

“We’re All Looking for Solutions”: A Qualitative Study of the Management of Knee Symptoms

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Objective. While the prevalence of osteoarthritis (OA) increases with age, the first signs begin in the fourth or fifth decade. Little is known about how younger adults respond to OA. This study explores how people ages 35–65 years manage knee symptoms.

Methods. Six focus groups were conducted with 41 participants (mean age 50.9 years, 63% women) who self-reported a diagnosis of OA or reported knee symptoms (i.e., pain, aching, or stiffness) on most days of the past month. Purposive sampling was used, seeking variation in age and sex. The principles of constructivist grounded theory guided data collection and analysis. Data were analyzed using a constant comparative method.

Results. Participants engaged in a process of proactively trying to find ways to control knee symptoms and disease progression. Their approach to management was not linear, but rather a process that moved back and forth between searching for “solutions” and active management (ongoing use of strategies). During the process, participants consulted health care providers, but often perceived that medical care offered limited options and guidance. Management was constructed as a “never-ending” process that entailed effort and personal resources.

Conclusion. Participants were proactive in seeking ways to manage knee OA symptoms. There is a mismatch between participants’ proactive approach and the reactive approach of the health care system that has focused on late-stage disease. Programs and supports within the formal and informal health care system are required to enable people to successfully manage knee symptoms across their lifespan.

INTRODUCTION

While osteoarthritis (OA) has mostly been viewed as a disease of older people, there is increasing evidence of the significant impact of OA symptoms earlier in life (1). The estimated incidence of OA increases exponentially in adults ages 20–50 years, with the largest number of incident cases in the 50–54 years age group (2). Approximately 9.29% of the US population is diagnosed with symptomatic knee OA, the most commonly affected joint, by age 60 years, with a higher prevalence in women than

men (1). There is evidence that OA is progressing to severe disease in younger people as demonstrated by a 311% increase in the number of total knee replacements (from 772 to 3,172 procedures) in those ages 45–54 years in Canada between 1996–1997 and 2006–2007 (3). Moreover, the majority of economic costs of OA accounted for by long-term disability are incurred by those ages 35–64 years (4). Despite the considerable impact of OA symptoms in people as early as the third or fourth decade of life (2), there is a paucity of research on OA management early in life. Rather, research has focused on OA management in older adults (5–10). The few studies including younger adults have focused on the lived experience of knee symptoms (11) and the process of recognizing emergent symptoms (12).

Scientific progress is being made in understanding the development of the disease, mechanisms responsible for progression, and potential advances in management (13). There is evidence that interventions such as exercise and weight loss decrease the pain and disability of OA (14–18). There is opportunity for interventions geared toward younger adults with OA in order to enable better management of knee symptoms, limit progression of OA, and delay the need for more costly interventions such as surgery. However, given the limited research, there is too

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Significance & Innovations

- People are engaged in a complex iterative process of trying to find solutions and maintain active management in order to control knee symptoms and prevent progression.
- People were generally aware of, and had tried many known best practices for osteoarthritis, but there was still some uncertainty about how to best manage their knee problems. People may require more personalized help to use selected strategies in effective ways.
- People often felt that medical care had little to offer them until they needed surgery, which was frustrating, particularly for younger adults. Health care interventions are needed to help support people to manage much earlier in life and across the life course.
- Active management of knee symptoms can be challenging to maintain over the long term. Mechanisms for ongoing support for knee symptoms, including health care followup, are needed.

inadequate of an understanding of how younger adults manage knee symptoms to even begin to develop interventions that address their needs earlier in life. We aimed to address this gap and explore how adults ages 35–65 years respond to and manage their knee symptoms.

MATERIALS AND METHODS

A qualitative study was conducted based on the principles and methods of constructivist grounded theory, including iterative data collection and analysis and constant comparative analysis. Grounded theory uses an inductive approach, which aims to describe, explain, and predict complex processes and represent the perspectives of the person (19). Grounded theory derives theoretical underpinnings from symbolic interactionism (19,20). This study drew on this theoretical perspective, which addresses the active processes through which people create and mediate meanings. Meaning arises out of actions and in turn influences actions (20). The researcher's role is recognized in the shared construction of the meaning of the accounts told by participants who live day-to-day with knee symptoms.

Sampling and data collection. Individuals in the greater Toronto area were recruited using advertisements in a community paper, an acute care hospital, and community centers. Interested individuals called the first author (CM) and were screened for eligibility using a screening questionnaire. We included individuals ages 35–65 years who self-reported a diagnosis of knee OA or who reported that they had knee symptoms (i.e., pain, aching, or stiffness) on most days of the past month, recognizing younger adults may not have a formal diagnosis or perceive their symp-

toms to be OA. The knee symptoms screening question was based on a widely used survey question on joint pain (21). Participants who had a knee injury, or had knee pain referred from the low back, were excluded as symptoms were unlikely to be related to OA. People with other types of arthritis (e.g., inflammatory arthritis) who were waiting for, recommended, or had undergone total joint replacement (TJR), or who had other chronic physical health conditions that affected their mobility (e.g., multiple sclerosis, stroke, or Parkinson's disease) were excluded. Qualitative research focuses in-depth on relatively small samples, selected purposefully (22). Purposive sampling was used seeking variation across age and men and women. Data collection was stopped at the point of saturation, when the authors agreed that further data gathering and analysis added little to the conceptualization (19).

Data were collected using focus groups. Group interactions may accentuate members' similarities and differences and give rich information about the range of perspectives and experiences (23). Focus group methodologists advocate bringing together participants that share some similar characteristics (24). Participants were grouped together in focus groups based on age (35–49 years and 50–65 years) to create groups with similar characteristics. The first author (CM) acted as moderator. A second individual kept a speaker log (participant's unique identifier and first words spoken) to facilitate transcription and took notes that summarized the participant's comments and nonverbal communication. These notes facilitated simultaneous data collection and analysis, allowing for emerging themes to be pursued in subsequent interviews. Focus groups were semistructured using a discussion guide (Table 1). The moderator used probing questions for elaboration and clarification. The focus groups lasted 1.5–2 hours and were conducted in private rooms in designated hospital conference space. Focus groups were audiotaped, transcribed verbatim, and entered into NVivo 9 software for data management. Field notes were written following each focus group to summarize the data and discuss questions arising from the data. To ensure transparency, an audit trail documented all study decisions (25).

Participants completed demographic questions and the Knee Injury and Osteoarthritis Outcome Score (KOOS) so that we could describe the extent of participants' knee symptoms and function. KOOS scores range from 0–100 for each subscale (100 indicating no symptoms and 0 ex-

Table 1. Focus group question guide

<p>Tell me about what is happening with your knee(s). We are interested in your experiences with your knee in your daily life. Can you tell me how your knee fits into your daily life? When you think of yourself 10 or 20 years down the road, what do you think might happen with your knee? What do you do for your knee? After having your experience, what advice would you give someone else who has just started to have knee issues? Do you have anything else you wish to say about living with your knee symptoms?</p>

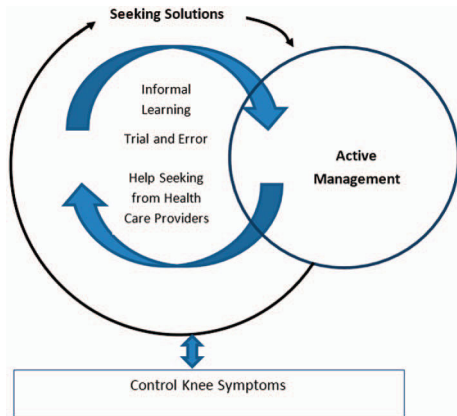


Figure 1. Taking action on knee symptoms.

tre symptoms) (26). The study was approved by the University Health Network Research Ethics Board.

Analysis. Data analysis was conducted concurrently with data collection. A constant comparative method of analysis was used (21). The analysis included open-coding the data (a process of breaking down, examining, comparing and conceptualizing, and categorizing data) and identifying the main categories and relating categories to each other (axial coding) (19). A core category was generated explaining the basic process of how participants managed knee symptoms. The data were progressively conceptualized into the resulting framework (Figure 1). The first author open-coded the transcripts independently and developed a coding scheme. All authors reviewed the transcripts and coding scheme and met regularly to discuss the data and ongoing analysis, including alternate interpretations of the data. Analytic memos were constructed to explicate emerging categories, make comparisons across data, and identify gaps in the analysis. Diagrams were used to tease out the relationships among categories. Analysis also included multiple readings of the transcripts to shed further light on the meanings and processes central to understanding how people manage knee symptoms. A field diary was written to facilitate reflexivity.

RESULTS

Six focus groups (3 groups ages 35–49 years and 3 groups ages 50–65 years) were conducted with 41 participants with moderately symptomatic OA based on their KOOS scores (mean domain scores ranged from 43.3 to 67.9). Table 2 shows patient demographics and Table 3 shows KOOS scores (27). The core category, taking action on knee symptoms, explains the main process of managing knee symptoms. An overview of the core category is presented first, followed by a more detailed description of the categories that encompass this core process (control of symptoms, seeking solutions, and active management). Illustrative quotes are presented throughout the text and in Table 4 (names are pseudonyms).

Core category: taking action on knee symptoms. Taking action on knee symptoms explains the active process by

Table 2. Participant demographics (n = 41)

Demographics	No. (%)
Age, years	50.9 (8.1) (range 38–65)
Women	26 (63)
Education	
High school	4 (9.8)
Trades certificate/diploma or college graduate	12 (29.2)
University graduate	25 (61.0)
Marital status	
Married/living as married	16 (39.0)
Divorced/widowed/never married	25 (61.0)
Work	
Currently working	34 (82.9)
Unemployed	5 (12.2)
Retired	1 (2.4)
Student	1 (2.4)

which people work to control knee symptoms and disease progression (Figure 1). Participants responded to their knee symptoms by “seeking solutions.” That is, people used informal learning (e.g., doing their own research), trial and error, and/or sought help from health care providers to find ways to manage their knee symptoms. In some instances, one or a combination of these methods helped participants find strategies they perceived to work (e.g., exercise, weight loss). Strategies were then actively incorporated into management of their knees on an ongoing or as needed basis (active management). Some strategies were only used temporarily, then given up and the search for other ways to manage resumed. Management was constructed as a “never-ending” process of “trying” to find solutions and maintain active management. This process entailed significant physical and mental work and personal resources such as time and money.

Figure 1 is a visual representation of the process of managing symptoms, illustrating that a participant’s approach to management was not an orderly, linear process, but rather moved back and forth within and between, seeking solutions and active management. The overlapping circles indicate that these also happened concurrently, whereby people actively managed their symptoms using certain strategies but indicated they were still on the lookout for new management strategies. “Control of symptoms” refers to the intent underlying this active management process. It is placed at the bottom of the figure to indicate that it underpins the management process.

Table 3. Knee symptoms and function*

KOOS subscales	Scores, mean ± SD
Symptoms	61.8 ± 15.8
Pain	62.0 ± 17.6
Function in daily living	67.9 ± 18.0
Function in sport and recreation	50.8 ± 27.4
Knee-related quality of life	43.3 ± 19.9

* KOOS = Knee Injury and Osteoarthritis Outcome Score.

Table 4. Themes and illustrative quotes

Control of symptoms

- a. It's a never-ending process, yeah. I guess we want a fast fix for everything. That's the way society is. It's unfortunate. I think most people have reflected that, that that's the wish to keep it well-maintained. (Idelle, age 46, FG06)
- b. I would say maintenance and prevention at the same time as in maintenance in keeping mobile through fitness; and prevention in knowing my limitations. (Marta, age 44, FG02)
- c. So for me, I'd like to enjoy activity, be capable of it and have that consistency where there's no peaks [in pain]. (Peter, age 57, FG01)
- d. I would love it if there were some way to halt the progress of it. If this were as bad as it was going to get, I can handle it. (Jean, age 65, FG01)
- e. But then if my knee totally gave out and I couldn't walk around, I wouldn't be opposed to going and having it replaced. But I'd like to do everything I can to avoid that or prolong it as long as possible. (Laila, age 60, FG03)
- f. We don't want that at all. We're all looking for solutions to avoid surgery. (Donna, age 56, FG03)

Seeking solutions

Informal learning

- g. So it's research and doctors and word of mouth. If you have the money, you can use that money wisely to different places that will help you out (Marta, age 44, FG02).
- h. I did a lot of research on the internet, WebMD and a few others. You know, I can't even remember them exactly, but I did a lot of research to see what would work, what wouldn't work, and some of it was just through trial and error. I knew that the bike would probably work because really the muscles that you're using are your quad muscles, which are up here, and you're not putting as much strain on your knee, you're putting the strain on your quads and your hips. (Samantha, age 40, FG04).
- i. It find that we talk. We talk to your friends, you talk to other people that have maybe had similar symptoms. What did your doctor say? What did you do? I read magazines, you know, I go to the internet and you have to kind of make sure that you're not being a little bit discriminating in what you're reading and not just taking everything there about, they'll try to sell you anything on the internet. (Rachel, age 55, FG01)
- j. Actually, it was recommended by the sports medicine friend of mine in Turkey. He's in the research part of it. They have like several people who have knee problems, you know, the injury, like a knee or tendons, tendonitis and that kind of stuff and it worked for the sauna. It helps with the toxins. (Eser, age 44, FG02)

Trial and error

- k. I think we take the best from everywhere, what works. And you try many things and find what works well. I would rather eat types of foods that are anti-inflammatory. I pay attention to that stuff and try and include a lot of those foods in my diet. (Laila, age 60, FG03)
- l. It's trial and error, some of it. And thinking very clearly about what caused this today. What hurt my knee today? What did I do wrong today? (Bill, age 61, FG03)
- m. So okay, there's so many different schools of thought, different views, that it's really an individual where you go through life and what path you chose. But, yeah, it's a lot of trial and error. (Helen, age 41, FG02)

Help-seeking from health care providers

- n. Yeah, stress. I don't find any supporting hand from my physician. Whenever I complain about my pain to my physician, first of all she did not take it seriously. (Safa, age 38, FG04)
- o. No, listen. You have to go in there prepared now, and they tell you this. When you see your physician. This is my knee pain. Okay, can I get physio done? Can I get, like she's saying, can I get a chiropractor? (Brent, age 45, FG04)
- p. Well, I think more people are becoming ... Just listening around this table, all the different things, alternative things people do. I think people are becoming much more aware that there's other ways. And that you almost have to start to take responsibility for your own health. (Laila, age 60, FG03)
- q. I keep asking the doctor, because I still see him because he works in the same office as my family doctor. I keep seeing him and I'm like, when can I get the surgery on my knee? He goes, I'm not. It's like, please. It's getting to the point. (Wilson, age 41, FG06)
- r. I just go to my doctor's. When I went through arthritis with my mom, who's 94 now, I've been to numerous of her arthritis appointments, it's always the same thing. We can't do anything. I can give you cortisone shots. And it's 50% whether it helps or not helps. She was getting acupuncture for herself years ago, before anybody else I knew was getting it and that gave her some relief. And then various on Celebrex until her doctor told her not to take it anymore. So I thought well what's the point? (Jean, age 65, FG01)
- s. I don't want to use, you know, any prescription medicine because I was also told that it, it could be it needs to be operated, but I don't want to be operated because they didn't give me any warrantee. Maybe it's going to get worse or, you know, it's a 50/50 chance. So, so I don't want to get anesthesia, general anesthesia. So right now I'm just managing to control like all the symptoms that I am having. (Eser, age 44, FG02)
- t. I don't think doctors are preventative enough these days. I think they're too treatment oriented. So you kind of have to approach them with a problem and then they just want to medicate it or they want to tell you that you've sort of imagined it and it's not quite as bad and kind of walk away from it. (Janet, age 49, FG02)

Active management

- u. This is sort of a recurring theme, but I made a conscientious effort to do three times a week an exercise regimen more consistent than I had been previously. That has not made it any worse that's for sure. It seems like I feel a lot better in general health to begin with, whether it's psychological or not, but I also think it has helped keep any kind of pain from occurring. (Ken, age 48, FG06)

(continued)

Table 4. (Cont'd)

- v. It's one of the things where I've pretty much always known, where I've always experienced the pain. I was heavier. I've lost like 100 pounds, and the main reason I did lose the 100 pounds was because it was very painful on the knee. And with the weight loss. And to start off the weight loss, I figured, with the pain, this adjusted like to pull up with it and swimming to help me lose the weight. So, with part of the weight loss I did that, but then the weight loss sort of stopped so the pain with the knees had gotten better, so I did the elliptical and I've gone onto the treadmill. (Isabel, age 48, FG04)
- w. Yeah, I use a knee brace, one of those elastic jobs. You can find them in the drug store sort of thing. I spend a lot of time not just on the exercise bicycle but on the treadmill. And there have been days when the 25 minutes that I'm supposed to be on the treadmill turns into 7 or 8 because I'm just pounding way too hard. But the next day, I can come back with the knee brace on and I can go the full distance. (Bill, age 61, FG03)
- x. What I found out was that I started natural, holistic nutrition because I don't want all this unnecessary conventional treatment. And I know when I apply peanut oil, it's an antidote for any kind of arthritis or any kind of pain muscle, I was as good as new too. (Jennie, age 63, FG03)
- y. So she's given me exercises and then every month she increases the exercises more to increase the strength of the inner leg and strengthen the knee. So, that's where I am at the moment. I stopped losing my balance and the locking and all that happens rarely. I do feel pain and stiffness if I sit for more than an hour. I can't get up. That's still there, but at least the severe pain while walking and falling down has gone. So, I just keep working at it and hope it becomes fine. (Savine, age 50, FG05)
- z. I work in a lab. I work in two labs actually. It is a workbench that I'm on. With some benches I need to actually stand a lot. So actually, because of my knee, I actually have to sit. Get a stool and sit okay for a bit. Otherwise I just cannot do my job anymore. (Sarah, age 57, FG03)

While the data were analyzed for patterns in younger and older age groups, the process of managing knees was generally similar for participants of all ages. When age was interpreted to influence participants' experiences with management, this is described in the results. The process of managing knees was generally similar for men and women.

Control of symptoms. Participants' actions were driven by a desire to control knee symptoms, such as pain, aching, and stiffness. Some participants remained hopeful of finding a "fix" to regain their former symptom-free bodies. One participant stated, "It's too tempting to think that there is a fix . . . In my mind, I haven't resigned myself to staying like this for the rest of my life" (Mark, age 46 years). However, most participants indicated they were learning that a "silver bullet" didn't exist, which meant that they believed there was unlikely to be one solution for everyone. More commonly, participants' accounts suggested that their motivation for working to control immediate symptoms was to remain active in social and physical activities that they perceived to be important. Some participants also sought to control progression. They constructed their knee problem as something that might "degenerate further" and sought to slow or halt progression through preventative actions, such as exercise. Participants often expressed a desire to prevent or delay the need for invasive interventions such as TJR. For instance, Samantha discussed her goal to "stave off" OA progression and surgery: "I know eventually that will happen, but the exercise I'm doing now will probably keep it at bay for a little while" (age 44 years).

Seeking solutions. Seeking solutions refers to the cognitive and physical efforts that participants used to find ways to manage their knee symptoms.

Informal learning. Participants recounted using informal learning processes to find solutions to their knee problems. This entailed intentional learning through social

interactions and doing their own research. Participants sought to confirm what was happening to their knee and find appropriate management strategies. They compared their experiences to others with knee problems to make sense of what was going on (e.g., parents, friends) and sought informal advice from peers. They did their own "research," which entailed consulting web sites, books, magazines, or other resources to help them understand and manage their knees. Some participants talked about evaluating the trustworthiness of information they encountered. For example, one participant explained, "You get it from people who know, like I don't believe anything until I hear it three times" (Peter, age 57 years).

Trial and error. Participants recounted the use of trial and error to find a solution to their knee symptoms. They employed a strategy and considered the effects of it to decide whether to use the strategy over the long term. For instance, a participant described how she was using trial and error to see how weight loss impacted her knee: "I've set up a thing where I'm bringing my weight down. I want to lose ten pounds in the next four months and then we'll look at that and see, well does that play a part in it" (Debbie, age 48 years).

Help seeking from health care providers. The majority of participants visited their primary care doctor and many consulted various health professionals (e.g., physiotherapists, chiropractors). Generally, participants felt that their role was to ask questions, engage in a dialog with their health care providers, and "push" for what they need while being an advocate for one's self. Participants conveyed a need to be persistent and if one avenue was unsuccessful, they perceived it was their responsibility to seek answers elsewhere.

Participants depicted the doctor's role as instrumental in getting a diagnosis. Their accounts suggested that a professional diagnosis had an important role in legitimizing the problem and guiding management. A few participants, often in the younger age groups, conveyed they did not understand what was happening to their knee or did

not feel that their complaints were “taken seriously” by care providers. This resulted in frustration and struggles to find ways to manage. For instance, one participant, who stated he did not understand his knee situation very well, tried a range of health care options in his search for a solution, including some he described were experimental procedures (e.g., injection of platelet-enriched plasma).

Participants recounted experiences with medical care and portrayed that there were few medical options available, except TJR. They invoked examples to illustrate the shortcomings of current medical treatments. They alluded to recalls of arthritis drugs and their understanding that some interventions only had a 50% chance of being effective. Others commented that “conventional” medicine was too focused on pharmaceuticals, failing to support alternative therapies, and not providing them with enough preventative options. One participant reflected, “When I went for my last appointment at [hospital], they said, chondroitin and glucosamine, it’s just hogwash. Well, how often does surgery work? You know, the allopathic medicines, the Celebrex or Vioxx . . . as a Canadian consumer, what are my choices?” (Nigel, age 61 years). Participants also recounted instances in which they had not received enough guidance on how to manage (e.g., what to do and not to do).

When participants experienced a lack of health care options and advice, it often resulted in them feeling upset or frustrated. These feelings were more prominent in focus groups with adults ages 35–49 years. For instance, Tiana (age 49 years) expressed frustration over her medical care: “I guess what I’m really frustrated with is my physician has not really given me any direction as to what could I do or what shouldn’t I be doing?” Unsatisfactory health care experiences prompted participants to consult other health care providers or resume using informal learning and/or trial and error as they continued to seek a solution.

Active management. Active management refers to the ongoing use of strategies as part of a regular routine of health practices or as needed. The purposive strategies participants recounted were many and varied (e.g., exercise, weight loss, supplements, orthotics, and acupuncture). While participants mentioned medications, discussions focused on nonpharmacologic strategies. The strategies participants regularly used reflected their perspectives about health more generally. For example, people engaged in physical activity for varied reasons, such as the perceived benefits for their overall health, perceived benefits for their knee, or social interaction. Other participants preferred “natural” treatments, which they perceived to be healthier than “conventional” medical management.

Some of the strategies participants consistently used were adaptive behaviors integrated within their daily life such as restriction or limitation of certain activities, planning of activities in advance, or modification or substitution of behaviors. For instance, one participant commented, “I avoid stairs. I will walk a lot to avoid a big flight of stairs. Because when I’m going up and down the stairs,

it’s as if it’s bone on bone and it’s just a really uncomfortable feeling” (Laila, age 60 years).

Participants expressed concerns about the challenges involved in maintaining efforts to manage knee symptoms. Management sometimes competed with other demands for their time (e.g., employment) and monetary issues. Participants used their own money in myriad ways to control knee symptoms (e.g., private health care). One participant commented, “I don’t think we mentioned also how much it costs you for your pocket money, that you had your knee problem . . .” (Marta, age 44 years). Regardless, most participants conveyed active management was what they should be doing. For example, one participant reflected, “. . . It’s a long process and I’m not regular with my exercises which I should be” (Savine, age 50 years).

DISCUSSION

By exploring how people ages 35–65 years respond to and manage knee symptoms, this study provides novel insights that may help us to better support OA management earlier in life. Taking action on knee symptoms explicates the complex process in which people try to find solutions and maintain active management to control knee symptoms and prevent disease progression. Our findings highlight that participants were proactive in working to manage their knee symptoms. In contrast, they perceived that medical care was often more reactive, with little to offer them other than TJR. Participants expressed interest in earlier intervention to support management or halt or delay OA progression and delay interventions such as TJR. Yet, there is currently a gap in providing such supportive conditions within the health care system. We suggest that a shift in how we conceptualize and deliver health care is needed to help people effectively manage symptoms earlier in life.

While research into new treatments that address symptoms and progression is critical, there are nonpharmacologic strategies, such as exercise, which have been shown to be effective in improving pain and function (14–18,28). Our findings highlight the need for changes in health care delivery to support use of such strategies. Most importantly, more nuanced information is required to tailor advice to individual symptoms within the context of peoples’ lives. Like other studies of managing chronic disease, participants conveyed they were already working hard to self-manage (10,29,30). They were aware of and had tried many known best practices for OA. However, participants often recounted that guidance from health care providers on how to manage symptoms was limited. Other studies have reported limited provision of advice on nonpharmacologic interventions for OA (e.g., exercise) in primary care and that physicians lack confidence in musculoskeletal management (31–34). Rather than broad statements on best practices, this study highlights that people may require more personalized help from health care providers to use strategies in effective ways, including how to use them, how often, and what outcomes to expect. Studies in older adults have also recommended improvements in the provision of management advice (35–37), including better information on management soon after OA diagno-

sis (37). Others highlighted missed opportunities for providing management advice when older individuals do not seek care, recommending a targeted and integrated approach between health care providers and health planners for primary and secondary prevention (35).

A professional diagnosis had an important role in legitimizing symptoms and guiding management, particularly for younger adults. Other research has shown that people wish to have symptoms acknowledged to be genuine by health professionals and peers. A diagnosis can also enable people to access information and treatments (38). This study points to the need for health professionals to recognize early symptoms and risk factors for OA to facilitate a timely diagnosis.

Participants portrayed themselves as being responsible for their health, reflecting evolving societal views that individuals have a responsibility or moral obligation to pursue health (39–41). Findings suggest this generation already conceptualizes their role as being “active” and “informed,” as promoted in chronic disease models (42). While participants often conveyed that maintaining active management was what they should be doing, they suggested it was challenging. Currently, OA is often not conceptualized as a chronic disease requiring long-term support. Single consultations may be insufficient to help people manage across the life course, particularly in ways that could have the potential to prevent deterioration. Mechanisms for long-term support for knee symptoms are needed. Routine regular followup with a primary health care provider may be beneficial for some individuals. For others, it may be sufficient to use community-based programs (e.g., exercise classes) and have the option to re-access the health care system for consultation as needed. In a study of older adults with OA, patients indicated that they would value the support provided by regular followup (37). Further research is needed to determine the best mechanisms for followup for younger adults with knee symptoms.

Support for OA self-management has mainly been provided through lay-led self-management programs. While outcomes are generally favorable, research suggests these programs tend to have older women participants with more advanced disease (43–45). Moreover, younger adults without a diagnosis may be less likely to attend an arthritis program. While prior research on older adults found that people normalized OA as a part of aging and did not seek professional help (10,46), participants in this study typically sought health care. Others have recognized that primary health care providers have an important role in providing support for self-management of chronic conditions (47–49). This role is not yet a routine part of primary health care in Canada (47). This study raises crucial questions as to how best to provide management advice and support to people with knee symptoms across the spectrum of age and disease. Further research is needed to understand more about people’s needs, gaps in health care interventions, and how people prefer to have assistance provided earlier in life.

While the role of age was considered in the analysis, the management process was generally similar across the age range. It is telling that people are working hard to manage

knee symptoms even at relatively young ages. These data are unable to disentangle potential relationships between age, stage of disease, and approach to management. However, prior quantitative research shows that once you have arthritis, there is little difference in outcomes by age (50).

The study has limitations. We relied on self-report diagnosis of OA or chronic knee symptoms. While we are unable to determine if participants reporting symptoms have OA, we based our question on a widely used survey question on joint pain (21) and careful exclusion criteria to recruit participants more likely to have OA. The majority of participants lived in an urban area and was working, potentially facilitating access to health care resources and insurance. This sample was also highly educated, which may have influenced our findings that participants were proactive in management. While the study was conducted in a large multicultural center, we did not sample based on ethnicity. Future research is warranted to understand the role of culture on management.

In conclusion, this study adds to our understanding of the complex process people engage in as they manage knee symptoms earlier in life. In particular, we shed light on the mismatch between the participants’ proactive approach and the health care system, which participants perceived to be more reactive. This study highlights opportunities for future research and provides guidance on important issues that need to be addressed in the health care system to support management of knee symptoms, particularly in younger age groups.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Ms MacKay had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. MacKay, Badley, Jaglal, Sale, Davis.

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