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How Do Older Adults Manage Osteoarthritis Pain? The Need for a Person-Centered Disease Model

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Abstract

In the United States, chronic pain affects at least 116 million Americans, differentially impacting older adults. One of the leading causes of pain for older adults is osteoarthritis. This disease affects approximately 14% of the United States population and can cause disability and mobility problems, in addition to having a high cost for the healthcare system. The methods individuals use to manage their pain are contingent upon their model of the disease (e.g., their beliefs about osteoarthritis pain management). The purpose of the present investigation was to: 1) understand what variables older adults with osteoarthritis believe impact pain, and 2) understand current approaches for self-management of osteoarthritis pain. We conducted structured interviews with eight older adults who have osteoarthritis. The interviews revealed current approaches in pain management, as well as gaps in knowledge. We propose an expansion of the idea of a general disease model for pain management that is patient-centered, allowing for personal customization of factors for reducing pain and increasing successful pain-management.

INTRODUCTION

Chronic pain is a growing problem in the United States. Defined as pain that lasts 30 to 60 days or more and takes a toll on personal and professional life, chronic pain affects at least 116 million Americans (Committee on Advancing Pain Research, Care, & Institute Of Medicine, 2011). There are many causes of chronic pain, ranging from cancer to arthritis. For all sufferers, chronic pain can cause problems with physical functioning as well as overall quality of life. Additionally, chronic pain costs the United States \$560 to \$635 billion each year within the healthcare system (e.g., bills) as well as through work (e.g., sick days).

For a growing population of older adults, a leading cause of chronic pain is osteoarthritis. Osteoarthritis is a joint disorder where cartilage between bones wears away, leading to declines in physical function and quality of life. Osteoarthritis affects approximately 14% of the population in the United States, including about one-third of older adults over the age of 65 (Lawrence, Felson, Helmick, Arnold, Choi, Deyo, et al., 2008). This disease is a leading cause of disability, mobility problems, and chronic pain among older adults (Michaud, McKenna, Begg, Tomijima, Majmudar, Bulzacchelli, et al., 2006; Peat, McCarney, & Croft, 2001). This poses a large financial burden on the healthcare system; the 1996–2005 Medical Expenditure Panel found that osteoarthritis accounts for \$185.5 billion per year in healthcare

costs in the United States. For these reasons, it is important to identify how to effectively manage pain associated with osteoarthritis.

Managing osteoarthritis pain can be complex, requiring goal selection, information collection, interpretation, decision-making, and action. These steps may involve a significant amount of disease-specific knowledge. For example, domain knowledge (e.g., knowledge about a specific task, information about an illness, or wellness) has been linked to successfully managing health-related activities (e.g., Klein & Lippa, 2008). This includes information gathered from organizations and medical sources, such as primary health care providers. A vast amount of resources exist that offer information about managing osteoarthritis (Rutten, Arora, Bakos, Aziz, & Rowland, 2005); for instance, the Arthritis Foundation provides a large amount of information about evidence-based treatments. However, this wealth of knowledge can be overwhelming because it is not well-organized and difficult to personalize.

In a study on the management of osteoarthritis pain, the importance of personalizing general osteoarthritis information from organizations and health care providers was noted (McBride, Tsai, Knott, & Rogers, 2011). Three osteoarthritis subject matter experts, including two Arthritis Foundation program directors and a director of an assisted living facility, identified “people’s awareness of their disease and how it affects them individually” as an important factor to successful self-management of pain. These findings highlight the fact that factors influencing osteoarthritis pain do not impact all individuals equally.

Similarly, it has been found that creating an action plan—over and above merely providing information—can lead to more effective self-management of osteoarthritis (Bodenheimer, Lorig, Holman, & Grumbach, 2002). One such approach is the Arthritis Self-Management Program developed by Stanford University. In this program, participants learn problem-solving skills, study general and disease-specific pain management techniques, and create action plans, thereby increasing self-efficacy (Lorig, Mazonson, Holman, 1993). Furthermore, an individual’s domain knowledge of a disease can change over time as personal experience with the disease grows (Costantini, Beanlands, McCay, Cattran, Hladunewich, & Francis 2008). Again, these findings suggest that personalization of disease knowledge is important to self-management.

Currently, it is unclear how individuals with osteoarthritis manage their pain. Although tools already exist for pain management, they focus on documenting pain experience via typical and limited sets of factors (e.g., medications, diagnosis). However, these tools are limited in that they exclude other known mediators (e.g., mood; Parmelee, Harralson, McPherron, DeCoster, & Schumacher, in press) and do not necessarily promote understanding relationships between pain and factors. Understanding pain management could provide insights into how to best support future pain management; for example, better dissemination of general education about osteoarthritis, as well as understanding personal symptoms’ relationship with pain, which can vary by individual. From a human factors perspective, these are key components in the needs assessment process.

To this end, the purpose of this study was to: 1) understand what variables older adults with osteoarthritis believe impact pain, and 2) understand current approaches for self-management of osteoarthritis pain, which could ultimately improve self-management. To investigate these questions, we interviewed older adults who have osteoarthritis.

METHOD

Participants

We conducted structured interviews with eight community-dwelling older adults, four males and four females (see Table 1). Eligible participants were between the ages of 70 and 80 ($M=76$, $SD=2.1$), and reported pain from osteoarthritis.

Procedure

The structured interview consisted of two main components: general experience with osteoarthritis and current management of osteoarthritis pain. In the general experience with osteoarthritis section, we asked participants questions about their diagnosis of osteoarthritis and how many days per week they experience pain from osteoarthritis. Average severity of osteoarthritis pain was reported on a scale of 0-no pain to 3-severe pain (see Table 1). In the current management approaches section, we asked participants about their strategies for reducing pain, whether they tracked any factors to reduce their pain, and what factors might be important—but difficult to track—for reducing their pain, and whether they desired additional support in managing pain. We also asked participants what advice they would give to someone newly-diagnosed with osteoarthritis.

Audio-recordings of the interviews were transcribed verbatim. We analyzed the data using a thematic analysis approach (e.g., Howitt & Cramer, 2011) to identify themes that represent the participants' responses.

RESULTS

General Experience with Osteoarthritis

The participants had been diagnosed with osteoarthritis, ranging from 3 to over 20 years since diagnosis. Half of the participants experienced pain from osteoarthritis every day of the week, with severity of pain most frequently categorized as mild to moderate pain (see Table 1).

Current Management Approaches

The participants discussed diverse approaches for self-managing pain. One theme that emerged was the use of the trial-and-error method towards understanding the impact of different pain factors and treating the disease. For example, two participants experimented with medication type and frequency; yet, they often did not document this process in a systematic manner. A participant stated, "I sort of just take my pills in the morning and I take the, you know, whatever I take. Let's say I take Advil or Aleve, and then at night I would take the Tylenol". All participants mentioned using medication on occasion.

Another emergent theme was that participants informally tracked a variety of factors. For example, participants sometimes noted types and frequencies of the activities they performed. One participant stated, “I try to limit the number of [strenuous activities] per week, and spread them out over the days of the week so I don’t overdo it any one day and get the job done without aggravating my [osteoarthritis]”. Other factors participants reported tracking included nutrition (e.g., salt intake) and amount of sedentary time.

Two participants, however, preferred not to focus on their pain, and therefore did not track factors for or symptoms of pain. For example, one participant stated, “Keeping track of my pain is not the problem at all. I try not to even focus on it, so I certainly don’t keep track of it”. Furthermore, four participants had a “just deal with it” attitude, including one who stated: “Just, [pain]’s part of old age. Get used to it, and don’t whine about it. There are times I’m uncomfortable- *very* uncomfortable. I don’t tell anybody.”

Another recurring theme in the data was participants’ awareness of their lack of knowledge about osteoarthritis. Although they were not directly asked about their knowledge, three participants mentioned wanting more information about osteoarthritis, including resources and advice on best practices. In terms of the benefits and drawbacks of exercise, one participant stated that s/he “...would like to know some [more]. If I can do some exercise, like sometimes I’ll sit and I just keep wiggling my fingers around, maybe I’m aggravating it by doing that [...but] maybe I need more exercise in my fingers so I can be more dexterous.”

Even if information related to osteoarthritis pain management was available, participants did not always find it useful. For example, one participant, in response to the high volume of medication information, stated, “Looking at what I see advertised available to me as an older person, to help me with arthritis, there’s three pages of things that could go wrong. So it’s scary [...] to read this stuff, and well if I take this, am I gonna end up with the problems that they’re outlining [...] so rather than take that, I would rather just watch myself and not expose myself to a situation that I would antagonize or agitate the arthritis.” Statements such as these demonstrate the importance of providing individuals with information relevant to osteoarthritis pain management in a salient and comprehensible manner.

DISCUSSION

Chronic pain affects individuals (e.g., disability) and society as a whole (e.g., burden on the healthcare system). The results of this study provide insights about how individuals with osteoarthritis are currently self-managing pain, as well as individuals’ needs for more support in these activities. Specifically, there is a need to provide support for individualized self-management of pain.

Participants had a variety of experiences with osteoarthritis, including different triggers of pain (e.g., activity, nutrition) as well as different strategies for managing their pain. These reports highlight the importance of personalization of management strategies, which can be applied to improving both patient training and information dissemination.

Although participants generally described their pain as mild to moderate in severity, they experienced it frequently—half of the participants experienced pain daily. Thus pain management can be needed on a regular basis and it is an ongoing process.

These data suggest that more education is needed. First, participants stated that they felt they lacked adequate knowledge about osteoarthritis, including an understanding of the factors that can cause or relieve pain. Second, the factors that participants reported tracking did not cover the full spectrum of factors that can influence pain as identified by the Arthritis Foundation (e.g., Arthritis Foundation, 2013). Also, it was unclear to participants how to relate general information about osteoarthritis pain management to their own management of pain. Hence, research and tools that help patients to identify important factors or mediators of their pain, and costs and benefits of using different interventions, could facilitate the successful self-management of pain.

When engaging in information-seeking behaviors, participants were reportedly overwhelmed and did not know which advice to follow. Specifically, they did not know how to best apply the information to their own pain management experiences. Although the older adults were aware that they lacked knowledge about how best to manage their pain, they were also uncertain about how to locate and identify relevant information.

A wealth of information on osteoarthritis already exists and can be overwhelming. Additional information might not be necessary for creating and maintaining the general disease model from domain knowledge. Rather, organizing available information, as well as teaching patients how to recognize which information and factors are important for their own experience with the disease, may be most beneficial. These results provide clear direction for the development of a tool to support pain management.

Consistent with participants' experiences and future needs for managing their pain, a person-centered disease model could be the future of pain self-management. As opposed to only educating patients about a general disease model, a customizable person-centered disease model could enable patients to more effectively manage their disease. Such a model could help patients learn about their own actualization of osteoarthritis, including what factors are most influential to their experience of pain.

The set of factors that participants tracked for managing pain varied across participants, showing the personal, individual-driven nature of disease management. Moreover, some participants used a trial-and-error approach to understanding how factors differentially impact pain. However, because this process was not conducted in a systematic manner by participants, it is unclear whether this approach was efficacious. Given the many factors that may impact someone's pain due to osteoarthritis, a systematic, experimental approach is needed to uncover which specific factors are important for an individual. Extant tools for tracking variables are limited in their utility (McBride, Tsai, Knott, & Rogers, 2011); thus there exists an opportunity for support tools to aid individuals in understanding the factors that influence their pain.

Despite evidence of the efficacy of patient-centered approaches, no commercially-available pain management tool supports this approach to pain management. Existing pain

management tools are primarily focused on documentation of factors known to contribute to pain. However, merely documenting behavior is insufficient for uncovering relationships between different factors and an individual's pain. Critically, they lack measures of key known mediators (e.g., mood) and the capability to integrate various measures for accurate understanding of a person's pain.

The ability for a support tool to track individual behaviors such as exercise and show relationships between these factors and an individual's pain is important for enabling a person to determine their own person-centered approach from a more general disease model. Such a system should: integrate the information with meaningful data output for different users; enable trend identification, tracking over time, and assessment of intervention efficacy; and support communication, education, and behavior change. This will ultimately support a person-centered disease model through pain experience education and management by capturing, integrating, and displaying information on pain and mediating factors important for managing an individual's pain.

To support this person-centered disease model, solutions need to go beyond patient education alone, to individualized education aided by a support tool. Approaches for pain self-management need to address both the complexity and individualized nature of self-management. A system for tracking and managing pain can help patients and their healthcare providers relate factors to symptoms, and then ultimately customize pain management to the individual.

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Table 1

Participant Demographics and Osteoarthritis Information

Age	Gender	Years Since Diagnosis	Pain Frequency (days/week)	Pain Severity *
72	Male	20–25	7	1 to 2
74	Female	3–4	7	1
75	Female	4–5	7	1
75	Female	10	7	2
75	Male	5+	Depends	1–2
77	Female	Several	5+	2–3
77	Male	4.5–5	1–2	1
79	Male	15–20	Depends	1

Note.

* Scale of 0 to 3: 0 = no pain, 1 = mild pain, 2 = moderate pain, 3 = severe pain