# PEER REVIEW HISTORY

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# **ARTICLE DETAILS**

TITLE (PROVISIONAL)	A Qualitative Study of the Consequences of Knee Symptoms: "It's
	like you're an athlete and you go to a couch potato."
AUTHORS	MacKay, Crystal; Jaglal, Susan; Sale, Joanna; Badley, Elizabeth;
	Davis, Aileen

# **VERSION 1 - REVIEW**

REVIEWER	Jane Richardson
	Keele University
	United Kingdom
REVIEW RETURNED	09-Jul-2014

GENERAL COMMENTS	This is a clearly written based on a simple, well-designed study. It explores an under-researched area (knee OA in younger adults). It is not clear whether focus groups were used as little more than group interviews – there is no evidence of the interaction between the group members sparking different experiences, stories etc. The topic guide also suggests that these were viewed simply as group interviews. If this is not the case, it needs to be made clearer in the article. At the very least, patient excerpts should identify if they are
	from individual interviews or focus groups.

REVIEWER	Ben Darlow
	University of Otago, Wellington, New Zealand
REVIEW RETURNED	20-Jul-2014

GENERAL COMMENTS	Thank you for asking me to review this interesting paper which addresses an important topic of research. These findings are useful for highlighting the impact which knee pain has upon the lives of people aged 35-65 years and should be informative for a range of clinicians. I have two key recommendations for improving this paper, a number of additional suggestions.
	1) Study Objective - My main concern is that there seems to be a general lack of clarity as to whether this is a study about knee symptoms or osteoarthritis. The title and the objective stated in the abstract suggest this is a study about knee symptoms, however, in the strengths and limitations it is stated that recruitment was designed to carefully select those who do not have OA. The introduction, discussion, and conclusion are almost entirely devoted to OA. The aim should be clarified and be consistent with other elements of the paper. This is particularly important for clarifying the populations to which the research may be applicable, as well as the limitations associated with the sampling frame.

2) Study Limitations - The limitations associated with this study should be discussed in more depth. If indeed the aim was to explore the consequences of OA, this is a significant limitation. The knee joint question only asks if someone has experienced pain, aching, or stiffness in or around the knee joint. People who have a number of other conditions such as patellofemoral pain, tendinopathy, Baker's cyst, and bursitis could also respond positively to this question and would not be excluded by the criteria used. If, as the stated aim suggests, the study is about the consequences of knee symptoms, this is less of a concern. It would also be worth expanding upon the effect that having few participants working in manual jobs may have had upon the analysis, the limitations of the analytical process used including only one researcher conducting the interviews and coding the data, and the ability to generalise these findings to other populations.

In addition, I have suggestions which the authors may wish to address to improve the presentation of their paper

### 1) Introduction

Paragraph 1 - this discusses the importance of a paradigm shift and screening for and treating osteoarthritis during the early stages of the disease to prevent structural changes. Although this may be very beneficial, it is unclear how this relates to the current study which is about the consequences of knee pain rather than how OA may be identified or managed.

Paragraph 2 - With regards to the study aim, it should be made clear that this report is part of a larger study of people with knee pain which had broader aims and that this analysis aimed to specifically explore the consequences. This would help to clarify why some of the topic areas from focus groups and interviews reported in Table 1 are not mentioned in this report.

### 2) Methods

Sampling and data collection

Paragraph 1 - It would be helpful to clarify why people who were awaiting TJR were excluded from the study when these people would quite clearly have osteoarthritis. It would also be useful to know if there was a minimum duration of symptoms required, or if one month of pain was sufficient to be included?

Paragraph 2 - 'these' should be inserted into the sentence 'The methods for conducting [these] focus groups have been described elsewhere.' I would suggest that this statement be moved to the start of the methods section to clarify that the methods have been described in more depth previously, and that the methods section in this paper is intended as a more succinct overview.

#### Analysis

Paragraph 1- as one researcher conducted the interviews and coded the data, it would be helpful to explain how the potential bias associated with this approach was managed.

Paragraph 2 - it is mentioned that an audit trail was maintained, was an audit conducted?

#### 3) Results

The results are generally well presented and they appear to be supported by the data.

### Physical disruption

Paragraph 1 - It would be very interesting to present data related to why participants reduced or gave up activities. Was this due to the pain itself whilst participating in activity, fear of pain afterwards, perceptions that activity may accelerate joint degeneration et cetera? Given the importance of physical activity, as discussed in paragraphs 3 and 7 of the discussion, data relating to participants views of the interaction between physical activity and their knee structure and function would be very illuminating. This also relates to the regret about previous activity mentioned in the last sentence of this paragraph, which would be interesting to expand upon.

#### "New Think"

This is an important finding which also has implications for pain perception by way of increased vigilance and attention, as well as the biomechanical alterations discussed. Although this sub-category title has been taken directly from a participant quotation, I do not feel that it adequately encapsulates the category. I would recommend changing it to something like 'New Awareness' or a 'New Way of Thinking'

Table 2 - The description of the participants could be improved by reporting the number of participants who had received diagnoses of OA and the duration of participants' symptoms.

Table 3 - It would be useful to report in a footnote what these scores mean. Although this information is available within the text, the table would be easier to interpret if it contained all of the relevant information

### 4) Discussion

Paragraph 1 - the final two sentences of this paragraph could be revised. It is unclear how recognising the consequences of knee symptoms will delay disease progression. I assume that the last sentence is intended to mean that people work proactively to manage their symptoms because these symptoms have a large impact upon their lives? This could be clarified.

## 5) General

Superscript reference numbers need to be moved after full stops and comma

REVIEWER	Poiraudeau, Serge AP-HP, Cochin Hospital, Department of RMDs, Physical and Rehabilitation Unit; University Paris Descartes;
REVIEW RETURNED	26-Jul-2014

GENERAL COMMENTS	The strength of this study is that the question of the burden of knee
	pain/OA is addressed among younger people that it has usually

been done.
Qualitative approaches are needed to better understand patients'
views and needs. Although, results of this study are not totally new,
they are helpful to define patient-centered treatment strategies.

### **VERSION 1 – AUTHOR RESPONSE**

### Response to Reviewer Jane Richardson

This is a clearly written based on a simple, well-designed study. It explores an under-researched area (knee OA in younger adults).

It is not clear whether focus groups were used as little more than group interviews – there is no evidence of the interaction between the group members sparking different experiences, stories etc. The topic guide also suggests that these were viewed simply as group interviews. If this is not the case, it needs to be made clearer in the article. At the very least, patient excerpts should identify if they are from individual interviews or focus groups.

Response: Further details have been added to the methods in order to illustrate that group interaction was encouraged in the focus groups in order to compare and contrast experiences. Specifically, participants were encouraged to share their experiences, even if they differed from others' experiences. Discussion amongst the group (e.g. questioning one another and commenting on others' experiences) was encouraged and facilitated by the moderator. For instance, after a participant shared an experience, the moderator might probe "Has anyone else had a similar or different experience?" These changes to the manuscript can be found on pages 6-7. In addition, evidence of this has been added to the results using quotes from the focus groups (within the manuscript on page 20 and in Table 4).

As suggested, the quotes have been revised to identify if they were from a focus group or interview.

# Response to Reviewer Ben Darlow

Thank you for asking me to review this interesting paper which addresses an important topic of research. These findings are useful for highlighting the impact which knee pain has upon the lives of people aged 35-65 years and should be informative for a range of clinicians. I have two key recommendations for improving this paper, a number of additional suggestions.

1) Study Objective - My main concern is that there seems to be a general lack of clarity as to whether this is a study about knee symptoms or osteoarthritis. The title and the objective stated in the abstract suggest this is a study about knee symptoms, however, in the strengths and limitations it is stated that recruitment was designed to carefully select those who do not have OA. The introduction, discussion, and conclusion are almost entirely devoted to OA. The aim should be clarified and be consistent with other elements of the paper. This is particularly important for clarifying the populations to which the research may be applicable, as well as the limitations associated with the sampling frame.

Response: For this study, we were interested in the consequences of knee symptoms on the lives of younger adults with a diagnosis of OA or OA-like symptoms in order to inform the development of early interventions. As such, we sought participants aged 35-65 years who had diagnosed OA or symptoms that were consistent with OA of the knee. Participants were recruited from the community using advertisements in a community paper, community centres and an acute care hospital. We included participants aged 35-65 years who self-reported a diagnosis of OA or responded affirmatively to a widely used survey question [1] on knee symptoms (pain, aching and/or stiffness on most days of the past month) since younger adults may not have a formal diagnosis or perceive their

symptoms to be OA. Exclusion criteria were used to restrict the study to participants who were likely experiencing OA symptoms. The exclusion criteria were: knee injury in the past year, knee pain referred from the low back, other types of arthritis, other chronic conditions affecting mobility, or those who had been recommended, were waiting for or had TKR.

To clarify the intent of the paper, the manuscript has been revised to state: "This study aimed to fill this gap and explore the perceived consequences of knee symptoms on the lives of people aged 35-65 years who had diagnosed knee OA or symptoms that were consistent with knee OA." This is revised in the abstract and body of the manuscript (page 5). Since not all participants had a diagnosis of OA, we will use the term knee symptoms rather than OA when describing the study results. This is stated in the manuscript. Limitations associated with the study are discussed in more detail in the discussion (see below).

2) Study Limitations - The limitations associated with this study should be discussed in more depth. If indeed the aim was to explore the consequences of OA, this is a significant limitation. The knee joint question only asks if someone has experienced pain, aching, or stiffness in or around the knee joint. People who have a number of other conditions such as patellofemoral pain, tendinopathy, Baker's cyst, and bursitis could also respond positively to this question and would not be excluded by the criteria used. If, as the stated aim suggests, the study is about the consequences of knee symptoms, this is less of a concern. It would also be worth expanding upon the effect that having few participants working in manual jobs may have had upon the analysis, the limitations of the analytical process used including only one researcher conducting the interviews and coding the data, and the ability to generalise these findings to other populations.

Response: The limitations paragraph in the discussion has been expanded to discuss the study sample and acknowledge the limitations of the inclusion/exclusion criteria. While we paid careful attention to the development of our inclusion and exclusion criteria in order to best meet our study aim, we acknowledge that there is a chance that some participant's knee symptoms could have been the result of conditions other than OA. However, in a study of middle-aged patients with chronic knee pain, the majority developed OA; the authors concluded that knee pain is often the first sign of knee OA [2]. Other research has shown that joint complaints (i.e. pain) are one of the most important predictors of the development of radiographic OA [3]. The reviewer mentioned a number of other conditions for which people might respond positively to the joint symptoms question. A recently published paper on patellafemoral pain found that underlying radiographic OA was highly prevalent in middle-aged and older adults (> age 40) with a clinical diagnosis consistent with chronic patellofemoral pain [4]. In addition, periarticular lesions, such as bursitis and Baker's cyst, can coexist with knee OA [5;6]. In sum, it is hoped that by clarifying the study sample in our study aim as well as discussing the potential limitations in our criteria, the study findings will be understood within the context of the work.

We have expanded on the effect of having fewer participants in manual labour jobs in the discussion comparing this paper to the literature (page 21-22). The following points were added to the discussion on the limitations of the study: "In addition, only one researcher conducted the focus groups and interviews and coded the data. There is the potential that this could limit alternative interpretations of the data and competing explanations. To mitigate this, all authors were involved in interrogating the data when reviewing the transcripts and participating in regular group discussions. Finally, qualitative methods allowed us to develop concepts that helped us to understand individuals' experiences with knee symptoms. Further work would be needed to investigate the transferability of our findings to the population of adults aged 35-65 years with knee symptoms."

Please note, in order to improve the flow of the manuscript, the paragraph on limitations has been moved to the end of the discussion.

In addition, I have suggestions which the authors may wish to address to improve the presentation of their paper

## 1) Introduction

Paragraph 1 - this discusses the importance of a paradigm shift and screening for and treating osteoarthritis during the early stages of the disease to prevent structural changes. Although this may be very beneficial, it is unclear how this relates to the current study which is about the consequences of knee pain rather than how OA may be identified or managed.

Response: In order to support early management, which may have the potential to prevent progression, we first need to understand the consequences of symptoms in peoples' lives. By understanding the consequences of symptoms, relevant interventions can be developed which address peoples' needs and are acceptable to them. The manuscript has been revised to emphasize this argument by adding a sentence to the end of paragraph 1: "A prerequisite to delivering accessible and acceptable care is an understanding of the effects of disease on people's everyday lives [7]. As such, an important first step in developing effective interventions to support early management in younger adults is understanding the experience of OA and its consequences."

Paragraph 2 - With regards to the study aim, it should be made clear that this report is part of a larger study of people with knee pain which had broader aims and that this analysis aimed to specifically explore the consequences. This would help to clarify why some of the topic areas from focus groups and interviews reported in Table 1 are not mentioned in this report.

Response: In order to maintain the flow of the introduction, a statement has been added to the beginning of the methods section to clarify this. It now reads: "This study used qualitative methods, comprising focus groups and one-on-one interviews. While this work explored the consequences of knee symptoms, it is part of a broader study exploring the perceptions, experiences and management of knee symptoms. The methods for conducting these focus groups have been described elsewhere.

#### 2) Methods

## Sampling and data collection

Paragraph 1 - It would be helpful to clarify why people who were awaiting TJR were excluded from the study when these people would quite clearly have osteoarthritis. It would also be useful to know if there was a minimum duration of symptoms required, or if one month of pain was sufficient to be included?

Response: People who were waiting for TJR were excluded from the study as they are more likely to have end stage OA with substantial pain and disability. This has been added to the text. The question asked participants about their knee symptoms in the last month. No additional minimum duration was required, although participants discussed their symptoms in terms of multiple months and years.

Paragraph 2 - 'these' should be inserted into the sentence 'The methods for conducting [these] focus groups have been described elsewhere.' I would suggest that this statement be moved to the start of the methods section to clarify that the methods have been described in more depth previously, and that the methods section in this paper is intended as a more succinct overview.

Response: As suggested, "these" was inserted into the sentence and the sentence was moved to the beginning of the methods section.

### Analysis

Paragraph 1- as one researcher conducted the interviews and coded the data, it would be helpful to explain how the potential bias associated with this approach was managed.

Response: To ensure credibility in the research process, all authors met regularly to discuss the data and ongoing analysis. All authors reviewed the coding scheme developed by the first author. Content of codes, including specific quotes, were presented and discussed at regular meetings and codes were subsequently further refined. Moreover, the senior author read all transcripts and discussed them with the first author at regular meetings. All authors read the majority of the transcripts and met regularly to discuss the data and ongoing analysis, including alternate interpretations of the data. Use of a reflexive diary and group discussions also provided an opportunity for reflexive sharing to consider how the researchers' assumptions and beliefs might impact interpretation of data. Revisions have been made to the methods to provide further detail on how the research processes mitigated the potential bias associated with one researcher conducting the interviews and coding the data.

Paragraph 2 - it is mentioned that an audit trail was maintained, was an audit conducted?

Response: An audit trail was maintained but an audit was not conducted. This has been clarified in the manuscript.

### 3) Results

The results are generally well presented and they appear to be supported by the data.

#### Physical disruption

Paragraph 1 - It would be very interesting to present data related to why participants reduced or gave up activities. Was this due to the pain itself whilst participating in activity, fear of pain afterwards, perceptions that activity may accelerate joint degeneration et cetera? Given the importance of physical activity, as discussed in paragraphs 3 and 7 of the discussion, data relating to participants views of the interaction between physical activity and their knee structure and function would be very illuminating. This also relates to the regret about previous activity mentioned in the last sentence of this paragraph, which would be interesting to expand upon.

Response: Thank you for the opportunity to expand further upon the disruption in physical activity experienced by participants. Some participants indicated that they gave up or changed their physical activity due to the symptoms, particularly pain, which they experienced while doing the activity. Another reason participants gave for changing physical activity was their concern that some physical activities, particularly those perceived to be high impact like running, might cause further "damage" or joint degeneration in their knee and even accelerate the need for surgery. This has been added to the manuscript with illustrative quotes.

Further detail and examples have also been provided to illustrate the final points in paragraph 1. Specifically, the manuscript now reads: "Some participants struggled with whether and when to give up activities. For instance, some participants expressed concern for their knee but were unclear what activities they should avoid. Other participants wished they had given up activities they perceived had caused damage to their knee, such as running, "collision" sports or squash, or changed activities earlier to prevent or reduce their current knee symptoms."

## "New Think"

This is an important finding which also has implications for pain perception by way of increased vigilance and attention, as well as the biomechanical alterations discussed. Although this subcategory title has been taken directly from a participant quotation, I do not feel that it adequately

encapsulates the category. I would recommend changing it to something like 'New Awareness' or a 'New Way of Thinking'

Response: Thank you for the suggestion. The category has been changed to "A New Awareness".

Table 2 - The description of the participants could be improved by reporting the number of participants who had received diagnoses of OA and the duration of participants' symptoms.

Response: While the duration of symptoms often emerged in the discussions, we did not ask all participants to report a specific number of months/years. As such, we have chosen not to present these data. The number of participants who had a diagnosis of OA/ OA-like symptoms has been added to the table.

Table 3 - It would be useful to report in a footnote what these scores mean. Although this information is available within the text, the table would be easier to interpret if it contained all of the relevant information

Response: A footnote has been added to the table to provide this information.

## 4) Discussion

Paragraph 1 - the final two sentences of this paragraph could be revised. It is unclear how recognising the consequences of knee symptoms will delay disease progression. I assume that the last sentence is intended to mean that people work proactively to manage their symptoms because these symptoms have a large impact upon their lives? This could be clarified.

Response: The last sentences of paragraph one of the discussion have been clarified. They now state: "Our findings underscore the importance of recognizing the consequences of knee symptoms in younger adults in order to develop health and community based supports to address peoples' complex needs. Our findings also provide insight into previous research which showed that people with knee symptoms were proactive in working to manage symptoms [8]. People may have been motivated to work hard to find ways to manage symptoms due to the significant disruption and change that resulted from symptoms (e.g. disruption in physical activity).

### 5) General

Superscript reference numbers need to be moved after full stops and comma

Response: These changes have been made to the manuscript.

Response to Reviewer Poiraudeau

The strength of this study is that the question of the burden of knee pain/OA is addressed among younger people that it has usually been done.

Qualitative approaches are needed to better understand patients' views and needs. Although, results of this study are not totally new, they are helpful to define patient-centered treatment strategies.

Response: Thank you for your positive review of the manuscript.

Thank you again to all the reviewers for their valuable comments and suggestions.

### Reference List

- (1) Centres for Disease Prevention and Control. QuickStats: Percentage of adults reporting joint pain and stiffness A National Health Interview Survey, United States, 2006. MMWR 2013; 57(17):467.
- (2) Thorstensson CA, Andersson ML, Jonsson H, Saxne T, Petersson IF. Natural course of knee osteoarthritis in middle-aged subjects with knee pain: 12-year follow-up using clinical and radiographic criteria. Ann Rheum Dis 2009; 68(12):1890-1893.
- (3) de Klerk BM, Willemsen S, Schiphof D, van Meurs JB, Koes BW, Hofman A et al. Development of radiological knee osteoarthritis in patients with knee complaints. Ann Rheum Dis 2012; 71(6):905-910.
- (4) Hinman RS, Lentzos J, Vicenzino B, Crossley KM. Is Patellofemoral Osteoarthritis Common in Middle-Aged People With Chronic Patellofemoral Pain? Arthritis Care Res (Hoboken ) 2014; 66(8):1252-1257.
- (5) Hill CL, Gale DR, Chaisson CE, Skinner K, Kazis L, Gale ME et al. Periarticular lesions detected on magnetic resonance imaging: prevalence in knees with and without symptoms. Arthritis Rheum 2003; 48(10):2836-2844.
- (6) Picerno V, Filippou G, Bertoldi I, Adinolfi A, Di S, V, Galeazzi M et al. Prevalence of Baker's cyst in patients with knee pain: an ultrasonographic study. Reumatismo 2013; 65(6):264-270.
- (7) Murray SA, Kendall M, Carduff E, Worth A, Harris FM, Lloyd A et al. Use of serial qualitative interviews to understand patients' evolving experiences and needs. BMJ 2009; 339:b3702.
- (8) Mackay C, Badley EM, Jaglal SB, Sale J, Davis AM. "We're All looking for solutions": A qualitative study of the management of knee symptoms. Arthritis Care Res (Hoboken ) 2014.

## **VERSION 2 – REVIEW**

REVIEWER	Ben Darlow
	University of Otago, New Zealand
REVIEW RETURNED	01-Sep-2014

GENERAL COMMENTS	The authors have appropriately revised the manuscript to address
	my concerns