

Report on the PaCER Component of the AS MOC Study

Research conducted by: Jean Miller & Sylvia Teare, PACER researchers and OA patients

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Introduction and Background

This is a report of the PACER research that was part of the Stage 1 of the *Creating an optimal model for the efficient delivery of appropriate and effective arthritis care* research study (known as the AS MOC study). The purpose of the AS MOC study is to evaluate alternative models-of-care to inform the development, implementation, and evaluation of a centralized referral process of triaging and managing arthritis care. This study is at the forefront of shifting the health system focus from episodic specialist surgical care to helping Albertans manage their arthritis over the long term. It also aligns with the PACER student internship study, *The experience of waiting for help with Osteoarthritis*. (Bryk, Lewis, Miller, Penman, & Teare, 2013). In that study OA patients reported many barriers to accessing help, from diagnosis on to surgery. Participants believed that if they had access to conservative management support early on they could manage their health better and perhaps avoid joint replacement surgery.

To ensure the AS MOC research is in line with patients' needs Dr Marshall's research team worked with the PACER program at U of C to integrate patient led research into the first stage of the study. The intent was to bring a collective patient voice to the forefront, informing the development of key performance indicators. The PACER research priorities were to gather patients' perspectives on what quality care means, along with the services and supports patients need and find most useful. The research was carried out by two trained PACER researchers with osteoarthritis: Jean Miller and Sylvia Teare.

This report is of particular significance as it represents the first time PACER research was built into a research project led by health care and academic researchers. PACER research will also be carried in the PRIHS study, another component of the central intake research program.

Before describing the study process and findings some background on the PACER research program is provided. Patient and community engagement researchers (PACERs) are people with various health conditions who are trained to design and conduct health research using an established protocol of qualitative inquiry. The protocol was originally developed by Dr Marlett and Dr Emes (Marlett & Emes, 2010) in a senior's resiliency project and further refined in an innovative collaborative project between Alberta Health Services, the University of Calgary, Vecova Centre for Disability Services and Research, and the Arthritis Society. The purpose of this collaborative project was to bring a stronger patient voice to health care transformation.

The PACER research has 3 phases: Set, Collect, and Reflect. (See Figure 1) The Set phase clarifies the scope and direction of the study. Data is then collected (Collect phase) from patients using focus groups; narrative interviews; observation; or questionnaires. In the Reflect phase patients participate in another focus group where they come to a common understanding of the 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 transformation. It results in a shared collective understanding of the issue, one that is solidly grounded in patient experience. The PACER office provides mentorship, support, and oversight throughout the research process. As this is a patient-to-patient research process findings are described using the first person plural, where "we" stands for the participants and researchers as one voice. (For more information on PACER: <http://www.iph.ucalgary.ca/PACER>)

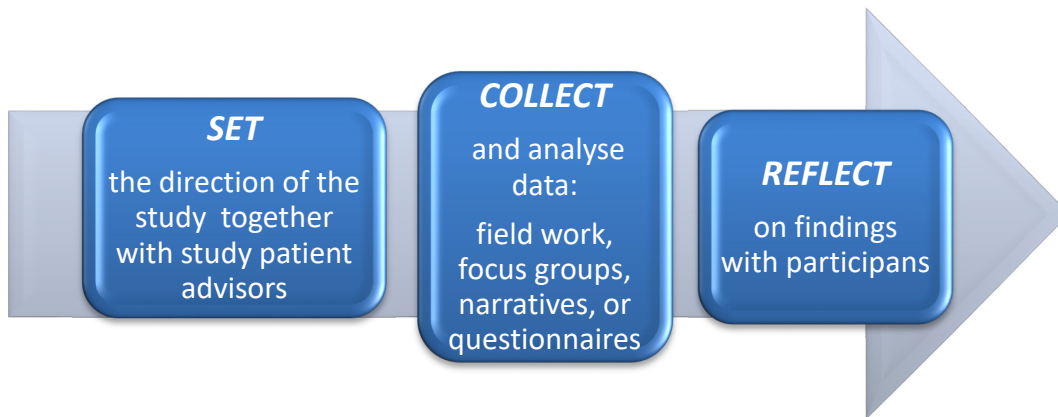


Figure 1: PACER Research Methodology

Patient Perspective on Quality Care in the Literature

Health professional research on quality care focuses on the knowledge and skills professionals need to deliver good patient care. The idea of patients engaging other patients in research about quality care is in its infancy. Further, health professional research on quality care tends to focus on patients who are awaiting joint replacement surgery, with little attention to quality care outside that episodic event.

In most of the professional led studies quality care is inferred based on the quality of care patients report while awaiting surgery. Researchers discover system deficits, leading to recommendations for improvement. Sjöling, Agren, Olofsson, Hellzen and Asplund (2005) described the patient waiting experience as a “continuous struggle against a faceless system” (p. 541) and they conclude their study by recommending patients have personal and regular contact with someone who can give them the information they need. The patients in Parsons, Godfrey, and Jester’s (2009) study reported getting little help in managing their pain and mobility while waiting for surgery, leading the researchers to recommend the development of easily available “models of care and support” (p.133). This lack of support was also evident in McHugh, Silman, and Luker’s (2007) study and these authors recommended that professionals provide the

information and support patients need. Conner-Spady, Johnson, Sanmartin, McGurran and Noseworthy (2006) studied patients' perspectives on acceptable wait times recommending strategies to help people while they wait need to be developed. In their study of the information patients need while awaiting arthroplastic surgery Sjoling, Norbergh, Malker and Asplund (2006) recommend patients have access to information and tools to help in pain management and maintaining fitness so they can keep doing their usual activities.

While these professional led studies are a starting point for understanding what quality care means for people with OA, the peer-to-peer process used here clearly shifts the focus from provider to patient. What we learn in this study will inform the development of key performance indicators and help the system design services and supports that align with patient needs over their life time of OA.

PACER Method for the AS MOC Study

We begin this section with information about our participants followed by a description of the PACER processes used in this study.

Participants

Twenty-five adults with osteoarthritis (OA) participated in this research. Some were people who had participated in earlier PACER OA research. Others were recruited from interested people who attended the 2013 *Woods Forum on Hip and Knee Osteoarthritis* in Edmonton, as well as referrals and links to acquaintances and friends. Each contact received an invitation email leaving them free to accept or decline participation. In the group of 25, 17 participants were women and 8 were men; 15 of the participants were 65 and older. Participants were people of average means and education.

PACER Process for AS MOC

The Set focus group was held in two locations (Calgary and Edmonton) where a total of 15 patients explored the issue of quality care and the resources they use. To facilitate the discussion we asked patients to envision what a quality care system would look like, including the supports and services they would use. Each point was documented on flip charts followed by a detailed discussion of the points. Participants spoke about holistic and efficient assessment; access to professionals with OA expertise and enough time to help them; and access to reliable resources, non-traditional as well as traditional. We used this information to adjust and solidify the telephone interview guide for the Collect phase which was then reviewed with the PACER program leaders. Nine people with OA were interviewed by one of the PACER researchers. Participants received the consent form prior to their interviews and they gave verbal consent at the beginning of the recorded interviews. Patients were guided in a discussion of what matters most to them; and makes for quality care experiences. The audiotapes and research notes were used to create a descriptive document for each interview. The descriptive documents from the first 4 interviews were discussed with the PACER program leaders which led to the addition of 3 probes: dealing with the problem when it first appeared; learning about alternate therapies; and considering options of greatest importance.

Each researcher independently reviewed the interview notes, creating sticky-notes on what she saw as the salient points. Through a collaborative iterative process we created these categories of findings: 1) what is most meaningful; 2) referral to trusted sources of information; 3) information on how OA progresses and corresponding treatments and resources; 4) treatment and self-management strategies that work and their expected results; 5) access to experts; 6)

choice and support; 7) partnership with health care providers; and 8) being able to come back when more help is needed.

We took these categories to the Reflect focus group which was composed of 5 patients who had participated in either the Set or Collect phases, and 1 person who was new to the study. Participants reflected on the fit between what they told us and what we reported, exploring some of the information in more detail. We ended the session with each participant creating a picture of what quality care now meant to them. Final analysis by the researchers led to three components that we as patients with OA consider important to quality care.

Quality Care from the OA Patient Perspective

Living with OA is a continuous process of adapting our lives and self-managing our health and we need a health care system that helps us do that: one that gives us options and lets us stay in control. We want to make good choices and to do that we need support that is appropriate to our individual needs and resources. As one person put it: “I want to go somewhere so I can be the best care provider for myself” (MOCI4). With that in mind, we describe three components of quality care: the right knowledge; the right professional support (including the resources we use); and the right relationship. (See Figure 2) We believe each is necessary but none are sufficient on their own.

To set the stage: **quality care is all about living meaningful lives through self-management, and to do that we must manage our pain, and maintain our function. One participant described it as “feeling free to do what you think you need to do” (MOCI1).** We do not want to give up the things that matter to us such as time with our grandchildren; meaningful work; travel; and physical activity. To that end we do all we can to stay mobile: as

one participant stated: “mobility....period...that’s what matters the most” (MOCI6): We value our independence and we want to avoid becoming a burden to our family. We realize this may mean moving from our own homes and while we are reluctant to do so, we do our best to accept such necessary adaptations. We also value maintaining our friendships and connections to people who share common interests.

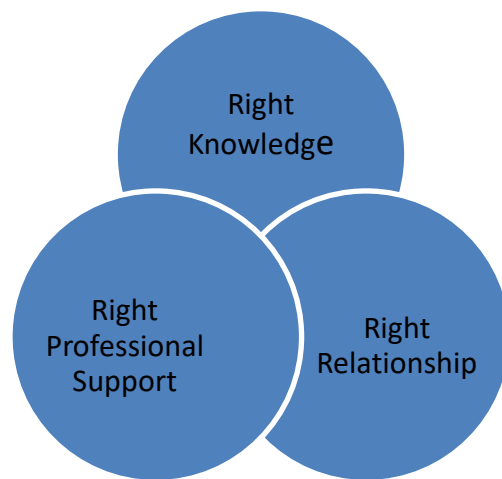


Figure 2: The three components of quality care for OA patients

The Right Knowledge

The right knowledge for self-managing osteoarthritis goes beyond what is typically found in self-help resources. It goes beyond knowing what osteoarthritis is, that exercise and weight loss are important, or there are ways to relieve the pain. As patients we need detailed knowledge about: how OA progresses; evidence informed management strategies; and how to deal with changes in our pain and mobility. This information needs to be specific: it needs to be “comprehensive, no-nonsense, what I should and shouldn’t do; first do *this*, then do *this*. Not a whole bunch of philosophy” (MOCI6).

We need to know where we stand with respect to the severity of our OA, how it is likely to progress, and how to deal with that progression. We think levels of severity are likely defined somewhere, but we are not sure: **for example, mild, moderate, or severe.** We also hope there are **specific treatments and self-management strategies that align with severity levels.** For example: perhaps a knee brace or a cortisone injection would be appropriate for ‘moderate’ OA. We need **specific information about the circumstances that should trigger a return to our health care provider.** For example, is it when we can no longer climb the stairs, or walk a block? We also need to know what criteria determine readiness for joint replacement and the potential risks should we choose to not have surgery. Once we decide to have surgery we need to know when that will likely happen, who will be contacting us and when, and what we should do in the meantime. To explain this more clearly we offer a schematic of what this might look like in Table 1. The management strategies and triggers are merely examples: they aren’t necessarily best or current practices.

Table 1: Our Suggested Schematic for Stages, Strategies, and Triggers

Stage of severity/ progression	Management Strategies	Triggers that should take me back to my health professional
1	Referral to effective weight loss program Guidelines on pain medication management	Weight loss program is not working Taking more pills than recommended without relief
2	Referral for a brace Referral for a cortisone injection	Pain in everyday activities
3	Referral to a surgeon	Unable to sleep at night, climb a flight of stairs or walk 2 blocks without pain

Quality care also means having easy access to information that is considered sound and trustworthy: for example, websites, journals, books. In a quality system this would include a broad range of OA specific resources, from weight loss programs and exercises, to acupuncture, chiropractic, and massage therapy. It is important to include non-traditional approaches as this is where many of us turn for help. Right now, we scout out resources on our own, and (as one patient put it) we wonder “why does the patient have to do all the work” (MOC11). A trusted source of information would help us choose sound self-management strategies appropriately as opposed to using this trial-and-error approach. For example, instead of purchasing a brace because it helped a friend, we would do so based on reliable evidence.

The Right Professional Support

We start this section by describing the resources we use and go on to describe the supports we need.

The Resources we use: In our experience the publically funded health care system offers two resources to help us with our OA: family doctors and orthopedic surgeons. One participant said she had seen a rheumatologist when she was first diagnosed and when she asked to see that person again her family doctor told her rheumatologists no longer see people with OA. Given this limited scope of public system resources it follows that most of the resources we use are outside the publically funded system.

After we are diagnosed our family doctors typically give us advice on how to deal with the pain, sometimes giving us a prescription for pain medication. In some instances they refer us to physiotherapists but only after confirming that we are open to paying for this service. Then we head off on our own, getting advice from family, friends, and acquaintances. One participant

said she learns about various treatments in her aquacize class, with each person offering their own “pet cure or treatment” (MOCRFG). Through trial and error we find a broad range of helpful providers: from physiotherapy, to chiropractic, to acupuncture, to Chinese medicine. We elect to pay for these services because of the benefits we experience. We regret that therapies such as physiotherapy, massage therapy, and chiropractic no longer fall under the provincial health care plan.

We put a lot of energy into finding the people and things that help us and we take some pride in our successes. However, we are often reluctant to talk to our family doctors about using non-traditional resources as we fear falling out of their favor, which down the road might impede access to publically funded joint replacement surgery. One patient noted her family doctor helps her with pain and depression, and for everything else she goes outside the health care system: “I’m an equal opportunity patient” (MOC11).

The support we need: Access to health professionals with OA expertise is important for quality care. This begins with our family doctors who need a toolkit of evidence-based treatments and strategies to help us. These strategies need to address all stages of OA progression, starting with early diagnosis, on to the more severe stages.

We also need access to other professionals with OA expertise for example, physiotherapists, trainers, psychologists, chiropractors, nutritionists, or acupuncturists. These professionals need to treat us as whole people, not just someone with painful joints. In some instances these professionals would work independently and in others they would be associated as a multidisciplinary team. Further, because so many of us get help from non-traditional therapies a quality care system would support access to these providers.

It isn't enough to just know who to go to and when. We need to know what each profession offers to people with OA; who can best help with a particular problem; when we should seek their help; how do we get in to see them; what they can and cannot do for us; how long we should keep seeing them; and when they can no longer help, who should we see next. In instances where we are referred to others we need to know when we can expect to be contacted for an appointment and approximately when that appointment will occur.

Once we are known to a particular provider we should be able to return without repeating time consuming referral processes. As one participant put it: "as you are coming back to a place that knows you, you wouldn't need to start at square one every time: telling them about you....and they'd know what you've already done" (MOC19).

This kind of access to people with OA expertise will contribute to our well-being, our health, our sense of control, and our confidence in the health care system. It is what we need to manage a chronic condition like OA.

The Right Relationship

While the right knowledge and the right support are essential to quality care, they are not sufficient: we also need to engage in a partnership relationship with our professional care givers. To help us self-manage professionals need to take the time to listen to us and to truly understand how OA is affecting our lives. In her depiction of quality care one patient (MOC11) put it this way:

- ✓ This is my first appointment, listen to me.
- ✓ This is my tenth appointment, listen to me.
- ✓ I don't know how to express my needs, listen to me.

- ✓ The treatment isn't working, listen to me.
- ✓ I am having trouble sitting for long periods, listen to me.
- ✓ What should I do next? Listen to me

This description implies continuity in the patient/health provider relationship: “someone who remembers me” (MOC11) and is there for us. We need to be able to come back to someone who remembers us as individuals and remembers us from our past visits.

We also need a partnership relationship with our health professionals. As one participant put it, “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” (MOC14). A patient in our Reflect focus group used a recreation analogy to describe the partnership relationship. On one of his first cross-country skiing outings he met an experienced skier who asked if he could give him some tips. Being someone who welcomes input from those who know more than he does, he said yes. This expert joined him on the trail offering encouragement and praise, along with some pointers. A short while later our study participant set off on his own, feeling more confident in his new skill.

This partnership relationship underpins an important component of quality care: a self-management plan. This plan needs to be personal and evolving, not one that is created and handed down by the professional. As one person said: “We need to figure it out together” (MOVI4). While this plan needs to be based on sound strategies it should take into account our personal circumstances, resources and preferences.

Our self-management plans should build from a foundation of choice and be guided by our expectations and goals. We should be asked what path we want to follow and then helped to understand where that is likely to lead us. It is important we understand the consequences of our

from each other and groups like this would facilitate that process”. The computer depicts a source of trusted information; a tool for developing personal treatment plans; patient records accessible to her and her team members; and a communication mechanism for asking questions, making appointments, and checking the queue. The patient exiting the vortex is happy because she is “a patient who has been empowered and able to take control and find a way through that allows them to return to enjoying life.”

Conclusion

Quality care for patients with OA is underpinned by what we value as we live with this chronic condition: staying mobile; doing the things that matter most; and enjoying our activities and relationships with family and friends. We use a broad range of resources to help us live meaningful lives. As the only public system resources available to us are our family doctors and medical arthritis specialists, primarily orthopedic surgeons, we turn to practitioners who are not covered by the provincial health care plan. Most of us can afford at least some of these services but we know there are many people who cannot.

As self-managers of our OA we believe quality care has three necessary and related components: the right knowledge; the right professional support; and the right relationship. Right knowledge is trustworthy, detailed and comprehensive, and should be based on disease severity and corresponding treatments and self-management strategies. Right professional support is access to traditional and non-traditional professionals with OA expertise in both individual and team environments. It also means easy re-access. Right relationship is establishing partnerships that lead to individual self-management plans that are jointly created, monitored, and revised over time. These relationships are underpinned by our need for choice and guidance in taking

responsibility for our own health. Depending on our individual situations some of us will need more support and guidance than others.

Not discounting the limitations of this small qualitative study with a relatively homogenous group we have some confidence that the components of quality care described here would not vary all that widely among people with OA. The engaging and iterative nature of our process contributes to that confidence. From our deliberations we also know there will be individual differences: some people want to avoid pain medications while others do not; some will go to a chiropractor while others will not. These choices will be strongly influenced by resources: financial, health and personal.

Before concluding we reinforce the issue of the gap in support for patients with OA: the gap between family doctors and orthopedic surgeons. This issue was raised at all stages of this study. The central intake work now underway will go some distance in closing this gap. However, to close the gap completely, patients with OA need the right knowledge, professional support and relationship from the point of diagnosis on.

Recommendations

Based on the findings of this PACER research we recommend:

1. Using the three components of quality care as a touch-stone in developing key performance indicators, and designing, implementing, and evaluating the central intake model.
2. Integrate personal self-management planning and plans into the central intake model.
3. Develop and widely distribute guides to the stages of osteoarthritis and accompanying evidence informed management strategies to patients, health professionals, and the public

4. Compile and widely distribute trusted information sources to Primary Care Networks, family doctors, and patients.
5. Ensure the multidisciplinary central intake team has OA specialty expertise.
6. Carry out research that addresses support for patients in the early stages of OA.
7. Work with BJSCN on evidence informed recommendations that will facilitate patient access to a wider range of publically funded supports.

Respectfully submitted

Jean Miller and Sylvia Teare on behalf of PACER

References

- Bryk, C., Lewis, T.R., Miller, J., Penman, C., & Teare, S. *The experience of waiting for help with osteoarthritis*. Retrieved May 5, 2014, from University of Calgary, Institute for Public Health website: <http://www.iph.ucalgary.ca/system/files/Experience+of+Waiting+for+Help+with+O+A+PER+Report+Aug+2013.pdf>
- Conner-Spady B., Johnson G., Sanmartin C., McGurran J., Noseworthy T., and the Saskatchewan Surgical Care Network/Western Canada Wait List Project Research and Evaluation Working Group Committee. A bird can't fly on one wing: Patient views on waiting for hip and knee surgery. *Health Expectations*, 10(2), 108-116.
- Marlett, N. & Emes, C. (2010). *Grey Matters: A guide to collaborative research for seniors*. Calgary: University of Calgary Press.
- McHugh, G., Silman, A., Luker, K. (2007). Quality of care for people with osteoarthritis: A qualitative study. *Journal of Clinical Nursing*, 16(7b), 168-176.
- Parsons G., Godfrey H., Jester R.F. (2009). Living with severe osteoarthritis while awaiting hip and knee joint replacement surgery. *Musculoskeletal Care*, 7(2), 121-135.
- Sjoling M., Agren Y., Olofsson N., Hellzen O., & Asplund K. (2005). Waiting for surgery: Living a life on hold – a continuous struggle against a faceless system. *International Journal of Nursing Studies*, 42, 539-547.
- Sjoling, M., Norbergh, K.G., Malker, H., & Asplund, K. (2006). What information do patients waiting for and undergoing arthroplasty surgery want? Their side of the story. *Journal of Orthopaedic Nursing*, 10, 5-14.