Osteoarthritis and Social Embarrassment: Risk, Pain, and Avoidance

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Abstract
Musculoskeletal pain from osteoarthritis (OA) is a prevalent concern for older adults. Despite recommendations from providers to be physically active, some people with OA fear physical activity and must decide whether it is safe or harmful to undertake physical activity. In this article, we examined the narratives of 10 people living with OA knee pain and the roles that pain and embarrassment played in their activity-related behavior. When asked about their physical activity, 6 of the 10 participants reported some type of embarrassment-related experience. Responses fell into two key categories: (a) embarrassment-related experience from engaging in activity or (b) embarrassment-related experience from avoiding activity. These categories contained subgroups of those seeking to avoid embarrassment and those seeking to avoid pain. Response clusters helped to contextualize the activity behavior of people with knee OA pain as it relates to social identity by providing examples of individuals resisting life disruption.

Keywords
knee osteoarthritis, pain, activity avoidance

Musculoskeletal pain from osteoarthritis (OA) is a prevalent concern for older adults (Bellamy & Buchanan, 1986; Zhang & Jordan, 2008). Pain is a primary reason for the majority of people living with OA to seek treatment (Donovan & Blake, 1992; M. Morgan & Watkins, 1988). According to the work of Sanders, Donovan, and Dieppe (2002) on the social significance of OA, “issues of identity and biography are central to the meanings ascribed to illness and aging” (p. 247). Intervention is often sought for OA once symptoms are “perceived to interfere with life,” indicating a need to gain a deeper understanding about how OA pain affects the lives of people (Campbell et al., 2001).

Because regular physical activity decreases OA pain over time, it is included in clinical practice treatment guidelines (Conaghan, Dickson, & Grant, 2008; Richmond et al., 2010). However, therapeutic exercise for OA can acutely increase pain (Badley & Papageorgiou, 1989; Farrell, Gibson, McMeeken, & Helme, 2000; Focht, Ewing, & Gauvin, 2002). Therefore, people with OA must decide whether to begin or continue exercise when activity-related pain is expected or occurs. Confusion about the meaning of activity-related pain can be a barrier to effective treatment (Clarke, Moreton, das Nair, Walsh, & Lincoln, 2014); people with OA frequently report fear and avoidance of activity when they believe that exercise will further damage their joints or activity is to blame for their condition (Hendry, Williams, Markland, Wilkinson, & Maddison, 2006; Thorstensson, Roos, Petersson, & Arvidsson, 2006).

Recent work has highlighted the underlying complexities associated with characterizing the relationship between pain, fear, and activity avoidance. For example, McCracken and Samuel (2007) reported that some patients with chronic pain report both high levels of physical activity and high levels of activity avoidance depending upon the situation. Furthermore, work by Kindermans and colleagues (2011) described two types of avoidance patterns and three types of persistence patterns of physical activity in people with chronic pain. The need to individualize self-management programs has been emphasized in the literature, due to a growing recognition that both the ability and desire for activity do not necessarily remain consistent throughout the life course (Moore, Richardson, Sim, Bernard, & Jordan, 2014; Ong, Jinks, & Morden, 2011). Based on these complicated findings, greater clarification of the contextual and individual factors that influence activity behavior is needed.

Research has only recently begun to consider the role of social and other contextual factors in the decisions of patients with chronic pain to persist in therapeutic exercise. For example, Mackichan, Adamson, and Gooberman-Hill (2013) highlighted the importance of issues such as the patient’s...
own explanations for his or her activity avoidance in contrast to the fear avoidance models commonly used to explain changes in the activity levels of older adults. Also, Torres’s (2013) research team suggested that “persistence” with a physical activity exists to “avoid” social disapproval. In addition, Graham, Kremer, and Wheeler (2008) described how people with chronic diseases such as arthritides believe that physical activity facilitates maintenance of their identity.

The existing literature on identity and personhood can also provide guidance on the role social factors play in cases of chronic pain. For example, social identity or personhood is “bestowed by society” and has to be “earned by achieving and maintaining expected social roles and ideals” (Luborsky, 1994, p. 240). Physical disabilities and impairments can contribute to the “diminishment of identity as a social person” (Armstrong & Fitzgerald, 1996, p. 274). Current research on embarrassment, identity, and pain indicates that medical conditions, which hinder function, occupation, independent living, and physical appearance, can diminish an individual’s sense of self (Hill, Dziedzic, & Ong, 2010; Kaptein et al., 2013; Keysor, Sparling, & Riegger-Krugh, 1998; M. Morgan & Watkins, 1988).

Social identity may be affected by contextual factors, such as expectations (Moore et al., 2014). Older adult patients as well as their health care providers expected increased pain with aging, and may not interpret the OA joint pain and stiffness as something requiring medical intervention (Grime, Richardson, & Ong, 2010; Hendry et al., 2006). These beliefs may negatively affect their pain management and motivation for full engagement in activity (Davis, Hiemenz, & White, 2002). Cultural and generational expectations that go unmet or unrealized can lead to the “experience of inner chaos and disruption” (Becker, 1994, p. 383). Disruption related to chronic pain has been shown to challenge the way people define themselves and change their health-related decision making (Fenwick, Chaboyer, & St John, 2012). Discrepancies between idealized and other “versions” of oneself can be a source of distress among people living with chronic pain and may offer insights into the motivations behind pain-related behavior (Huijnen et al., 2011). Similar insights may be gained from a clearer understanding of how individuals define the concept of risk, especially as it relates to health-related behavior (Zinn, 2005).

Embarrassment is the feeling of self-consciousness, inadequacy, shame, and awkwardness in social situations or in public. Little is known about how embarrassment may influence physical activity patterns in the context of pain, life disruption, and threats to personhood. To address this, we examined the narratives of 10 people living with OA knee pain as part of a larger ongoing mixed-methods project. This article focuses on the role that social pressure and embarrassment played in their activity-related decision making.

### Method

This study was part of an ongoing mixed-methods research project, which was approved by our university Institutional Review Board to discover and document the relationships among OA knee pain, physical activity, and emotions. The mean age of the participants ($N = 10$) was 60 ($SD = 10.40$ years), and 70% of the sample were women, as is appropriate given the increased likelihood and severity of OA in women (O’Connor, 2007). Ninety percent of the sample described themselves as Caucasian. We used the following inclusion criteria: (a) 40 years old or older, (b) community dwelling, (c) self-reported physician diagnosis of unilateral or bilateral knee OA, (d) unilateral or bilateral knee pain that increases with ascending and/or descending stairs, (e) recommended to begin an exercise program by a health care provider, (f) on a stable medication regime for 6 weeks, and (g) able to provide a physician clearance to participate in lower extremity resistance training. The exclusion criteria are the following: (a) unstable medical conditions, (b) hip or knee arthroplasty, (c) inability to independently transfer with or without assistive device, (d) wheelchair dependence, (e) body mass index $\geq 35$, (f) <18 of 22 on telephone version of Mini-Mental State Examination (Roccaforte, Burke, Bayer, & Wengel, 1992), (g) regular participation in a lower extremity resistance training program within the last year, (h) lower extremity intra-articular injections in the previous 6 months, and (i) regular substance abuse within the previous 6 months.

Volunteers who met the above-mentioned inclusion criteria completed three lab visits, which lasted about 2 hr each. At the initial visit, participants provided informed consent and completed questionnaires about demographics, health history, and self-care behaviors, including medications and overall physical activity. After the questionnaires were completed (during first visit), participants were invited to describe experiences that explained or supported their responses to the questionnaires via interview. The second and third lab visits were held with 1 month in between, participants’ height, weight, and pressure pain threshold (PPT) were measured again and they were asked to repeat the questionnaires about their self-care behavior, physical activity, and knee pain. In addition, they were asked to recall their knee pain from previous sessions. Furthermore, they completed five physical activities with activity-specific assessments of expected, actual, and recalled pain, harm, fear, and the probability that they would repeat the activity if it had been recommended by a health care provider.

The data described here were based on interviews by trained research assistants to explore participants’ decision-making process for appraising the safety of activity-related knee pain. These interviews were conducted during the first lab visit and were digitally recorded for subsequent transcription. An investigator (first author) inductively analyzed the interview transcripts to identify and code themes using a
grounded theory (Charmaz, 2006) or constant comparative method. This thematic analysis produced the key findings upon which our study results were based.

**Results**

When asked questions about living with OA knee pain, particularly issues of physical activity, and emotions such as fear, frustration, and embarrassment, 6 of the 10 participants self-identified as having some type of embarrassment-related experience, usually general embarrassment and frustration over their physical limitations due to the OA pain. When explicitly asked about embarrassment, responses fell into two basic categories: (a) embarrassment-related experience from engaging in activity or (b) embarrassment-related experience from avoiding activity. Within these two categories were nested subgroups of those seeking to avoid embarrassment and those seeking to avoid pain. The term risk is used throughout the “Results” section. In these instances, risk means the chance of exposing oneself to an unfortunate or unwelcome outcome (e.g., the risk of social exclusion or the risk of acute physical pain).

**Risk Pain and Embarrassment**

When asked about OA knee pain and embarrassment, one participant shared that she continued to be physically active in her community, although she was concerned that others perceived her as being far older than her chronological age. For her, embarrassment came while “. . . getting up and down in a restaurant or in church . . . it’s like I’m 80 years old instead of 52.” Another woman recalled feeling embarrassment when she attempted to hike on a vacation with friends in the American Pacific Northwest but dropped out: “We were with . . . six other people, close friends that we’ve known for years, and I really couldn’t keep going.”

**Risk Pain, Avoid Embarrassment**

Participants also gave examples of persisting with a painful activity and risking intensifying the pain because of social pressure or the desire to avoid embarrassment and disapproval, self-imposed or otherwise. Comments such as “Well, I was walking with a couple that came to visit and I was really in pain and I just kept going . . . I didn’t want to cop out.” Similarly, this example from a yoga enthusiast:

> I was doing yoga last night and there was this awkward position and uh I sort of was reluctant and I had a feeling it was something I shouldn’t be doing but I kind of wanted to fit in and I still did it, and uh I mean it wasn’t a traumatic injury, but I was a little bit sore and just tender and fairly immediately knew that I had probably made a mistake.

**Avoid Pain, Risk Embarrassment**

Two participants, who were both hikers, reported limiting effects of OA knee pain and risking embarrassment to avoid/end pain. The first example comes from a participant who avoided pain by slowing down while hiking, and as a result, could not keep up with her companions. She continued the hike but did not feel comfortable pushing herself to keep pace with her family: “I couldn’t keep up with everyone else and felt like I was dragging them behind or they felt like they were with an old woman.” A second hiking example came from a participant who accompanied friends to a local hiking attraction, only to discover her knee was not up to it:

> . . . I only walked until we got to the first set of stairs and then I just stuck around and waited for the rest of the crew to come back so, I wasn’t even going to try and attempt all those stairs. I knew I would never make it.

**Avoid Pain and Embarrassment**

A grandmother shared fears and concerns regarding dropping or falling on her grandchildren due to both hand and knee pain. She wished to avoid the pain and embarrassment and in this case, possibly harming loved ones, by avoiding this very meaningful activity: “I’d hate to fall on one of those babies or drop one of them . . . .” One male participant expressed embarrassment due to his wish that he “. . . could play (basketball) better . . . . I wish I could make the cuts and jump and you know, rebound.” He described sitting out and just shooting hoops rather than playing basketball with his friends. He engaged in modified activity, not playing as aggressively as he wanted to, to avoid pain but did not opt out of the activity completely.

**Discussion**

This study focused on embarrassment in the context of life disruption, physical activity, and personhood in people with knee OA. This socially contextualized approach informs our perspective of the intersections of identity, risk, and pain. Participants were explicitly asked about embarrassment and knee OA, and 6 out of our 10 participants reported some type of embarrassment-related experience. They shared that they risked embarrassment by avoiding activity to the disappointment of themselves or their peers, or they risked embarrassment by engaging in modified or uncompleted activity. These participants encountered situations where their OA knee pain threatened to disrupt their sense of self and sense of personhood by interfering with or preventing the pursuits and activities they found meaningful. The participant narratives provided a context to better understand the role of embarrassment within the complex patterns of pain-related physical activity. The subgroups of responses, which vary by risk and avoidance of pain and physical activity, helped to
illuminate the influence of embarrassment within the physical activity avoidance and persistence phenomena.

The participants revealed both individually as well as socially relevant experiences and frustration [an individual orientation] and embarrassment [a social orientation] over the OA knee pain, particularly regarding the physical limitations accompanying the pain. For example, the woman who attempted to hike, but was forced to sit idle, as well as the participant who was concerned about looking “old” in church each risked both pain and embarrassment by attempting to engage in meaningful activities. They had to adjust their expectations of their abilities and themselves. These adjustments described by our participants reflected the findings of Hill et al. (2010) on hand OA and identity, Morgan’s (2006) study on hip pain and mobility challenges, and a study on chronic pain management barriers by Davis et al. (2002). Participants in these studies reported embarrassment, disappointment about looking “old,” self-perceived threats to dignity and social identity due to pain, compromised mobility, and dependence on adaptive devices (Davis et al., 2002; Hill et al., 2010; R. Morgan, 2006). Interestingly, however, some of the individuals in our study (e.g., one of the hikers and the church-goer) did not opt out of physical activities, indicating a reluctance to count themselves out of meaningful pursuits. This reluctance hints at a larger tension between the abilities of the idealized version of themselves and their actual physical capacities, as well as the desire to maintain social participation.

Participants who reported persisting with a painful activity for fear of embarrassment or disapproval mirrored the persistent chronic pain patients described by quantitative investigations in the literature (e.g., Kindermans et al., 2011; Torres et al., 2013). Multiple, co-existing interpretations of how chronic pain may disrupt the life course and yet be considered a normal or expected part of the aging process have been documented in previous studies (Sanders et al., 2002). For instance, the behavior of the yoga enthusiast who “. . . had a feeling it was something I shouldn’t be doing but I kind of wanted to fit in . . . ” represented a pattern of activity that exemplifies the need for context when attempting to interpret pain-related behavior. Specifically, embarrassment, fear of disapproval, or social exclusion was a motivating factor for activity in specific instances.

Physical impairments can result in “. . . an individual’s identity as a complete person [being called] into question” (Luborsky, 1994, p. 239). When researching the context of activity level changes among older adults, Mackichan et al. (2013) discovered facets of pain-related behavior that could not be explained by the existing fear avoidance model. The fear of losing autonomy and independence influenced the activity level of older adults with chronic pain, often causing them to limit activity and social connectivity in what has been described as “paradoxically result[ing] from a desire to preserve function” (Mackichan et al., 2013, p. 7). Also, the use of assistive or adaptive mobility devices to help them remain active may be an affront to their dignity and a cause for embarrassment (Morgan, 2006). In fact, participants with chronic pain reported avoidance of meaningful activity once it became clear that they needed an adaptive device to continue with the activity (Davis et al., 2002). The self-discrepancies between ideal and actual abilities described by Huijnen et al. (2011) fall in line with this notion. For example, OA pain may have interfered with participants’ deeply held notions of their ideal selves, threatening to alter the identities they would like to continue promoting or the face they would like to continue presenting to the world (Fenwick et al., 2012; Luborsky, 1994).

The pattern of avoiding pain and risking embarrassment was exemplified by our two hiking enthusiasts, who each reported feeling socially uncomfortable because of the limiting effects of OA knee pain and the compromises they had to make in terms of activity level. One of them discovered too late that her knee was not up to hiking and chose to risk embarrassment or disapproval from their peers by limiting activity. The second participant avoided pain by slowing down, and as a result, could not keep up with companion hikers. She continued on with the hike but did not feel comfortable pushing herself to keep pace with her family. Both hikers in these examples appeared to be in the process of readjusting life course expectations but experienced frustration over the need to do so, in contrast to a study by Davis et al. (2002) who reported older adults expected pain and increased mobility challenges as a normal part of aging. These examples also illustrated the value of activities, such as hiking, that transcended the physical health-related advantages associated with them. In addition, they demonstrate the distress caused by the threat of losing these abilities (Keysor et al., 1998). Hiking was meaningful and beneficial for these participants and echoed other studies where restrictions on favored physical activities “. . . were a source of distress and signaled a loss to their identity” (Kaptein et al., 2013, p. 1074). The woman who had to cut back on holding grandchildren for fear her knees would give out expressed a sense of dissatisfaction in the lifestyle compromises OA pain required her to make. It is possible that her compromises regarding meaningful activities, such as holding grandchildren, indicate discrepancies between the culturally and generationally engrained life course expectations and the current reality regarding her abilities (Becker, 1994). Her decisions on how to manage these compromises and uncertainties reflect the notion of “biographical embeddedness of health and illness” (Zinn, 2005, p. 2).

The man who had to modify his sport-related activity, particularly basketball, indicated that making these adjustments to his game was about more than just avoiding getting injured or “overdoing it” on the basketball court. He was frustrated by the things he could once do so easily, much like the participants in existing studies on physical activity, identity, and arthritis (Kaptein et al., 2013). His modified persistence may have been an attempt to minimize the discrepancy between
his actual and ideal abilities, as well as maintain engagement within his social group, allowing him to feel more connected to the “ideal” version of himself. These results resembled Huijnen and colleagues’ (2011) work on self-discrepancy and activity-related behavior. The authors reported that people with chronic pain who feel closer to the “ideal” versions of themselves are more likely to exhibit an activity pattern of persistence.

It is noteworthy that we found no example of a participant discussing risking pain and avoiding embarrassment by avoiding activity. On the surface, it would seem reasonable that one could not risk pain by avoiding physical activity. However, a paradox of inactivity exists (Mackichan et al., 2013) in that some people with knee OA report knowing that remaining active is important for pain control. Therefore, some people with OA are knowingly risking pain by avoiding physical activity. These examples shed light on need for a holistic approach to the context and complexity required when managing chronic conditions (Morden, Jinks, & Ong, 2012). This is especially relevant when considering pain-related avoidance and persistence behavior to expand our current understanding of how embarrassment can influence physical activity in people living with OA.

The small sample size and the fact that participant narratives were not accompanied by observations of physical activity outside of the research setting are limitations to these findings. Further research is required to determine whether or not multiple patterns of activity engagement and avoidance co-exist within one individual, as has been indicated in other studies (Kindermans et al., 2011; Mackichan et al., 2013; McCracken & Samuel, 2007). Comprehensive knowledge of these patterns of activity engagement, avoidance, and self-management are necessary for more effective individualized recommendations and clinical advice (Grime et al., 2010). Knowledge of patient expectations for activity throughout the life course (Moore et al., 2014) is necessary to help patients identify when OA pain prevents them from being the person they want to be.

Declaration of Conflicting Interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The author(s) received no financial support for the research and/or authorship of this article.

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