

PaCER REPORT

Report on the PaCER Component of the Knee OsteoArthritis and Self-management Knowledge (KOASK) Translation Project

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Introduction and Background

This is the report of the PaCER component of the *Building Partnerships to Improve Care of Early Knee Osteoarthritis Patients* a knowledge translation project funded by CIHR and led by Dr. Deborah Marshall, Faculty of Medicine, the University of Calgary. The aim of this co-design project is to create a tool called KOASK that provides a quantitative measure of a clear, expected course of osteoarthritis (OA) and promote the use of self-management strategies to slow the progress of knee OA. The PaCER component informed the basis of a workshop where patients, family physicians and researchers co-designed a tool to assist patients self-manage their osteoarthritis and help their family physicians assess their risk for disease progression.

The PaCER research was done by Jean Miller and Sylvia Teare, two Lead Researchers with knee OA from the Patient and Community Engagement Research (PaCER) program at the University of Calgary. The PaCER program provides support in designing research projects; supervising and mentoring PaCER researchers; and overseeing the activities to assure methodological quality and the consistency of PaCER methods in the context of a particular study. As people with related health conditions PaCER researchers have been trained in an established protocol of qualitative inquiry to carry out patient-to-patient research that leads to a robust collective patient voice to health research. The protocol was originally developed by Dr. Marlett and Dr. Emes (Marlett & Emes, 2010) for a seniors' resiliency project and further refined in an innovative collaborative project between Alberta Health Services and the University of Calgary with support from Vecova Centre for Disability Services and Research and the Arthritis Society, and funded by the Canadian Foundation for Healthcare Improvement. This collaborative project led to the PaCER program which has been shown to be successful in

bringing a stronger patient voice to health care transformation (Marlett, Shklarov, Marshall, Santana, & Wasylak, 2014).

The PaCER Method in the KOASK Project

This section begins with an overview of the inductive PaCER method founded in grounded theory and the method used for the KOASK. This is followed by information about the participants, and a description of the data collection and analysis.

PaCER in KOASK

The PaCER research method has 3 phases: *set*, *collect*, and *reflect*. The *set* phase focus group clarifies the scope and direction of the study. Data is then collected (*collect* phase) from patients using focus groups, interviews, observation, or questionnaires. In the *reflect* phase patients participate in another focus group where they come to a common understanding of the *collect* findings and make suggestions on future research directions and knowledge dissemination. This iterative approach driven by patients working with patients brings a clearly patient voice to health system change. It results in a shared collective understanding of the issue, one that is solidly grounded in patient experience. In consultation with Dr. Marshall's research team it was decided the PaCER approach for KOASK would build on the findings of two earlier OA PaCER studies that used this method which is founded in grounded theory: the internship study carried out by Jean, Sylvia and their classmates (Bryk, Lewis, Miller, Penman, & Teare, 2013); and the PaCER component of the Arthritis Society Models of Care (AS MOC) research project (Miller & Teare, 2016).

Participants in the internship study found their first challenge was getting the attention of their family physicians who sometimes sent the message that OA is part of aging and they should

“just suck it up and live with it” (Bryk et al, p16). They were told to come back when the pain gets worse, but they weren’t sure just how bad “worse” is. This left study participants not knowing what to expect and do, leading to a “vicious cycle of more pain, less mobility, more weight gain which in turn leads to less activity, more pain and more weight gain” (Bryk et al, p25). What they needed was to be told what they should report to their physicians and when, and what they should be doing in the meantime. The need for better information was also reported by the participants in the AS MOC study. Here participants were more specific about what they needed to know: the stages of OA progression and corresponding self-management; triggers for returning to their health professional; and easy access to trusted information that is “comprehensive, no-nonsense; what I should do and shouldn’t to” (Miller & Teare, p7). Along with information participants said they need timely access and re-access to health professionals with OA expertise: “You are coming back to a place that knows you: you don’t need to start at square one every time, telling them about you, and they’d know what you’ve already done” (Miller & Teare, p11). They also needed to know what each professional can do for them and where to turn when the help they are getting isn’t working. Their relationships with these health professionals needs to be an ongoing partnership, one that supports their self-management of their OA: “I want the system to reflect my willingness to be a partner in all of this. It’s mine to live with the rest of my life” (Miller & Teare, p12). The OA patients in both these studies experienced gaps between what they need to manage their osteoarthritis and what is available from the health care system. They made it clear that what they need is specific up-to-date information and ongoing self-management support, needs that align well with the ongoing nature of the patient/family physician relationships.

The results of these studies were considered a solid starting point for developing a tool that helps patients’ self-manage their arthritis and facilitates communication with their family doctors. Building on these findings that used an inductive method, the PaCER Leads used a deductive approach for the KOASK project: their interviews focused on OA patients’ experiences with their family physicians and their perspectives on a tool that would help them self-manage their arthritis.

Participants

Participants were recruited from among those who had taken part in previous OA PaCER studies. The Lead Researchers focused their recruitment efforts on those they thought would be interested in providing input into the development of an electronic tool. Seven people received email invitations to be interviewed and the 5 people who expressed an interest were emailed the consent form. This was followed by a phone call from one of the Lead Researchers where the study and the consent form were explained. All participants met the inclusion criteria: they had experienced knee pain on most days of the month at any time in the past and any pain in the last 12 months. Three women and 2 men took part in the study. Typically they had experienced knee pain for several years before seeking help from their family physicians, had injections in the past few years. None had had knee replacement surgery. Their ages ranged from 57 to 72 and their average age was 63.6. The age groups are listed in Table 1.

Age Groups	Number/percentage of participants
50s	2 (40%)
60s	1 (20%)
70s	2 (40%)
	Total: 5

Table 1: Participant Age Groups

Data Collection and Analysis

The interview guide was developed by Jean and Sylvia and approved by the KOASK research team: See Appendix A. One Lead Researcher set up the individual face-to-face appointments. Prior to the interview participants received the consent form which included a description of the research. Both researchers were present for 4 of the 5. Interviews began with a review and signing of the consent form. The interviews were done in a conversational style with one researcher posing the questions and the other taking notes. As is the nature of patients talking to other patients, the interviews became a three way conversation. Interviews lasted between 45 and 60 minutes. Interviews were taped and transcribed.

The data from each interview was coded according to the interview guide: when they first went to the doctor with knee pain; what happened at the first and subsequent physician visits and what suggestions and referrals did they make; whether they had had x-rays; what things they had done to help their OA; barriers they face in managing their OA; and what the family physician could do better. The coded information for all 5 participants was compiled into separate documents for each of these areas. The two PaCER researchers analyzed this data for key messages related to participants' visits to their family physicians about their OA and their perspectives on a tool to help them and their physicians monitor their OA and self-management strategies.

Findings

In this section of the report the findings pertaining to participants' encounters with their family physicians about their OA are presented. This is followed by participants' perspectives on a tool to help them and their family physicians monitor and manage their OA.

Participants’ encounters with their family physicians

With respect to their encounters with their family physicians participants said they need:

- 1) their knee pain to be taken as seriously as their more life-threatening health problems; 2) to know what lies ahead and what they should be doing now; 3) them to be receptive to non-traditional arthritis treatments; 4) to be able to openly tell their physicians what they are doing to manage their OA; 5) them to take the time to listen to their issues about weight loss and help them find something that works; 6) to be told when they should come back to see the physicians; and 7) specific information on exercises, equipment (e.g. TENS, ice), and links to resources.

Participant quotes related to each of these are presented in Table 2.

<p>Patients need their knee pain to be taken as seriously as their more life-threatening health problems</p> <ul style="list-style-type: none"> • P1 thinks physicians have “<i>a prejudice</i>” about the disease: “<i>they think there’s not much they can do about it and its old people and they don’t like treating old people</i>”. • A lady who recently had open heart surgery: “<i>It’s (OA) one of those things they can’t do much about so they don’t want to deal with it....there are other more important things</i>” “<i>I don’t know, I just feel it’s not that important to him.</i>” (P2)
<p>Physicians need to tell patients specifically about what lies ahead and what they should do to manage their OA.</p> <ul style="list-style-type: none"> • <i>I’ve never heard about what stage I am, no one has ever mentioned that to me</i>”. When asked: do you want to know: “<i>yes</i>” “<i>surprisingly I’ve asked and I’ve been told that’s not important at this stage, whatever that means</i>”. (P1)
<p>Patients need physicians to be receptive to non-traditional arthritis treatments as well as those that are evidence-based.</p> <ul style="list-style-type: none"> • One participant told her physician she was taking turmeric, adding that the arthritis society classed it in the “<i>maybe category</i>” of treatments. He told her not to take as it’s not a recognized treatment. “<i>He said I don’t want to hear you talking about that stuff, it’s not in my protocol</i>”(P1)
<p>Physicians need to be open to hearing all the things people do to manage their OA.</p> <ul style="list-style-type: none"> • P2 doesn’t tell her doctor she puts magnets under her knee wraps: “<i>I’ll need his help to get a driver’s license eventually</i>” • One person’s doctor told her: “<i>I’m the sole source, do no use the web, do not ever tell me you look at it</i>”. She said he doesn’t want to hear getting information from the web.... “<i>he hates it, hates it, hates it</i>”. She gets in “<i>fight</i>s” about it with him so has learned not to mention it (P1).
<p>Physicians need to listen to patients’ weight loss issues and help them finding something that works even if it’s not in the scientific literature.</p> <ul style="list-style-type: none"> • The weight loss plan to which one person was referred did not work for her: “<i>I had to find one that worked for me</i>’. <i>You kind of starve yourself 2 days a week and the rest of the time you don’t think about it</i>”. <i>I find those diets (calorie counting) they just...I can’t do them. You’re thinking about food all the time: it makes you crazy...because they make you food obsessed. That’s why I like the 2 day approach</i>”. (P1) • A lady who kept referring to her inability to lose weight:

<p><i>“And I’m sure I was told I had to lose weight which means I’ve had 5 years to lose weight and it hasn’t happened. If nothing else being a person to be interviewed makes you aware of things you haven’t done.” (P4)</i></p> <ul style="list-style-type: none"> Participant 5 said his doctor has told him he needs to lose weight and that she won’t refer him to surgeon until he does. He has tried to lose weight and finds this stance <i>“frustrating and marginally insulting”</i>.
<p>Participants need to be informed about when they should come back to their family physicians.</p> <ul style="list-style-type: none"> About 2 years ago one participant started getting hip pain and got very depressed. <i>“I thought, oh no, here I go again, it’s going to be my hips too and I actually did not go to my doctor, I just thought here it is...”(P1)</i>. It turned out it wasn’t arthritis: <i>“I guess that’s why going to your doctor is so important and not getting depressed about this disease because you can think that things are just getting bad.”</i> P2 doesn’t keep going back to her doctor for her knees as she knows there’s nothing he can do other than cortisone. <i>“In the meantime you just learn to cope, that’s really what it’s about”</i>.
<p>Participants need specific information on a range of strategies such as how much and what exercises to do; what equipment to try and links to good sources</p> <ul style="list-style-type: none"> <i>“There’s more than...lose weight, get exercise and take pain pills: and I’m a living example of that.” (P3)</i> <i>“It’s almost like weight loss is the only answer” “His view is that pain pills are sort of a secondary thing...he doesn’t like people taking them so weight loss was the first”. (P1)</i>

Table 2: Participants’ Encounters with their Family Physicians

Participants’ Perspectives on an Electronic Tool

Participants responded positively to the idea of an electronic tool to help them self-manage their OA. (They did not see the need for the tool to be hard-copy.) One participant saw it as a “win-win for all of us” (P3), referring to both patients and family physicians: “it’s brilliant” (P3). When asked what he thought the outcome of the tool could be one man said: “as the arthritis progresses and starts limiting your ability for safe activity...there would be a shorter period of time from needing help to getting it...surgery” (P5). There was some individual reticence about the tool: one participant said that because she’s not good at dieting she wouldn’t want to enter her weight “month after month” (P4) and another wasn’t sure how useful the pain monitoring would be when she doesn’t feel pain until it’s severe. Participants thought the tool would give them specific information about OA, allow them to enter information, monitor their progress and facilitate communication with their family physicians. Participant quotes related to the tool are presented in Table 3.

<p>The tool should include specific evidence-based information about OA and how it is managed</p> <ul style="list-style-type: none"> • One participant said that in addition to information on weight loss, exercise and medications, the tool could include information on specific exercise types of exercise such as low impact; equipment for pain such as TENs for example and ice machine; access to the latest research information. • One lady said it should include an option for patients to enter alternative approaches, for example turmeric or acupuncture
<p>They would use the tool to enter information and monitor their progress</p> <ul style="list-style-type: none"> • Participants would monitor: pain, weight, diet, sleep and activity • <i>“If it somehow helped my thinking about the disease that would be a positive thing”</i> (P1) • The tool <i>“would keep you focused on areas that need attention”</i> (P5). • A man who struggles with his weight said that sometimes he gets the feeling that <i>“you sit down and explain what’s going on and the feeling I get is, oh this is just a standard answer...I don’t much believe what the patient is doing all the things they are supposed to be doing. Because they don’t see results that they want to see. That’s just a feeling...I don’t have any....”</i> (P5). He thought he tool would be good as it would be a way of tracking what you’ve done.
<p>They would use it as a communication tool with their physicians</p> <ul style="list-style-type: none"> • <i>“If it helped my communication with my doctor that would be positive...”</i> (P1) • A lady who also has a heart condition thought the tool might help her get her family physician to pay more attention to her OA during her appointments: <i>“He wants to focus on my heart all the time and I can understand that”</i> Later she said: <i>“Maybe they (family physicians) should think about your lifestyle and how it (OA) affects you. And maybe think of things you could do that would help: give you suggestions: take more time to listen about arthritis vs heart problem....that’s (now) under control”</i> • One participant thought a <i>“mutually available”</i> (P3) tool could lead to a discussion about non-weight bearing exercise versus hiking or mountain climbing. • When asked if she would talk to her doctor about the information on a tool she said: <i>“I don’t know if the app is the key or if getting back to the doctor is the key”</i> (P4).

Table 3: Participants’ Ideas for a Tool to Help them Self-manage their OA

Conclusion

The findings from the interviews reinforced what we learned in our other two PaCER studies about the health care system support patients need as they live with their OA. These needs align well with the ongoing nature of patient/family physician relationships. We also learned patients’ perspectives on how an electronic tool could assist them in self-managing their OA. These findings were condensed into a one page document for a co-design tool development workshop of patients, family physicians, and researchers: See Appendix B. This collective

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patient voice was added to that of the research done with family physicians and is continuing to shaping the development of the tool. We look forward to our involvement as the tool evolves.

Respectfully

Jean Miller and Sylvia Teare, Lead Researchers, PaCER

References

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Appendix A: KOASK Interview Guide

Part 1: Participants initial experience with knee pain and their early encounters with their family physicians about that pain.

Tell us about your first visit to your family doctor with knee pain

(To be explored: How long after the onset of knee pain, did you seek help? What was the procedure and what questions did your FP ask? Were you referred for an x-ray? What were the suggestions of the FP? Were you referred to a specialist such as rheumatologist, physiotherapist, etc.? Was there any suggestion with regard to self-management treatments including weight reduction, exercise or education? Were you referred to any website or was you given any educational booklet?)

After seeing the doctor what did you do to help you manage your OA pain?

(To be explored: information seeking; exercise; weight loss)

How did that go?

(To be explored: what worked, what didn't, barriers to implementing your self-management strategies)

Tell us about subsequent early visits to your family doctor

(To be explored: what did you talk about; what did you decide to do)

What could your family doctor do to help you better manage your OA?

Part 2: The tool to help family physicians understand the severity of their patients' OA now and guide treatment; and help patients gauge their progress on self-management actions.

Do you think this tool would be beneficial? In what ways?

Would you be comfortable with filling out your portion of the tool online?

Would you like a print out of the information?

What would you like to see as the outcome of such a tool: your current stage of the disease, treatment options?

What exactly do you need to know about self-management strategies?

What other thoughts do you have about managing your early OA?

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Appendix B: Patient and Community Engagement (PaCER) Research Handout for KOASK Co-design Workshop

Two Lead Researchers from the PaCER program with knee OA (Jean Miller and Sylvia Teare) interviewed 5 other patients about how they manage their OA including their experiences with their family physicians about this condition. What they learned echoed what OA patients told them in other patient-to-patient studies they've done. Participants also shared their perspective on a tool that would help them self-manage their condition.

What participants need in their encounters with their family physicians

- their knee pain to be taken as seriously as their more life-threatening health problems;
- to know what lies ahead and what they should be doing now
- them to be receptive to non-traditional arthritis treatments
- to be able to openly tell their physicians what they are doing to manage their OA
- them to take the time to listen to their issues about weight loss and help them find something that works
- tell them when they should come back to see them
- specific information on exercises, equipment (e.g. TENS, ice), and links to resources

Participants' ideas for a tool to help them self-manage OA and use with their family physicians

- The tool would include specific evidence-based information about OA and how it is managed
- They would use the tool to enter information, monitor their progress, and use as a communication tool with their physicians.
- The tool would help put their OA up-front “on the radar screen” (P2) in their doctor appointments
- It would give evidence of the things they are and aren't doing.
- The tool “would keep you focused on areas that need attention” (P5).
- It would monitor: pain, weight, diet, sleep, and activity.

Respectfully

Jean Miller and Sylvia Teare, Lead Researchers, Patient and Community Engagement Research Program