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Understanding the pain experience in hip and knee osteoarthritis – an OARS/OMERACT initiative

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Summary

Objective: To examine the pain experience of people with hip or knee osteoarthritis (OA), particularly changes over time and most distressing features.

Method: Focus groups in individuals aged 40+ years with painful hip or knee OA obtained detailed descriptions of OA pain from early to late disease. A modified Patient Generated Index (PGI) was used to assess the features of OA pain that participants found most distressing. Content analysis was performed to examine response patterns; descriptive statistics were used to summarize PGI responses.

Results: Mean age of the 143 participants (52 hip OA; 91 knee OA) was 69.5 years (47–92 years); 60.8% were female and 93.7% Caucasian. Participants described two distinct types of pain – a dull, aching pain, which became more constant over time, punctuated increasingly with short episodes of a more intense, often unpredictable, emotionally draining pain. The latter, but not the former, resulted in significant avoidance of social and recreational activities. From PGI responses, distressing pain features were: the pain itself (particularly intense and unpredictable pain) and the pain's impact on mobility, mood and sleep.

Conclusions: Two distinct pain types were identified. Intermittent intense pain, particularly when unpredictable, had the greatest impact on quality of life.

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Key words: Osteoarthritis, Pain, Qualitative studies, Hip, Knee.

Introduction

In the context of an OMERACT/OARS initiative to develop a new outcome measure, “total joint replacement (hip or knee) indication”, for use in clinical trials of osteoarthritis (OA) disease-modifying agents, three working groups were established to evaluate existing measures, and make recommendations regarding the best method for measurement of pain, physical function, and joint structure.

Prior qualitative work conducted by members of the OA pain working group in the UK^{1,2} and Canada³ had found

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that the pain experience of people living with hip and knee OA was not adequately captured by existing measures. Furthermore, evaluation of hip or knee OA pain using the commonly used WOMAC pain scale⁴ is confounded by poor physical functioning as this scale asks patients to report on pain experienced with five specific activities (walking, standing, stairs, at night and at rest); as a result, WOMAC pain and physical function subscale scores are highly correlated⁵. Together, these studies and prior experience suggested the need for a new OA pain measure.

Among people with knee OA, the presence and severity of knee pain are recognized risk factors for disability and radiographic progression^{6–8}. Pain accounts for most primary care visits for OA and for most non-steroidal anti-inflammatory drug use⁹, and is the number one reason why people with OA choose to have joint replacement surgery¹⁰. Despite the importance of pain in OA, relatively little is known about the quality and characteristics of OA pain; in particular, there has been little research to assess how pain in OA changes over time as the disease progresses, or which features or combination of features in OA pain are most important to people living with this disease. Our incomplete understanding of the characteristics and evolution of pain in OA is a barrier to appropriate clinical care and clinical research in OA. In particular, greater understanding of the key elements of pain in OA that trigger changes in level of physical activity and that drive decision-making by patients around use of various treatment modalities, such as joint replacement surgery, would facilitate the development of tools to assist clinicians in their clinical practice as well as provide much-needed information on which to base the development of relevant outcome measures for clinical trials of disease-modifying agents in OA.

We conducted focus groups and one-on-one interviews to examine the pain experience of people with hip/knee OA from early to late disease, including those aspects of the pain experience that were considered most distressing. The study aimed to provide the basis for the development of a new pain measure for OA for use in clinical practice.

Methods

STUDY PARTICIPANTS

Focus groups and one-on-one interviews were conducted in six centers: Canada (Toronto and Vancouver), the United States (North Carolina and Texas), Australia (Sydney) and the United Kingdom (Bristol). Participants were drawn from the community (using advertisements and flyers), from investigators' clinical practices, and from among members of investigators' existing OA cohorts. Those eligible to participate were: English-speaking men and women with hip or knee OA, aged 40+ years, who responded "yes" to the question: "Have you experienced aching, discomfort, pain and/or stiffness in or around a hip or knee on most days of at least 1 month (15 or more days of the month) during the past year?", who had not experienced an injury to the joint area within the last year, or a joint replacement of the symptomatic joint. Confirmation of OA diagnosis was based on radiographic findings in the symptomatic hip or knee (OARSI grade 1+ for any of: joint space narrowing, osteophytes, sclerosis, or subchondral cysts)¹⁰. X-rays or X-ray reports were reviewed for eligibility by a single investigator at each site. Anyone with concurrent rheumatoid arthritis or any other type of inflammatory arthritis, fibromyalgia, chronic low back pain, or another chronic pain disorder, such as diabetic neuropathy, was excluded.

Sampling was performed to ensure approximately equal representation of individuals with mild, moderate and severe pain, hip and knee OA, across three age groups (40–54 years, 55–64 years and 75+ years), men and women, and education level (\leq high school and post-secondary education). With respect to hip or knee pain, subjects were allocated to groups based on their response to a 10-point Likert rating scale for usual pain experienced in the most painful joint over the past 3 months (from 1, no pain, to 10, extreme pain); participants were categorized as mild (scores of ≤ 4), moderate (scores 5–7) or severe (scores 8–10).

Ethics approval was obtained from each of the participating centers' Institutional Research Ethics Review Board. Informed, written consent was obtained from all participants.

Focus groups/interviews

Focus group format and methodology was standardized across centers. One-on-one interviews were also conducted in Toronto using the same format. Focus groups, comprised of up to eight participants, were approximately 2.5 h in length. Each focus group or one-on-one interview used a "funnel approach", starting with broad open-ended questions followed by increasingly focused questions. Initial questions were directed at obtaining detailed descriptions of hip and knee pain or other sensations, exploring changes in these characteristics over time; later questions focused on the impact of the pain on the participants' lives.

A modification of Ruta *et al.*'s¹¹ three-part Patient Generated Index (PGI) was used to assess the priorities and concerns of individuals living with hip or knee OA pain, and the varying weights and values that they attach to the concerns. In Part 1, participants were asked to identify up to five OA pain or symptom characteristics that they considered most distressing (e.g., pain is unbearable). In Part 2, participants were asked to score their level of distress for each of the items listed in Part 1, on a 7-point Likert scale, from 0 (the least distressing it could possibly be) to 6 (the most distressing it could possibly be). Finally, in Part 3, participants were asked to "spend" 10 points in total to buy relief from their distress. They were instructed to "spend" more points on items indicated in Part 1 that they felt were most important and less on areas they felt were less important. They were not required to "spend" points on all aspects of their pain, but they could not spend more than 10 points in total. An example is shown in Fig. 1.

At the end of the focus group, participants were asked to complete a brief questionnaire assessing their sociodemographic characteristics (age, level of education, racial/ethnic background, and marital status), the duration of their OA pain in the index joint (How long has it been since you first noticed your hip/knee?), and their level of hip/knee OA severity. The latter was assessed using a valid and reliable Hip Disability and Osteoarthritis Outcome Score¹², HOOS, for hip OA, and the Knee Injury and Osteoarthritis Outcome Score¹³, KOOS, for knee OA. Participants additionally completed two other measures of pain severity: a 10-point numeric rating scale (NRS) ('Please rate the usual severity of your arthritis pain over the past 3 months') with anchors at 'no pain' and 'most extreme pain', and a 5-point Likert scale ('Please indicate the usual severity of your arthritis pain over the past 3 months') with response options from 'no pain' to 'extreme pain'. Using similar NRS and Likert scales, participants also rated their level of pain distress from 'not at all distressed' to 'extremely distressed'. Although content was standardized across the centers, the UK group asked additional questions to explore subject's joint pain in the context of the HOOS and KOOS¹⁴.

The questionnaire and PGI data were entered into an Access database. Double data entry and logic checks were used to ensure data quality. The focus groups and interviews were audio-taped and the tapes were couriered to the coordinating center where they were transcribed verbatim by a single transcriber, with one exception: the UK group transcribed their own. Each set of transcripts was reviewed independently by a minimum of two researchers to identify distinct themes. Themes were compared, consensus reached and entered into N6 (QSR N6 Full Version, Release 6.0, QSR International Pty Ltd 1991–2000).

Content analysis was then performed on all coded transcripts to examine for consistency of responses across study sites, by men vs women, across age groups, and for individuals with hip vs knee OA¹⁵. Similarly, the coded transcripts were examined for trends in responses over time. To do this, participants were grouped into OA durations of less than 10 years, between 10 and 20 years, and greater than 20 years, reflecting approximated tertiles of disease duration. A similar analysis was performed on the PGI responses, to examine for differences in "most distressing" features of the pain over time and by age, gender, site, and index joint (hip vs knee).

Similar to the focus group and interview analysis, PGI item responses were grouped thematically. For each item, we calculated the frequency of report by participants in PGI Part 1, the mean distress score (0–6) from PGI Part 2, and the mean number of points allocated to each item in Part 3 of the PGI, allowing items to be rank-ordered by: frequency, by level of distress, and by importance.

Results

Characteristics of the participants by index joint (hip or knee) are presented in Table I. Twenty-eight focus groups and eight interviews were conducted with 143 participants (52 with hip OA and 91 with knee OA) in six centers. The mean age of participants with hip and knee OA was similar, at 69.5 years (range: 47–92 years); 48% of hip and 68% of knee participants were female and 88% and 97%,

PART 1: List Characteristics	PART 2: Score Characteristics	PART 3: Spend Points																								
<p>In this part, we would like you to think of the 5 most distressing characteristics of your hip arthritis pain or other symptoms. We want to know what it is about the pain or other symptoms that is most distressing to you. Write these in the boxes on your page. Please try to be as descriptive as possible about the physical sensations in your hip that you find most distressing.</p> <p>If you cannot think of 5 characteristics then just fill in as many boxes as you want.</p>	<p>Please score each characteristic you listed in Part 1. The score should show how distressing you found each characteristic over the <u>last month</u>. Give each characteristic a score by circling one number, where 0 is the least distressing it could possibly be and 6 is the most distressing it could possibly be.</p>	<p>We want you to "spend" 10 points to show which characteristics of your pain you feel detract the most from your overall quality of life. In other words, we want you to "buy" relief from your distress.</p> <p>Spend more points on characteristics where you want more relief and less on characteristics where you don't want as much relief. You don't have to spend points on every characteristic. You can't spend more than 10 points in total, but the total points you spend must add up to 10.</p>																								
<p>A. <input style="width: 100%;" type="text"/></p> <p>B. <input style="width: 100%;" type="text"/></p> <p>C. <input style="width: 100%;" type="text"/></p> <p>D. <input style="width: 100%;" type="text"/></p> <p>E. <input style="width: 100%;" type="text"/></p>	<table style="margin: auto;"> <tr> <td style="text-align: left; padding-right: 10px;">the least distressing it could possibly be</td> <td style="text-align: center;">0</td> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: right; padding-left: 10px;">the most distressing it could possibly be</td> </tr> </table>	the least distressing it could possibly be	0	1	2	3	4	5	6	the most distressing it could possibly be	<table style="margin: auto;"> <tr> <td style="width: 20px; text-align: right;">→</td> <td style="width: 60px; text-align: center;"><input style="width: 100%;" type="text"/></td> <td style="width: 20px; text-align: left;">←</td> </tr> <tr> <td style="width: 20px; text-align: right;">→</td> <td style="width: 60px; text-align: center;"><input style="width: 100%;" type="text"/></td> <td style="width: 20px; text-align: left;">←</td> </tr> <tr> <td style="width: 20px; text-align: right;">→</td> <td style="width: 60px; text-align: center;"><input style="width: 100%;" type="text"/></td> <td style="width: 20px; text-align: left;">←</td> </tr> <tr> <td style="width: 20px; text-align: right;">→</td> <td style="width: 60px; text-align: center;"><input style="width: 100%;" type="text"/></td> <td style="width: 20px; text-align: left;">←</td> </tr> <tr> <td style="width: 20px; text-align: right;">→</td> <td style="width: 60px; text-align: center;"><input style="width: 100%;" type="text"/></td> <td style="width: 20px; text-align: left;">←</td> </tr> </table> <p style="text-align: center;">Total number of points that you spend must add up to 10</p> <p style="text-align: center;">Total = 10</p>	→	<input style="width: 100%;" type="text"/>	←	→	<input style="width: 100%;" type="text"/>	←	→	<input style="width: 100%;" type="text"/>	←	→	<input style="width: 100%;" type="text"/>	←	→	<input style="width: 100%;" type="text"/>	←
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Fig. 1. Patient Generated Index for OA pain (modified from Ruta *et al.*¹¹).

respectively, were Caucasian. Approximately one-third of participants had high school education or less. Median self-reported duration of symptoms in the index hip or knee was 6 years (range: 0–54 years) and 12 years (range: 1–58 years), respectively. The mean pain rating (out of 10) was 5.0 (SD 2.6) for hips and 5.5 (SD 2.4) for knees, with mean pain distress ratings (out of 10) of 4.3 (SD 2.6) and 5.1 (SD 2.3), respectively. The mean WOMAC total and pain subscale scores were similar for hip and knee participants, at 36.7/96 (0–81) and 7.4/20 (0–17), and 40.1/96 (0–75) and 7.8/20 (0–17), respectively. Hip participants' HOOS scores and knee participants' KOOS scores were similarly well distributed across the range of possible values.

PAIN DESCRIPTORS

Participants used a wide range of terms to describe their hip or knee pain. As shown in Table II, pain characteristics could be broadly grouped into the following categories: descriptors of pain intensity, from mild (e.g., aching, throbbing, dull, nagging) to extremely intense pain (e.g., sharp, intense, unbearable, stabbing); descriptors related to pain frequency or duration (e.g., constant, persistent, ever present); descriptors relating to the predictability of pain (e.g., happens any time, unpredictable, irregular); night pain (e.g., wake up, sleep disturbed, bothers sleeping); descriptors suggestive of neuropathic pain (e.g., pins and needles, burning pain); effect of pain on mood (e.g., debilitating, depressing, distracting); and other symptoms (e.g., grating, clicking, cramping, crunching).

Participants were also asked about the impact of their hip/knee pain on their quality of life. By far, the greatest impact

reported by participants was on their ability to do the activities they needed, or wanted to do. One participant noted,

"It's awful because you like to be active. I mean I used to go on a treadmill and do all these kinds of things. Can't do it. Can't do it anymore. And you depend more on people. Like, I depend on my husband a lot more now. You just, you know, you don't like to be that way." (Female, aged 62 years).

Another said, "I've modified everything. If it hurts, I won't do it." (Female, aged 68 years).

CHANGES OVER TIME

As expected, participants described their pain as worsening over time:

"With my right knee, it started about ten or twelve years ago. Then it was an ache, you know, uncomfortable. Couldn't do stairs – well I could do them with effort but ah, now it's progressed...Oh, it's got progressively worse." (Female, aged 86 years)

"Intensity was not much at first, but gradually more and more" and "It's more like a knife pain than it was an ache before." (Female, aged 62 years)

Interestingly, participants clearly described two distinct types of pain as their OA progressed: a dull, aching, throbbing pain, which became more constant over time, punctuated increasingly with shorter episodes of a more intense, often unpredictable, and emotionally draining pain. The latter, but not the former type of pain resulted in significant

Table I
Characteristics of the focus group participants

	Hips	Knees
Number of participants	52	91
Number of focus groups and/or interviews	16	20
Age in years, mean \pm SD (min–max)	68.7 \pm 9.0 (47–84)	69.9 \pm 10.3 (47–92)
Female, <i>n</i> (%)	25 (48.1)	62 (68.1)
Caucasian, <i>n</i> (%)	46 (88.4)	88 (96.7)
Education, <i>n</i> (%)		
<High school	7/37 (18.9)	12/77 (15.6)
Completed high school	11/37 (29.7)	12/77 (15.6)
\geq Post-secondary	19/37 (51.4)	53/77 (68.8)
Duration of OA*, median (mean, min–max)	12.0 (16.8, 1–58) (<i>n</i> = 40)	6.0 (10.2, 0–54) (<i>n</i> = 76)
NRS pain severity (1–10), mean \pm SD (min–max)	5.0 \pm 2.6 (1–10)	5.5 \pm 2.4 (1–10) (<i>n</i> = 77)
NRS distress (1–10), mean \pm SD (min–max)	4.3 \pm 2.6 (1–10) (<i>n</i> = 37)	5.1 \pm 2.3 (1–10)
WOMAC†, mean \pm SD (min–max)		
Total (0–96)	36.7 \pm 21.5 (0–81)	40.1 \pm 19.3 (0–75.3) (<i>n</i> = 90)
Pain (0–20)	7.4 \pm 4.6 (0–17) (<i>n</i> = 51)	7.8 \pm 4.1 (0–17) (<i>n</i> = 90)
Function (0–68)	26.0 \pm 16.0 (0–58)	28.4 \pm 14.4 (0–55.3) (<i>n</i> = 90)
Stiffness (0–8)	3.5 \pm 1.7 (0–7)	4.1 \pm 1.6 (0–7) (<i>n</i> = 89)
KOOS‡ subscales, mean \pm SD (min–max)		
Pain	N/A	73.4 \pm 21.9 (22.2–100.0) (<i>n</i> = 90)
Symptoms	N/A	72.1 \pm 19.6 (25.0–100.0) (<i>n</i> = 90)
ADL	N/A	73.5 \pm 22.0 (20.6–100.0) (<i>n</i> = 89)
Sports/rec	N/A	54.3 \pm 37.7 (0.0–100.0) (<i>n</i> = 86)
Quality of life	N/A	58.8 \pm 27.0 (0.0–100.0) (<i>n</i> = 90)
HOOS§, mean \pm SD (min–max)		
Pain	77.5 \pm 24.2 (17.5–100.0) (<i>n</i> = 51)	N/A
Symptoms	74.4 \pm 23.4 (15.0–100.0)	N/A
ADL	73.9 \pm 25.7 (14.7–100.0) (<i>n</i> = 51)	N/A
Sports/rec	64.5 \pm 36.3 (0.0–100.0) (<i>n</i> = 50)	N/A
Quality of life	69.3 \pm 26.8 (6.3–100.0)	N/A

*As determined by response to question: “When did you first notice your hip/knee?”.

†For worst hip joint for hip participants and for worst knee joint for knee participants.

‡For worst knee, possible range: 0 (extreme problems) to 100 (no problems).

§For worst hip, possible range: 0 (extreme problems) to 100 (no problems).

avoidance of social and recreational activities. Although some variability was observed, participants described these two types of pain in the context of their OA pain progression as follows:

Early OA – stage 1: Pain was characterized by predictable sharp or other pain, usually brought on by a trigger (usually an activity, such as a sport) that eventually limited high impact activities, such as skiing, but had relatively little other impact.

Mid OA – stage 2: Predictable pain is increasingly associated with unpredictable locking (knees) or other joint symptoms. The pain becomes more constant, and begins to affect daily activities, such as walking and climbing stairs.

Advanced OA – stage 3: Constant dull/aching pain is punctuated by short episodes of often unpredictable intense pain that leaves one exhausted. This pattern of intermittent, intense and often unpredictable hip or knee pain resulted in significant avoidance of activities, including social and recreational activities.

COMPARISONS BY GENDER, HIP/KNEE, REGION, RACE/ETHNICITY

In general, male participants tended to downplay their pain and used less intense language to describe their pain when compared with female participants. However, significant variability was observed. No other gender differences were apparent. Results were generally similar

for participants with hip vs knee OA, with a few notable exceptions: those with hip OA described, in general, a more abrupt or rapid progression from mild to severe complaints, more often used ‘intense’ descriptors (such as

Table II
Pain descriptors used by focus group participants

Category	Example descriptors
Pain intensity	Very intense/severe, quite bad, mild, moderate, less severe, worse, better
Mild discomfort	Ache, hurts, sore, nagging, throbbing, uncomfortable, gnawing, discomfort, tenderness, dull
Severe pain	Sharp, stabbing, shooting, knife-like, needle-like, brings tears to your eye, excruciating, unbearable
Frequency and duration	Every day, consistent in morning, comes and goes, constant, gradual, there all the time, background pain
Predictability	Unsure when pain will come on, unsure how long pain episode will last, pain “comes out of nowhere” sometimes
Night pain	Sharp pain comes on at night, difficult to sleep, that’s when it really aches, just lie awake there hurting
Neuropathic pain	Burning, pins and needles, numbness, like sitting too close to the fire
Effect on mood	Paralyzing, terrorizing, want to scream, want to cry, you get mad about the pain
Other symptoms	Weakness, grinding, stiffness, seize up, gives way, locking, unstable

icepick, pickaxe, spike, paralyzing), and more often made comparisons of their pain with other extremely painful conditions (such as childbirth, broken bones, surgery) than did knee OA participants.

No differences were observed by study site or by race/ethnicity, although there were insufficient numbers of non-Caucasian participants to make any definitive conclusions about differences in the pain experience by race or ethnicity.

MOST DISTRESSING FEATURES OF OA PAIN – RESULTS FROM PGI RESPONSES

Although participants were permitted to provide up to five distressing aspects of their pain, approximately one-third (34.4%) provided fewer than five items on the PGI. Distressing features of OA hip/knee pain could be broadly grouped into those related to the pain characteristics themselves, those related to the impact of pain on physical functioning, mood and sleep, and other symptoms, as shown in Table III. Tables IV and V show the frequency with which these common themes were cited for knee and hip participants, respectively, as well as the mean ‘distress’ scores (/6) and ‘points awarded to relieve this aspect of their pain’ (/10).

For both knee and hip participants, both types of pain noted above, i.e., sharp pain and aching pain, were cited frequently and separately as distressing (for both hips and knees, within the top three noted distressing aspects of pain). Among hip participants, aching discomfort was the most frequently cited distressing feature of pain (48/52, 92.3%), while sharp pain was cited next often, by 33/52 (63.5%) participants. For knee participants, sharp pain ranked first in frequency (65/91, 71.4%) and aching pain third (60/91, 65.9%). For both knee and hip participants, mean distress scores were higher for sharp (4.2/6 for both) than for aching pain (3.6/6 for knees, 3.3/6 for hips).

Hip or knee pain that was seen as unpredictable was also cited as distressing, as were the impact of the pain on sleep (due to pain at night) and mood (particularly fear for the future) (Tables IV and V). Among the ‘other symptoms’ that participants cited as distressing, stiffness was cited most often, ranking in frequency of reporting within the top 10 distressing aspects of pain (26.4% of knee and 13.5% of hip participants). Cramping, clicking, locking, grating and swelling were also cited, but with much less frequency. However, when these symptoms were cited, they generally received among the highest distress ratings, e.g., cramping was cited by only three knee and one hip participants, with mean distress scores of 4.7/6 and 5/6, respectively. The most distressing aspects of hip/knee OA pain appeared consistent, regardless of duration of symptoms (data not shown).

Summaries of our findings were sent to some participants and all site coordinators and focus group moderators for their feedback. In particular, we invited input regarding our description of pain over time. There was general agreement that the summaries reflected the discussions that had occurred.

Discussion

Despite the importance of pain in OA, the qualities, determinants and consequences of OA pain have been relatively little studied^{16–19}. To our knowledge, this is the first study to examine the pain experience in OA, focusing explicitly on the pain itself, and exploring pain related distress and changes over time.

Table III
Distressing pain themes identified through PGI responses

Theme	Descriptors within the theme
Pain descriptors	
Ache	Ache, dull, discomfort, unable to find comfortable position, nagging pain, sore, throbbing
Sharp pain	Sharp, knifing, stabbing, hurts, extreme, worst pain, acute
Burning pain	Burning, fiery, knee on fire
Constant	Constant, persistent, ever present, always there
Unpredictability	Sudden, happens at any time, irregular, unpredictable
Dental pain	Aches like a toothache, like dentist hitting nerve, constant toothache-like throbbing
Night pain	Pain at night, wake up, sleep disturbed, pain bothers sleeping
Pressure	Pressure, tightening, crushing, heavy feeling, weighted feeling
Radiating pain	Pain travels to different areas, secondary pain in other areas, extends from groin to knee
Pain impact	
Mood	Annoying, irritating, debilitating, stressful, draining, embarrassing, depressing
Limitation of activities	Decreased mobility, prevents enjoyment of/participation in activities, slows me down
Triggered by activity	Pain with activity such as walking, going up/down stairs or bending
Weakness	Weakness, tiring, joint feels weak
Use of medications/devices	Need for medications and ointments, pillow between knees to relieve pain during sleep
Fear	Fear of losing ability to do things in future, knee giving way or falling, knowing it is incurable
Inactivity	Pain/symptoms related to periods of inactivity (e.g., sitting too long)
Other symptoms	
Stiffness	Stiffness at night/after activity/in morning
Cramping	Cramping, muscle spasms
Clicking	Clicking, cracking
Grating	Grating, crunching, rubbing, grinding, bones rub together
Numbness	Pins and needles, numbing pain, numb, no feeling at time
Unstable	Loss of balance, gives way, instability, knee collapses, feeling that it won't support body weight
Locking	Locking of joint, unable to straighten or bend
Swelling (knees only)	Swelling, “fluid build-up”, swollen

People living with hip and knee OA identified two very distinct types of OA pain – pain that was intermittent but generally severe or intense, and a more persistent ‘background’ pain or aching. Participants were clearly able to distinguish these two pain types, identifying them separately as distressing. The more intense but less frequent pain that comes and goes, particularly when unpredictable, had a greater impact on quality of life than did background aching pain. Participants described how the more intense, unpredictable pain had negative effects on their mood, as well as their ability to participate with confidence in social and recreational activities. Many described how they had significantly curtailed these activities to avoid triggering an episode of such pain.

Participants frequently reported that OA pain had a negative impact on sleep, including both sleep onset and

Table IV
PGI results for knee OA subjects (n = 91)

Rank	Feature	Frequency N (%)	Distress (/6) mean \pm SD (range)	Points (/10) mean \pm SD (range)
1	Sharp pain	65 (71.4)	4.2 \pm 1.4 (1–6)	2.8 \pm 2.1 (0–9)
2	Limitation of activities	63 (69.2)	4.1 \pm 1.3 (0–6)	2.6 \pm 2.1 (0–10)
3	Ache/dull	60 (65.9)	3.6 \pm 1.6 (0–6)	2.4 \pm 2.1 (0–10)
4	Triggered by activity	46 (50.5)	4.2 \pm 1.3 (1–6)	3.0 \pm 2.1 (0–10)
5	Stiffness	24 (26.4)	4.0 \pm 1.2 (2–6)	2.9 \pm 2.7 (0–10)
6	Unpredictability	23 (25.3)	3.4 \pm 1.6 (1–6)	1.4 \pm 1.5 (0–6)
7	Constant	21 (23.1)	3.9 \pm 1.5 (1–6)	2.1 \pm 1.4 (0–5)
8	Unstable	20 (22.0)	4.3 \pm 1.6 (1–6)	2.2 \pm 1.5 (0–5)
9	Night pain/impact on sleep	16 (17.6)	3.9 \pm 1.4 (1–6)	2.9 \pm 1.4 (1–5)
10	Mood	16 (17.6)	3.8 \pm 1.5 (1–6)	1.6 \pm 1.7 (0–5)
11	Swelling	14 (15.4)	3.9 \pm 1.8 (0–6)	1.6 \pm 1.2 (0–4)
12	Grating	12 (13.2)	4.3 \pm 1.3 (2–6)	1.8 \pm 1.3 (0–4)
13	Inactivity	12 (13.2)	3.5 \pm 1.2 (1–5)	2.0 \pm 1.0 (0–3)
14	Burning pain	6 (6.6)	4.2 \pm 2.3 (0–6)	3.7 \pm 1.4 (2–6)
15	Weakness	6 (6.6)	2.5 \pm 1.9 (0–5)	2.2 \pm 0.8 (1–3)
16	Fear	6 (6.6)	4.0 \pm 2.0 (1–6)	2.0 \pm 1.7 (0–4)
17	Use of medication/devices	5 (5.5)	4.2 \pm 1.3 (3–6)	1.4 \pm 1.1 (0–3)
18	Numbness	4 (4.4)	3.5 \pm 2.1 (1–6)	1.5 \pm 1.9 (0–4)
19	Locking	4 (4.4)	4.5 \pm 1.3 (3–6)	2.3 \pm 1.3 (1–4)
20	Cramping/muscle spasms	3 (3.3)	4.7 \pm 0.6 (4–5)	2.3 \pm 2.3 (1–5)
21	Clicking/cracking	3 (3.3)	3.0 \pm 0.0 (3)	2.0 \pm 2.7 (0–5)
22	Radiating pain	1 (1.1)	6 (6)	1 (1)

sleep maintenance. This is consistent with prior cross-sectional studies^{20,21} that have found that sleep disturbances are common in people with OA, and are associated with not only greater pain but also greater fatigue, disability and depressed or anxious mood. In addition to pain's effect on sleep onset and maintenance, it has also been hypothesized that poor sleep exacerbates pain in people with chronic pain disorders like OA, by decreasing pain tolerance^{22,23}. Despite this, few studies have examined for the presence of concomitant primary sleep disorders, which are common in older people, in women, and in those who are obese – the same groups in which OA is most prevalent. Our findings suggest the need for research to better understand the relationship between pain and sleep in OA, in particular to understand the

impact of sleep disturbances on the pain experience in this population.

Cross-sectional population and clinical studies consistently suggest that OA pain and disability are found together with depression more frequently than would be explained by chance^{8,24–27}. Elucidation of the nature of this relationship has been difficult due to the fact that the symptoms of OA, including difficulty sleeping, difficulty getting out of bed in the morning, and lack of energy, overlap substantially with those of depression^{28,29}. Thus, it has been suggested that the prevalence of depression in arthritis cohorts has been over-estimated due to the overlap of somatic symptoms in these diseases³⁰, for which existing pain and depression measures have not accounted. However, consistent with the hypothesis of increased mood disorders

Table V
PGI results for hip OA subjects (n = 52)

Rank	Feature	Frequency N (%)	Distress (/6) mean \pm SD (range)	Points (/10) mean \pm SD (range)
1	Ache	48 (92.3)	3.3 \pm 1.5 (1–6)	3.3 \pm 3.0 (0–10)
2	Sharp pain	33 (63.5)	4.2 \pm 1.5 (1–6)	2.8 \pm 2.7 (0–10)
3	Limitation of activities	24 (46.2)	4.6 \pm 1.4 (1–6)	2.7 \pm 2.7 (0–10)
4	Triggered by activity	18 (34.6)	3.7 \pm 1.7 (0–6)	4.2 \pm 3.3 (0–10)
5	Mood	16 (30.8)	3.3 \pm 1.4 (0–5)	3.1 \pm 2.4 (0–10)
6	Constant pain	13 (25.0)	3.5 \pm 1.8 (0–5)	3.1 \pm 2.2 (0–7)
7	Night pain/impact on sleep	9 (17.3)	3.4 \pm 1.7 (0–5)	2.9 \pm 2.6 (0–8)
8	Triggered by inactivity	7 (13.5)	3.3 \pm 1.5 (1–5)	1.4 \pm 1.5 (0–4)
9	Stiffness	7 (13.5)	3.0 \pm 0.6 (2–4)	1.9 \pm 1.2 (1–4)
10	Burning pain	6 (11.6)	4.0 \pm 1.7 (1–6)	2.8 \pm 1.8 (1–5)
11	Radiating pain	6 (11.6)	3.5 \pm 1.6 (1–5)	1.8 \pm 1.7 (0–4)
12	Numbness	5 (9.6)	3.6 \pm 0.9 (3–5)	2.6 \pm 1.7 (1–5)
13	Unstable	4 (7.7)	3.3 \pm 1.7 (1–5)	1.8 \pm 0.5 (1–2)
14	Unpredictability	3 (5.8)	3.3 \pm 2.5 (1–6)	0.7 \pm 0.6 (0–1)
15	Clicking	2 (3.8)	1.5 \pm 2.1 (0–3)	6.0 \pm 5.7 (2–10)
16	Weakness	2 (3.8)	4.0 \pm 1.4 (3–5)	2.0 \pm 1.4 (1–3)
17	Cramping	1 (1.9)	5 (5)	1 (1)
18	Fear	1 (1.9)	6 (6)	0 (0)
19	Use of medication/devices	1 (1.9)	3 (3)	0 (0)
20	Locking	1 (1.9)	5 (5)	1 (1)
21	Grating pain	0 (0.0)	–	–
22	Swelling	0 (0.0)	–	–

among individuals with chronic painful OA, participants in our study independently noted that a distressing aspect of their pain experience was the effect on their mood. They described a breadth of moods, from frustration and anger, to depression. In light of studies that have consistently shown that depression may be under-diagnosed and under-treated among older people, our findings support the need for strategies to increase the detection and management of mood disorders among people living with OA. This is particularly important because there is evidence to suggest that depressed mood may affect OA outcomes (e.g., adherence to therapy³¹) and where identified, depression is eminently treatable³².

Historically, pain associated with OA has been attributed to local tissue injury and referred to as 'nociceptive pain'. For this reason, neuropathic pain symptoms are not typically elicited in patients with OA and have not been evaluated scientifically. However, many participants in our study used pain descriptors that might typically be associated with a neuropathic pain process, such as burning and pins and needles. In keeping with recent studies^{33–36}, our results suggest that patients with OA may experience pain due to both nociceptive and neuropathic mechanisms to varying degrees. If so, elicitation of such pain characteristics may identify patients who might benefit from neuropathic pain medications. Further research is warranted to examine the role of neuropathic pain in OA.

Through our use of the modified PGI, we sought to obtain a greater understanding of the key elements of pain in OA that individuals find most distressing. We hypothesized that these aspects would be those most likely to trigger changes in level of physical activity and/or mood. In turn these might drive decision-making by patients around use of various treatment modalities, such as joint replacement surgery. In this respect, we have learned that while intense pain is distressing, that which is both intense and unpredictable has even greater impact on quality of life.

Strengths of our study were the inclusion of OA participants across many geographic sites, levels of education, age and both men and women. There were, however, some limitations. First, the majority of our study subjects had experienced hip or knee symptoms for many years; there were too few with symptoms lasting less than 1–2 years to comment on the pain experience of individuals with early symptomatic OA. Second, as noted above, there were insufficient numbers of non-Caucasian individuals to draw any conclusions about any ethnic differences in the pain experience. Third, only English-language countries were included. Further research could determine whether our findings are generalizable to other groups.

In conclusion, our study is the first to comprehensively examine the pain experience of people living with hip and knee OA, focusing specifically on the pain and those features of the pain that most distressed them. Two distinct types of pain were identified. Of these, intermittent and intense pain, particularly when unpredictable, had the greatest impact on quality of life. This study has laid the foundation for the development of a new OA pain measure to assist clinicians in their clinical practice as well as to serve as an outcome measure for clinical trials of disease-modifying agents in OA.

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Conflict of interest

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