Qualitative Study Exploring the Meaning of Knee Symptoms to Adults Ages 35–65 Years

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Objective. While osteoarthritis (OA) has mainly been viewed as a disease affecting older people, its prevalence in younger adults is substantial. However, there is limited research on how younger adults understand knee symptoms. This article explores the meaning of knee symptoms to adults ages 35–65 years.

Methods. This qualitative study comprised 6 focus groups and 10 one-on-one interviews with 51 participants (median age 49, 61% female), who self-reported knee OA or reported knee symptoms (i.e., pain, aching, or stiffness) on most days of the past month. Constructivist grounded theory guided the sampling, data collection, and analysis. Data were analyzed using a constant comparative method.

Results. Central to participants’ understanding of knee symptoms was the perception that symptoms were preventable, meaning that there was the potential to prevent the onset of symptoms and to alter the course of symptoms. This understanding was demonstrated in participants’ explanation of symptoms. Participants commented on the cause, prevention, and course of symptoms. Moreover, participants reflected on their experience with symptoms, indicating that symptoms made them feel older than their current age. However, they did not perceive their symptoms as normal or acceptable.

Conclusion. Participants interpreted knee symptoms as potentially preventable, suggesting that they may be open to primary and secondary prevention strategies.

INTRODUCTION

Osteoarthritis (OA) is recognized as one of the greatest public health challenges facing many societies. While the highest prevalence of OA is in older adults, the incidence of OA in adults ages 20–50 years is substantial (1). A recent US study reported that the median age at diagnosis of knee OA is 55 years, earlier than that reported in prior research (2). A variety of etiologic risk factors contribute to OA, including obesity, genetics, aging, and joint injury (3–6). Knee injury and obesity, both of which are on the rise (7–9), are likely to lead to even higher rates of OA in younger adults (10). In order to mitigate the increasing burden of OA, there is a pressing need to develop interventions that support the management of it through the use of evidence-based strategies (e.g., exercise, weight loss) (11) beginning in the third or fourth decade of life, when symptoms may begin. A greater focus on preventing the onset of OA and altering the course of OA is also needed.

Illness meanings reflect people’s personal experiences and explanations of their conditions (12). Researchers have suggested that a failure of clinicians to understand how people understand their condition is one of the key obstacles to the success of public health programs (13,14). Prior research related to illness meanings in OA has focused on what individuals believed were the causes of OA (often “wear and tear” and aging) (15–18). It is less well understood how younger adults understand their knee symptoms. One study of Taiwanese adults (mean age 50 years), mainly laborers, found that participants attributed their knee OA to excessive joint loading, injury or other disease, diet, and genetics (19). Given the paucity of research in younger populations, we aimed to explore the meaning of knee symptoms to people ages 35–65 years, focusing on how people understood or perceived their knee symptoms. A better understanding of how adults understand their knee symptoms is a critical first step in the development of interventions in OA prevention and management.

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MATERIALS AND METHODS

Study design. This study used qualitative methods drawing on the principles and methods of constructivist grounded theory (20). It is part of a broader qualitative program of research exploring the perceptions, experiences, and management of knee symptoms. Methods used for the study have been described elsewhere (21,22). In constructivist grounded theory, researchers aim to understand participants’ beliefs and actions from their perspectives and locate participants’ meanings within larger social structures and discourses (20). This study draws on symbolic interactionism, which posits that meanings arise out of social interaction, and are modified through an interpretative process that occurs as persons respond to their circumstances (23).

Sampling and data collection. Individuals from the Greater Toronto Area were recruited through advertisements in a community paper, an acute-care hospital, and community centers. Individuals were included if they were ages 35–65 years and self-reported a diagnosis of knee OA or reported that they had knee symptoms (i.e., pain, aching, or stiffness) on most days of the past month, since younger adults may not have a diagnosis or perceive their symptoms to be related to OA. The knee-symptoms screening question was based on a widely used survey question on joint pain (24). Participants were excluded if they had a knee injury in the past year (to exclude acute injuries); had knee pain referred from the low back; had other types of arthritis (e.g., inflammatory arthritis); were waiting for, recommended, or had undergone total joint replacement; or had other chronic physical health conditions (e.g., Parkinson’s disease, stroke) that affected their mobility. Knee pain referred from the hip was not an exclusion criterion; in a study of hip joint pain referral patterns, only 2% of patients had knee pain (25). Since some of the participants had OA-like symptoms but did not have diagnosed OA (25 of 51 [49%]), we use the term “knee symptoms.” If findings pertained only to participants who self-reported diagnosed OA or who reported OA-like symptoms, they were specified as such in the study results.

Purposive sampling was used, initially seeking variation across age and sex. As the data collection and analysis progressed, we continued to seek variation in age to explicate emerging categories. Data collection was stopped at the point of saturation, when no new information relevant to our research question (e.g., categories) was generated (26).

This study employed focus groups and individual interviews. Focus groups were used to explore the range of participants’ experiences; individual interviews contributed to the detailing of the experiences (27). Interviews built on the analysis of focus group data. First, 6 semistructured focus groups (n = 41) were conducted in hospital boardrooms. Participants were grouped in focus groups by age (35–49 years and 50–65 years) to create homogeneous age groups (27). The focus groups were moderated (CM) and a second researcher kept a speaker log and took notes summarizing verbal and nonverbal communication. A focus group guide was used to facilitate discussions (Table 1). Following the focus groups, 10 semistructured one-on-one interviews were conducted with new participants. The interview guide was refined based on the analysis from the focus groups (Table 1). Interviews took place in a private room at the hospital or the participant’s workplace. A single researcher (CM) conducted all interviews. The focus groups lasted 1.5–2 hours and interviews lasted approximately 1 hour.

All focus groups and interviews were audio-recorded, transcribed verbatim, and entered into Nvivo9, a qualitative software program. Field notes were written to summarize data and reflect on any questions that arose concerning the data. Following the focus groups or interviews, participants completed the Knee Injury and Osteoarthritis Outcome Score (KOOS) questionnaire. These data were used to describe participants’ knee symptoms and function in order to enable readers to place the findings of this study in the wider context of other studies of knee OA (28). This study was approved by the Research Ethics Board of the University Health Network and the University of Toronto. Written informed consent was obtained from all participants.

Analysis. Data analysis was conducted concurrently with data collection in order to allow for developing themes to be pursued in subsequent focus groups/interviews. A constant comparative method of analysis was used (20). Analysis included open coding, axial coding, and developing a core category that explained the central theme of the data (29). The data was open-coded and a coding scheme created by a researcher (CM), which was reviewed by all authors. More than one author read all transcripts, and all authors met regularly to discuss the ongoing analysis, including alternate interpretations of the data. The analysis included multiple readings of the transcripts, in order to understand the meanings central to the research question.
Meaning of Knee Symptoms

RESULTS

Fifty-one individuals with moderately symptomatic OA based on their KOOS scores (33) participated (Tables 2 and 3). An overview of the core category is presented, followed by a more detailed description of the 2 categories under the core category. Illustrative quotes are presented in Table 4. All names are pseudonyms.

Core category: knee symptoms are preventable. Central to participants’ understanding of knee symptoms was the perception that symptoms were preventable, meaning that there was the potential to prevent the onset of symptoms and to alter the course of symptoms. Participants conceptualized their symptoms as a health problem that had a physical cause that might have been prevented and should be amenable to control. This understanding was reflected in how participants explained symptoms and described their experiences with symptoms (Figure 1). When explaining symptoms, participants reflected on their understanding of the cause, prevention, and course of symptoms. These conceptualizations were interconnected, as their perceptions of cause influenced their views on how the onset of symptoms may have been prevented and their beliefs about the future course of symptoms. Participants often attributed symptoms to modifiable actions (e.g., jogging), incidents (e.g., injuries), or characteristics (e.g., being overweight). As a result, they often believed that they might have been able to prevent the onset of symptoms had they changed their behavior earlier in life. Most participants believed that symptoms could progress but that the course of symptoms could be controlled to some extent through their actions. Moreover, participants reflected on their experience with symptoms, indicating that symptoms made them feel older than their actual age. They did not perceive their symptoms as normal or acceptable for this stage of life.

EXPLANATION OF KNEE SYMPTOMS

Cause of symptoms. Participants explained knee symptoms by recounting their personal biographies and relating their symptoms to prior actions, incidents, personal characteristics, or family histories.

Table 1. Question guides

| Focus group guide |
|-------------------|
| 1. Tell me about what is happening with your knee(s). |
| 2. 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? |
| 3. When you think of yourself 10 or 20 years down the road, what do you think might happen with your knee? |
| 4. What do you do for your knee? |
| 5. After having your experience, what advice would you give someone else who has just started to have knee issues? |
| 6. Do you have anything else you wish to say about living with your knee symptoms? |

Table 2. Sample demographics (n = 51)

| Demographics | No. (%) |
|--------------|--------|
| Median age, years | 49 |
| Minimum | 37 |
| Maximum | 65 |
| Interquartile range | 44–58 |
| Female | 31 (60.8) |
| Education | |
| High school | 9 (17.6) |
| Trades certificate/diploma | 16 (31.4) |
| or college graduate | |
| University graduate | 30 (58.8) |
| Marital status | |
| Married/living as married | 21 (41.2) |
| Divorced/widowed/never married | 30 (58.8) |
| Employment status | |
| Currently working | 40 (78.4) |
| Unemployed | 7 (13.7) |
| Retired | 3 (5.9) |
| Student | 1 (2.0) |

Table 3. Mean Knee Injury and Osteoarthritis Outcome Score scores

| Subscales | Mean ± SD scores* |
|-----------|--------------------|
| Symptoms | 67.02 ± 14.08 |
| Pain | 63.69 ± 18.01 |
| Function in daily living | 68.78 ± 18.26 |
| Function in sport and recreation | 52.05 ± 27.86 |
| Knee-related quality of life | 43.0 ± 19.22 |

* Range 0–100 for each subscale, where 0 = extreme symptoms and 100 = no symptoms.
tory. While participants’ explanations of the cause varied, a common feature across their accounts was at least partial attribution of symptoms to actions or incidents that were modifiable.

Some participants, particularly adults with a diagnosis of OA, understood their symptoms as part of a lifelong condition, but still believed they could manage it (Rebecca, age 37, interview). Some participants talked about how they had “pushed” their bodies too far. They perceived the knee as having a finite capacity to withstand activity. For example, one participant, who attributed his knee pain to years of jogging and playing squash, said, “What has happened is in some ways when you abuse or overuse it, there is a wear...in my case, I overused it more than a normal function which the body was supposed to do” (Chata, age 65, interview).

Some participants, particularly younger ones, accounted for their knee symptoms by referring to a knee injury, some of which occurred when they were recreational athletes. Marta described an injury that she linked to her knee symptoms, saying, “I’m a master in tae kwon do. And I was in the [championship] in ’95 and I had to flex my knee and my knee popped. That was the first time that my knee gave out” (Marta, age 44, focus group 2). Others recounted knee injuries from falls. Adam (age 54, interview) explained, “The right side was [injured] coming off of a stepladder.”

Being overweight was considered a cause or contributing factor to knee symptoms by putting excess load on the knee. One participant shared his understanding of the effect of weight on his knees, saying, “I carry about 10 pounds, which I’ve been told that it’s multiplied by 15 on your knee” (Peter, age 57, focus group 1). Another participant explained that carrying her backpack increased her

### Table 4. Illustrative quotations by category

| Explanation of symptoms | Cause of symptoms |
|-------------------------|------------------|
| “I’ve thought about it, but from what I understand it’s wear and tear. I mean, I’ve worked a lot. I’ve been on my feet a lot. I’ve had my sports things that I used to do, like windsurfing and tennis and all these things, so maybe that’s caused some of it, and I’ve had sedentary periods” (Audrey, age 63, interview). | “I was trying to get the casing off the light, so I twisted, and when I twisted I lost my footing on the stepladder. I landed on my feet, but when I landed my leg was twisted, so it was just enough to kind of mess everything up” (Emma, age 42, interview). |
| “But I played a lot of rugby. And I had a bad injury” (Nigel, age 61, focus group 3). | “The right side was [injured] coming off of a stepladder.” |
| “My problem also is with my left knee as well. I had a ski injury when I was in my 20s and now I’m in my late 40s. I never really had it formally diagnosed” (Idelle, age 46, focus group 6). | “I've thought about it, but from what I understand it’s wear and tear. I mean, I've worked a lot. I've been on my feet a lot. I've had my sports things that I used to do, like windsurfing and tennis and all these things, so maybe that’s caused some of it, and I’ve had sedentary periods” (Audrey, age 63, interview). |
| “Mine goes back, it’s probably 15 to 20 years. 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” (Isabel, age 48, focus group 4). | |
| **Prevention of symptoms** | |
| “If I could rewind, I would try and be as equally active as I ever was, but in different sports. I wouldn’t play collision sports, because as well as knee pain, I mean, there’s head trauma...but swimming, or sports that don’t require unnatural strain and stresses on joints. If I could rewind for my sons, I would discourage them to play contact or collision sports as well, because both did and who’s to say what will happen when they’re my age” (Davis, age 61, focus group 5). | |
| **Course of symptoms** | |
| “It’s a degenerative disease, so it’s going to be worse” (Katia, age 43, focus group 4). | “I just think the future will be like this, unless I do something stupid like try to run or play hockey too much or do something that really injures it permanently” (James, age 42, interview). |
| “I’m assuming it’s just going to be a lifelong condition, but I feel good now at least about how I can manage it” (Rebecca, age 37, interview). | “Well I’m hoping they keep as they are, they don’t get any worse. So with good management and careful activity and consciousness of not breaking them or pushing the strain I can keep them as they are” (Oscar, age 59, interview). |
| “I just think the future will be like this, unless I do something stupid like try to run or play hockey too much or do something that really injures it permanently” (James, age 42, interview). | |
| **Experience with symptoms** | |
| Symptoms made participants feel old, but were not perceived as an inevitable part of aging | “Then my family doctor says you have to recognize the fact that you’re getting older. So you’re going to get pains. Then I started to say well, wait a minute” (Nigel, age 61, focus group 3). |
| “Well, yeah, I mean, our generation is never going to get old” (Rachel, age 55, focus group 1). | |
| “I guess it’s more relating to people differently, more with older people, I guess. It doesn’t usually happen to kids, to teenagers, but then I didn’t think I was that old either. I guess it was sort of a little bit of a wakeup call that I’m middle-aged now” (James, age 42, interview). | |
| “Mine goes back, it’s probably 15 to 20 years. 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” (Isabel, age 48, focus group 4). | |
| “Then my family doctor says you have to recognize the fact that you’re getting older. So you’re going to get pains. Then I started to say well, wait a minute” (Nigel, age 61, focus group 3). |

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**Figure 1.** Core category: knee symptoms are preventable.
knee pain. She then stated, “Obviously, what I’m carrying on my body must contribute to my knee pain” (Yvetta, age 57, interview).

Some participants indicated that family members had OA and suggested that heredity may have put them at risk for their knee symptoms. Samantha (age 44, focus group) explained, “It’s hereditary because my grandmother has it, my mom has it, my sister has it.” Interestingly, participants did not attribute their symptoms solely to age. Like heredity, when age was mentioned by a few participants as contributing to their symptoms, it was typically in conjunction with other causes.

Prevention of symptoms. In linking their symptoms primarily to actions or incidents, some participants believed that they could have prevented the onset of symptoms had they changed their behavior earlier in life. Some participants indicated that if they had not engaged in high-impact activities, reduced the extent to which they performed activities, or avoided injuries, they might have prevented their knee symptoms. This was particularly common in older adults. For example, one participant said, “What should I have done different? I think I would have stopped jogging. I would have gone more on a bike … It was nice at that time, but there is a payback” (Chata, age 65, interview).

Course of symptoms. Most participants believed that symptoms had the potential to “get worse” over time. In particular, participants with diagnosed OA believed that OA was a progressive “degenerative disease.” However, common to most participants’ accounts was a belief that they could halt or slow the progression of symptoms to some extent through behaviors, such as exercise and diet. One man reflected, “I think you can control the pace of it [degeneration] and I think you can control your lifestyle, your eating habits, and I think you can stretch it out” (Brent, age 45, focus group 4).

Some participants with a history of knee injury believed that their symptoms would not progress as long as they did not “injure” their knee again. Others believed they could have limited progression of symptoms had a prior knee injury been dealt with at the time of injury (e.g., with appropriate health care interventions). For instance, one participant who injured her knee as a teen figured skating, recalled that neither she nor her family thought much of the injury at the time, and had not sought treatment. However, she believed the repercussions of the injury were long term, saying, “If you circle it all back, it goes right back to that knee injury and the inability really to get it solved permanently” (Sadie, age 47, interview).

Experience with symptoms. Symptoms made participants feel old but were not perceived as an inevitable part of aging. Participants expressed that the changes they experienced in their physical abilities due to their knee symptoms made them feel “old.” Participants suggested that their physical symptoms drew their attention to their age and made them think about what that age meant. It was particularly common for adults in their 50s and 60s to reflect on aging. One participant commented, “I don’t like being reminded that I’m getting older” (Davis, age 61, focus group 5). Some younger participants also reported that their knee symptoms made them feel older. A 42-year-old male spoke about how young he felt when he was running. He stated that, after he gave up running, because of his knee symptoms “… it’s like I’ve aged 20 years” (James, age 42, interview).

Another way participants indicated that their symptoms made them feel older was through shifts in their social relationships. Some participants conveyed that they related more to older individuals with health problems. For example, one participant said, “I’ve had a couple of really good friends that have been there for me. And, I mean, they’re older people, so they have their own health issues, so they understand a bit better” (Emma, age 42, interview).

While participants felt older as a result of some of their symptoms, they did not perceive their symptoms as normal or acceptable. Some participants in their 30s and 40s had difficulty accepting a diagnosis of OA, because they perceived that OA was a condition common to older adults. Other participants believed that their bodies should still be capable of healing. For instance, one participant commented, “As a youth, when you got injured, your body would repair itself. I still can’t figure out why my body is not repairing itself” (James, age 42, interview).

Older participants did not normalize symptoms as an inevitable part of aging. They compared themselves to peers who did not have symptoms and associated physical limitations, as well as their expectations of their bodies, which suggested to them that their symptoms were not normal. Older participants often suggested that the social messages they received indicated that they would have long, active lives in which they would not “grow old.” For example, one 63-year-old woman reflected, “The other thing is all the ads. In my mind, when I was this age, up until I was 90, I envisioned myself continuing to play tennis, continuing to ski, [doing] all these things that I like to do. My friends from California send me pictures and they’re hiking in the mountains with their partners and they’re the same age that I am” (Audrey, age 63, interview).

While participants believed that symptoms were not normal or inevitable, they often recounted interactions with health care professionals in which their symptoms were viewed as something that could not be significantly changed. Some older adults felt that symptoms were dismissed by their health care provider as an inevitable part of getting older. One participant recounted, “I went to a rheumatologist. He said, ‘You probably have osteoarthritis. That’s an old-age thing. You just have to live with it’” (Sarah, age 57, focus group 3). This resulted in incongruence between participants’ understanding of symptoms and their interpretation of the health care providers’ understanding of symptoms.

DISCUSSION

Central to participants’ understanding of their knee symptoms was the perception that there was the potential to prevent the onset and limit the progression of symptoms. Symptoms were not perceived as normal or inevitable. These findings are in contrast to prior research, primarily studying adults >60 years old, which suggested that people constructed OA as a normal part of aging (16–18). These findings have implications for how OA is managed. Initiatives targeting primary and secondary prevention of OA are still in their
infancy. However, there are calls to shift the focus of OA management to persons at high risk of developing OA, and to those with early disease, where structural changes may be preventable or reversible (34,35). While participants in this study did not use these terms, their understanding of symptoms as potentially preventable suggests that they may be open to primary and secondary prevention strategies.

Studies have shown that injuries and joint trauma are risk factors for OA (36,37). Some participants in our study linked their symptoms to prior injury or “overuse” and suggested that their symptoms may have been preventable. However, they conveyed that they did not think much about injuries or actions at the time that they occurred. There may be a need for public health messages that could provide information about the risk factors for OA and ways to maintain physical activity and healthy joints throughout life. Some imroads have been made in providing public health messaging on OA prevention and management in the US (38). However, more widespread interventions in schools and sports and recreation systems could create awareness of the musculoskeletal system, healthy joints, and ways to prevent and treat injury at an early age.

Our findings suggest that there was a disconnect between some participants, who believed their symptoms were preventable, and their health care providers, who sometimes indicated that OA symptoms were part of getting older. Other researchers have found that some health care providers have a fatalistic view of OA (39), assuming that it is an inevitable, progressive disease (35) and trivialize it in clinical practice (39). Any incongruence between patients’ explanations of their condition and health care providers’ explanations could result in less effective communication and poorer health care results (12). Shifting how health care providers view OA is critical to ensuring that people feel supported in their health care interactions and receive up-to-date information. Primary health care providers have opportunities to provide personalized advice on OA risk factors and education on secondary prevention of pain and disability through exercise and weight management.

Prior research in older adults demonstrated that people believed that “wear and tear,” occupation, diet, and genetics contributed to their OA (18,19). In contrast to our findings, most research in older adults has shown that people often perceived OA as a normal and natural part of aging (15,16,18,40). Research in older samples also found that people viewed OA as incurable and likely to progress (15,18). While the participants in this study believed that symptoms may progress, they also indicated that they believed that they could potentially slow this process. It is possible that the younger age of the participants may account for these differences. However, the contexts within which health and illness are defined and experienced are constantly shifting (41), and it is also possible that a more general shift in how we construct health and illness is occurring.

While participants did not focus on aging as a cause of symptoms, they conveyed that their experience with symptoms made them feel older. It was not age itself but their experience with their bodies that made them consider age. Laz (42) argues that age gains meaning in social interaction and in the context of larger social forces; individuals draw on resources, such as media, community beliefs, and relationships, to enact their age. In this study, participants compared themselves to others as they made sense of their symptoms. They also seemed to draw on broader social understandings of health, such as healthy aging (43) and healthism. Healthism assumes that “the problem of (and solutions to) health and disease are at the level of the individual” (44). Governments and individuals regularly speak of pursuing healthy lifestyles and being responsible for one’s own health (45). Given these potential influences, it may not be surprising that participants constructed symptoms as preventable rather than as an inevitable part of aging.

The core category, knee symptoms are preventable, was common across participants. However, there was variation within categories, suggesting that some findings were more prominent in older or younger participants (e.g., it was particularly common for older adults to reflect on aging). These findings highlight the need for health care providers to listen to patients in order to understand how they view their symptoms and provide support to people with knee symptoms, regardless of age.

This qualitative study developed concepts that helped us better understand what participants’ knee symptoms meant to them. Most of the sample lived in urban areas, were employed, and had postsecondary education. Further research is needed to understand how different socioeconomic groups understand knee symptoms.

This study has limitations. To be included, participants self-reported a diagnosis of knee OA or reported that they had knee symptoms (i.e., pain, aching, or stiffness) on most days of the past month. We were unable to verify that participants’ symptoms were due to OA. However, the research question was based on a widely used survey question on joint pain (24) and careful exclusion criteria in order to recruit participants more likely to have OA symptoms. Findings show that participants’ mean KOOS scores are similar to those of people with OA in other research (33).

In conclusion, people ages 35–65 years interpreted knee symptoms as potentially preventable, suggesting that there may be opportunities to promote primary and secondary prevention strategies. As OA awareness and intervention improves, there is the potential to reduce the impact on individuals and society. Further research is needed to design optimal interventions that address primary and secondary prevention in people at risk for or with early OA symptoms.

**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, Sale, Badley, Jaglal, Davis.

**Acquisition of data.** MacKay.

**Analysis and interpretation of data.** MacKay, Sale, Badley, Jaglal, Davis.

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