be amended to make the comment on the lack of correlation between pain and radiographic findings clear and relevant. The relevance of this comment was to show that the current focus of treatment of knee osteoarthritis is to address biological changes (joint pathology). However, since painful symptoms do not correlate well with the severity of biological changes (x-ray), this suggests the focus of treatment may need to address other factors (apart from biological changes) that may affect the lived experience. Therefore, we have amended the manuscript accordingly.
Changes: Page 4. (Introduction) '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).'

Comment 2, Line 14: I wonder if you could give the reader the stats on unsuccessful outcomes (e.g. 20% of knees still have pain, 9% of hips following TJR)
Response: We agree that adding data about the rate of unsuccessful outcomes will improve the manuscript. Therefore, we have amended the paragraph in the introduction and cited two new references.
Changes: Page 4. (Introduction) '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 (Mannion et al 2009), and about 20% were not satisfied with surgical outcome one year after surgery (Bourne et al 2010).'
Changes: (References). The following two references have been added to the reference list:
- Mannion A, Kampfen S, Munqinger U, Kramers-de Quervain I. The role of patient expectations in predicting outcome after total knee arthroplasty. Arthritis Research and Therapy. 2009;11(5):R139.
- Bourne R, Chesworth B, Davis A, Mahomed N, Charron K. Patient satisfaction after total knee arthroplasty: Who is satisfied and who is not? Clin Orthop Relat Res. 2010;468(1):57-63.

Comment 3: While I appreciate the number of studies may be small, it would be useful to incorporate OA specific studies that include psychosocial interventions. I believe there has been a systematic review on psychological interventions for OA (Zhang et al 2018) and I am aware of some individual studies using cognitive behavior interventions and pain coping skills training that may warrant consideration in the intro or discussion.
Response: We agree it would be useful to incorporate results from studies using cognitive behavioural interventions specifically addressing psychosocial factors in people with knee osteoarthritis. Therefore, we have amended the introduction by citing three new references, including preliminary evidence from a systematic review (Zhang et al 2018), and a trial of cognitive behavioural interventions such as pain coping skills training (Bennell et al 2016). We have also added a reference highlighting that psychosocial interventions for another chronic musculoskeletal condition (low back pain) have received greater attention (Henschke et al 2010)

Changes: Page 4. (Introduction) ‘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 more 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 - Henschke et al 2010). 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 - Zhang et al 2018). Further, there is preliminary evidence from a randomised controlled trial that combining physiotherapist-delivered pain coping skills training with exercise therapy, can lead to greater improvements in function compared to either treatment alone (14 - Bennell et al 2016). 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.’

Changes: (References). The following three references have been added to the reference list:

- Zhang L, Fu T, Zhang Q, Yin R, Zhu L, He Y, Fu W, Shen B. Effects of psychological interventions for patients with osteoarthritis: a systematic review and meta-analysis. Psychology, Health & Medicine. 2018;23(1):1-7.
- Henschke N, Ostelo RW, van Tulder MW, Vlaeyen JW, Morley S, Assendelft WJ, Main CJ. Behavioural treatment for chronic low-back pain. Cochrane database of Systematic Reviews. 2010 (7).
- Bennell KL, Ahamed Y, Jull G, Bryant C, Hunt MA, Forbes AB, Kasza J, Akram M, Metcalf B, Harris A, Egerton T. Physical therapist–delivered pain coping skills training and exercise for knee osteoarthritis: randomized controlled trial. Arthritis care & research. 2016 May;68(5):590-602.

Methods

Comment 4: For data collection, were data on “results” like quotes extracted from papers?

Response: We extracted text related to the themes and subthemes presented in the results section of each of the included papers. Quotes (where provided) were also read. We then assigned codes (inductively) to the extracted text. These processes were adapted from the Sandelowski and Barroso approach. We have amended both the data collection and data analysis sections of the manuscript for clarity.

Changes: Page 9. (Methods - Data collection process) ‘From the results section of each included paper, we extracted the main themes and subthemes as outlined below’

Changes: Pages 10-11. (Methods - 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.’

Changes: (References). The following reference has been added to the reference list:

• Sandelowski M, Barroso J. Handbook for Synthesizing Qualitative Research. New York: Springer Publishing Company Inc; 2007.

Comment 5, Data analysis: Please provide more clarity and details on the analytic approach, including the process for conducting the thematic analysis and content analysis (e.g. what "text" was assigned codes, process for grouping codes into themes…).
Response: Greater detail has been provided in the data analysis section as per comment 4 and repeated below.
Changes: Pages 10-11 (as per changes to comment 4). (Methods -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.'
Changes: (References). The following reference has been added to the reference list:
• Sandelowski M, Barroso J. Handbook for Synthesizing Qualitative Research. New York: Springer Publishing Company Inc; 2007.

Discussion
Comment 6, 2nd paragraph: "psychological and social impact of knee osteoarthritis emerged as the key factor…". It seems there was a specific intent to understand the psychological and social impact – if so, it may not be surprising this emerged as a key finding. Suggest the wording of the sentence be revised to indicate that this was not a finding in prior reviews but there is evidence of impact based on your analysis.
Response: Our aim was to understand the lived experience of people with knee osteoarthritis (and their carers) and the psychological and social impact of knee OA emerged as a clear theme from the data analysis. We agree we need to amend the wording of this sentence in the discussion to reflect this. We have also amended the wording in the introduction to clarify the aim of this review.
Changes: Page 22. (Discussion) '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.'
Changes: Page 6. (Introduction) '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.'

Comment 7, Page 25: paragraph 1: As per #3, could integrate what we already know about psychological interventions in OA.
Response: We have amended the discussion as recommended to integrate what we already know about psychological interventions in OA, and cited a clinical practice guideline for the management of knee and hip osteoarthritis (RACGP 2018).
Changes: Page 23. (Discussion) 'Hence, offering a psychological intervention such as cognitive behavioural therapy (13 - Zhang et al 2018) 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- RACGP 2018). Combined with exercise, the guidelines suggest these interventions may improve pain, self-efficacy, pain coping, depression, and anxiety (48 - RACGP 2018).'

Comment 8, Page 25, line 38: As you mention, health professionals are sometimes perpetuating the perceptions of OA as part of aging or "wear and tear". How do we overcome this to dispel patient misconceptions?
Response: We agree it is important to discuss possible strategies to dispel patient misconceptions and we have included a new reference to support this (Bunzli et al 2019). One example to change health professional behaviour is to apply 'audit and feedback', to improve the education and language used to describe osteoarthritis and to overcome and dispel patient misconceptions. Audit and feedback has been used management with other conditions, and we have added two supporting references (Vratsistas-Curto et al 2017, and Ivers et al 2012).
Changes: Page 24. (Discussion) '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 - Bunzli et al 2019). 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 - Vratsistas-Curto et al 2017). 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 - Ivers et al 2012).'
Changes: (References). The following three references have been added to the reference list:
- Bunzli et al. 2019. Misconceptions and the acceptance of evidence-based non-surgical interventions for knee osteoarthritis. CORR
- Vratsistas-Curto A, McCluskey A, Schurr K. Use of audit, feedback and education increased guideline implementation in a multidisciplinary stroke unit. BMJ Open Qual. 2017 Nov 1;6(2):e000212.
- Ivers N, Jamtvedt G, Flottorp S, Young JM, Odgaard-Jensen J, French SD,O'Brien MA, Johansen M, Grimshaw J, Oxman AD.Audit and feedback: effects on professional practice and healthcare outcomes.Cochrane Database of Systematic Reviews 2012, Issue 6. Art. No.: CD000259

Comment 9: Can you comment further on similarities and differences between your findings and prior systematic reviews? What has this study added to the literature?
Response: Our study highlights the magnitude of the psychosocial impacts of living with knee osteoarthritis. We have amended the manuscript (discussion) to highlight this, as well as the similarities and difference with two prior systematic reviews.
Changes: Page 22-23. (Discussion) '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 - Bakas et al 2012), 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.'
Changes: (References). The following reference has been added to the reference list:
- Bakas T, McLennon S, Carpenter J, Buelow J, Otte J, Hanna K, et al. Systematic review of health-related quality of life models. Health and Quality of Life Outcomes. 2012;10

Comment 10: Were there any patterns in the findings related to patient characteristics or stage of disease across studies?
Response: Themes were consistent between studies that included people with severe OA (5 studies) and mild-moderate OA (3 studies).
Changes: Page 17. (Results) 'Themes were consistent between studies that included people with severe osteoarthritis and mild to moderate osteoarthritis.'

Reviewer: 2
Reviewer Name: Jesper Knoop
Institution and Country: Vrije Universiteit Amsterdam, Netherlands

Comment 1: The authors conducted this study for the following reason: "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." With this in mind, I would say that the authors could provide more of their thoughts on how their study findings have provided new insights into the 'role of the psychological and social dimensions of the knee osteoarthritis experience' and how this could optimize current treatment options.
Response: The new insights on the role of the psychological and social dimensions of the knee osteoarthritis experience from our review is the magnitude of the impact in these dimensions. Therefore, we believe greater attention could be paid to addressing these dimensions of knee osteoarthritis (rather than just being aware of it), which may not be addressed with common interventions such as exercise or surgery that don't specifically target these elements. For example, to optimise treatment with the addition of new psychological or social interventions makes sense from a biopsychosocial perspective. We also found patients want to be listened to, be offered hope for the future, and be provided with recommendations for managing knee osteoarthritis. We have amended the discussion to reflect this, and including a new reference (13 - Zhang et al 2018) and cited a clinical practice guideline (RACGP 2018) with preliminary findings that adding psychosocial interventions may improve outcomes for people with knee osteoarthritis.
Changes: Page 22. (Discussion)
'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.'
Changes: Page 23. (Discussion) 'Hence, offering a psychological intervention such as cognitive behavioural therapy (13 - Zhang et al 2018) 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 - RACGP 2018). Combined with exercise, the guidelines suggest these interventions may improve pain, self-efficacy, pain coping, depression, and anxiety (48 - RACGP 2018).'
Changes: Page 22. (Discussion) '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.'
Changes: (References). The following reference has been added to the reference list:
- Zhang L, Fu T, Zhang Q, Yin R, Zhu L, He Y, Fu W, Shen B. Effects of psychological interventions for patients with osteoarthritis: a systematic review and meta-analysis. Psychology, Health & Medicine. 2018;23(1):1-7.

Comment 2: In addition to this first suggestion, I would be very interesting if the authors could further elaborate on the differences between patients and caregivers in their experiences that have been

identified in the included studies, and if these differences could play a role in the current suboptimal OA management.
Response: The study including caregivers (family members of the participants from one trial), captured 6 of the 7 major themes. We have added this to the results. Given the similarities in themes identified by participants and their carers, this suggests including carers in management may be an important strategy to improve outcomes of people with knee osteoarthritis. For example, involving carers in conversations or education sessions with health professionals may help to dispel any carer misconceptions of the causes of knee osteoarthritis and its management. We have amended the discussion to address this and include one new reference (59 - Lawler et al 2019).
Changes: Page 17. (Results) '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.'
Changes: Page 24. (Discussion) '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 - Lawler et al 2019), and may lead to improved patient adherence to treatment and better outcomes.
Changes: Page 24. (Discussion) '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.'
Changes: (References). The following reference has been added to the reference list:
• Lawler K, Taylor NF, Shields N. Family-assisted therapy empowered families of older people transitioning from hospital to the community: a qualitative study. Journal of Physiotherapy. 2019 Jun 13.

Comment 3: Can the authors explain how they made the decisions for yes vs no in the Critical Appraisal Skills Programme (CASP) assessment?
Response: Two authors independently read the descriptors for each item of the CASP, and then made a judgment of yes or no. The individual descriptors were not weighted or scored. The two authors then met and discussed any discrepancies to reach a consensus. We have amended the manuscript accordingly.
Changes: Page 9. (Methods) 'The Critical Appraisal Skills Programme (CASP) checklist was used to assess methodological quality of the included studies (15). 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 (16, 17).'

Comment 4: The authors state that "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." For me it is unclear why the authors decided to exclude such studies. Please provide your rationale for this in the Methods and the Discussion.
Response: The focus of this review was on the lived experience with knee osteoarthritis, and was not focused on the response from receiving specific interventions for knee osteoarthritis. Therefore, studies that explored experiences of participation in specific interventions for knee osteoarthritis were excluded in this review, and we acknowledged that this is an area of further research. We have added a rationale in the methods and also amended the rationale in the discussion.
Changes: Page 7. (Methods) '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).'
Changes: Page 25. (Discussion) '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.'

VERSION 2 – REVIEW

REVIEWER	Crystal MacKay West Park Healthcare Centre, Canada
REVIEW RETURNED	26-Aug-2019

GENERAL COMMENTS	Dear Authors, Thank you for the opportunity to review your manuscript again and for the extensive revisions that have addressed all of my comments. I have no further comments or questions. All the best with your work.