

## RESEARCH PAPER

# The experience of living with knee osteoarthritis: exploring illness and treatment beliefs through thematic analysis

Nektaria Pouli, Roshan Das Nair, Nadina Berrice Lincoln, and David Walsh

Arthritis Research UK Pain Centre, University of Nottingham, Nottingham, UK

### Abstract

**Purpose:** Knee osteoarthritis (OA) is a major cause of disability in older adults. However, there is limited research on the daily experience of living with knee OA. We aimed to offer insight into the beliefs of patients with knee OA about their illness and treatment. **Method:** Twenty-four semi-structured interviews were conducted with 17 women and 7 men with physician-diagnosed knee OA, aged between 48 and 84 years (mean = 62, SD = 7). The audio-taped interviews lasted from 30 min to 1 h, and were transcribed verbatim. The data were subjected to thematic analysis. The transcripts were independently coded by two researchers to increase reliability of coding. **Results:** Six themes were developed and two of these are examined in further detail: (i) Illness representation and (ii) Beliefs about the medical and surgical control of pain. Illness representation comprised beliefs about people's understanding of OA and their pain experience, as well as expectations about the course of illness. The second theme presented experiences of limited pain relief and concerns about the use of drugs and surgery. **Conclusion:** Exploring illness representations and beliefs about medical and surgical control of pain may provide the basis for initiating psychological interventions for people with knee OA.

### Keywords

Knee, osteoarthritis, pain

### History

Received 17 July 2012

Revised 8 May 2013

Accepted 10 May 2013

Published online 21 June 2013

### ► Implications for Rehabilitation

- People with knee OA place pain at the core of their living, and hold beliefs about knee OA being an incurable disease of a progressive nature, linked to specific causal factors.
- People with OA have concerns and worries about use of medication to control pain, and are ambivalent towards relying on medical or surgical interventions.
- Exploring and addressing patient illness beliefs and treatment expectations may help improve concordance with and outcomes from intervention.

### Introduction

Knee osteoarthritis (OA) is one of the most common types of arthritis [1], causing pain, disability and loss of function, as well as emotional distress [2–4]. Even though a diagnosis of knee OA is often based on radiographic and structural changes, in many cases there is a mismatch between these changes and the symptoms reported by patients [5]. OA knee pain can be viewed as a product of the interaction between structural changes and psychosocial factors, such as people's beliefs or perceptions about their illness [6,7].

The impact of people's beliefs and attitudes on health behaviour has been included in social cognition models [8–11]. One particular approach, the Common Sense Model of Illness [12], has focused on patients' beliefs or mental representations of their illness. Leventhal et al. [12,13] proposed that individuals structure their illness beliefs around five components: identity (beliefs about the nature of the illness and associated symptoms),

time-line (beliefs about the time course of the illness), cause (beliefs about what caused the illness), consequences (beliefs about the personal impact of the illness) and cure/control (beliefs about whether illness can be cured or controlled). According to the model people's cognitive representations of the illness determine their emotional responses and guide coping strategies.

The Common Sense Model has informed research on the link between illness representations and clinical outcomes for a variety of chronic illnesses. The dimensions of a strong identity (more perceived symptoms), perceived serious consequences and chronic timeline have been consistently linked to lower social, physical and psychological functioning [14–16]. In patients with rheumatoid arthritis, illness beliefs about curability, consequences and identity also appeared to predict emotional outcomes and disability [17–19]. However, only a few studies have explored illness beliefs in patients with OA.

Botha-Scheepers et al. [20] reported that a strong illness identity (perception of more symptoms), serious consequences and chronic time-line, were associated with more limitations in activity levels in people with OA. Bijsterbosch et al. [21] investigated changes in illness representations in people with OA over a 6-year period and showed that changes in illness perceptions were related to progression of disability, defined as

a decrease in functional status which was measured by assessing activities of daily living and mobility. Participants with progressive disability also showed increases in symptoms attributed to OA, perceived consequences, perceived disease chronicity and decrease in perceived control, compared to those who did not show changes in disability scores. In a later longitudinal study with the same cohort of participants with OA, negative changes in illness representations, in the dimensions of time-line, personal control and illness coherence (how much people understand their illness) were associated with worse functional status, pain and disability [22]. All these studies explored beliefs using quantitative measures, which may have limited their ability to tap the *essence* of participants' experience. Moreover, the samples were predominantly female participants recruited from the community. Hampson, Russel, Glasgow and Zeis [23], however, used semi-structured interviews to explore personal models of OA and participants' accounts included beliefs about OA as a serious, painful, chronic and incurable condition. Turner, Barlow, Buszewicz, Atkison and Rait [24] also used semi-structured interviews to examine patients' beliefs about causes of OA, and the most frequently reported cause was that of "wear and tear".

Considering the limited research on beliefs about OA and the preponderance of quantitative methodologies to understand these, we chose to use a qualitative approach, which has been judged as being well suited to address questions about patients' experiences and fit well in a patient-centred framework of care [25]. The aim of the study was to explore participant's experience of living with knee OA and their beliefs about knee OA and its treatment. The current article focuses on exploration and description of illness and treatment beliefs.

## Method

The data were collected through semi-structured interviews, which provided an unobtrusive way of gaining insight and allowed participants to express themselves freely, while allowing the interviewer to keep the interview focussed. This focus was needed to facilitate meaningful comparisons between participants' accounts. The use of open ended questions combined with a conversational style of interviewing promoted less restricted accounts, compared to use of structured, closed-ended questions [25]. It offered participants the opportunity to talk freely about issues that were of concern. The interview schedule was developed from the relevant literature on arthritis and chronic illness and previous published qualitative work with people with OA. The schedule aimed to elicit participants' experiences of living with knee OA on a day to day basis, their beliefs about what might have caused their knee OA and what they believed was causing them pain, their emotions in relation to their condition, the day to day management of OA and their experiences of treatment. For example, the opening question invited participants to explore their understanding of arthritis, followed by a question on the impact of arthritis in their life. The interviewer also used clarifying questions and probes, when appropriate, in order to gain a more in-depth understanding of participants' experience. Even though a semi-structured interview schedule was used, participants were also able to introduce their own topics of interest and the interview content was flexible to adapt to participants' needs. The current article only focuses on people's beliefs about their illness and treatment.

## Participants

Participants were purposively selected based on the inclusion criteria of self-reported diagnosis of knee OA, combined with radiological evidence of osteophytes and current knee pain, aged over 18 years, and the absence of inflammatory condition or joint

surgery during the past 3 months. Attempts were made to select participants who had experienced different treatment modalities, including pharmacological, physiotherapy and surgical treatments, to elicit diverse experiences. Recruitment was stopped when theoretical saturation was achieved. Although saturation as a concept has been interpreted in different ways, Strauss and Corbin [26] have suggested that it is a "matter of degree". They argued that saturation should be concerned more with reaching the point where it becomes "counter-productive" and that "the new" that is discovered does not necessarily add anything to the overall story, model, theory or framework (p. 136). In the current study, the above recommendation was followed in relation to reaching saturation of themes.

Participants were identified from a community database of people with knee OA who had agreed to be contacted for research purposes. A research co-ordinator sent invitations to participants who met the inclusion criteria. The group was enriched by recruitment of patients attending hospital rheumatology and orthopaedic specialist clinics for knee OA. Patients were identified and contacted by letter from the consultant responsible for their care. Out of 52 participants who were contacted, 24 (16 community, 8 hospital participants) responded to the invitation and were interviewed. The sample consisted of 17 women and 7 men, aged between 48 and 84 years (mean = 62, SD = 7). All participants were White British. Fifteen participants were retired and nine participants were in either full- or part-time employment. Symptom duration ranged from 3 to 20 years (mean = 11, SD = 5). We also asked how intense constant knee pain had been recently with a response scale of 0 (not at all), 1 (mildly), 2 (moderately), 3 (severely) and 4 (extremely) (median = 3, range 1–4). Most participants reported using medication to control pain with only four participants with less severe pain using medication infrequently or rarely. Types of medication used were analgesics, non-steroid anti-inflammatory (NSDAIDs), capsaicin cream and steroid injections. Five participants also reported use of complementary treatments, such as cod liver oil and herbal tablets, while six participants reported benefits from physiotherapy sessions. Three participants had had unilateral knee replacement surgery in the past 2 years and were currently experiencing pain from their remaining knee, and two participants were due to have a knee replacement surgery the following month. Table 1 presents participants' main demographic information and pseudonyms. The study was approved by Nottingham Research Ethics Committee 2 and also received Research and Development approval from a Nottingham University Hospitals NHS Trust. All participants provided informed consent.

## Procedure

Participants were interviewed by one researcher (N.P.). The interviews took place at participants' homes ( $n=9$ ), at the university ( $n=13$ ) or in a hospital clinic ( $n=2$ ), and lasted between 30 min and an hour. Interviews were digitally recorded and transcribed verbatim.

## Analysis

The data were analysed using thematic analysis, following Braun and Clarke's [27] and Boyatzis' [28] guidelines. The flexibility of thematic analysis and its theoretical freedom, along with the well established guidelines for performing the analysis, informed the choice of the method. Other methods, such as Interpretative Phenomenological Analysis were also considered, but given some of their theoretical insufficiencies [29] and requirement for small sample sizes [30] which would limit heterogeneity, thematic analysis was considered to be a better method to address the aims of the study. Given the limited research in the field of experiences

Table 1. Participant's pseudonyms and demographics.

Pseudonym	Gender	Age	Employment status	Symptom duration	Pain* intensity
Tom	Male	48	F/T	15 years	4
Sue	Female	84	Pensioner	15 years	2
Anna	Female	63	Pensioner	10 years	3
Fiona	Female	59	P/T	9 years	2
Amy	Female	72	Pensioner	12 years	3
Sharon	Female	59	P/T	12 years	3
Kate	Female	58	P/T	4 years	3
Peter	Male	58	Pensioner	4 years	3
Stacey	Female	71	Pensioner	4 years	3
Britney	Female	65	P/T	13 years	3
Tony	Male	62	F/T	3 years	3
Teresa	Female	70	Pensioner	20 years	2
Brandon	Male	65	Pensioner	20 years	2
Alicia	Female	57	Pensioner	3 years	3
Jenny	Female	60	Pensioner	15 years	4
Amanda	Female	59	P/T	20 years	4
Stewart	Male	63	Pensioner	20 years	3
Nicky	Female	58	Pensioner	10 years	2
Danny	Male	52	P/T	7 years	2
Mary	Female	72	Pensioner	15 years	3
Wendy	Male	62	Pensioner	7 years	3
Nicole	Female	63	Pensioner	12 years	3
Lisa	Female	61	Pensioner	4 years	1
Scot	Male	53	F/T	15 years	3

\*Pain intensity of recent constant knee pain: 1 (mild), 2 (moderate), 3 (severe) and 4 (extreme)

and beliefs about knee OA, the current study adopted an exploratory approach and thematic analysis was chosen to unpack the meaning of people's experiences of OA. Before performing thematic analysis, researchers need to make certain choices in regards to the analysis of data and explicitly state these to increase the clarity and trustworthiness of findings. In the current study, and according to Braun and Clarke's recommendations [27], a theme was considered to represent an important aspect of the studied experience and also showed a pattern across the data. An inductive approach to identifying themes was employed due to the exploratory nature of the study. However, analyses never happen in an "epistemological vacuum" [27, p. 84] and researchers need to acknowledge that their own theoretical and epistemological commitments will inevitably impact on the data analysis. In this study, the first author adopted a critical realist epistemological approach. Critical realism acknowledges the "impossibility of knowing objects except under particular descriptions" [31, p. 249] but at the same time propose that experiences are linked to structures such as social, economic or biochemical, whose effects can be manifested in people's accounts [32]. The choice of critical realist epistemology was informed in this case by the aim of the study, to explore and offer rich descriptions of individual experiences in a relatively under-researched field, but also account for the influence of biopsychosocial factors.

The data analysis involved a process of engaging with the data and was performed in a series of steps, following recommendations of Braun and Clarke [27]: (i) familiarizing with the text; this step involved reading and re-reading the transcripts in order to get familiar with the depth and breadth of the material, (ii) generating initial codes; in order to identify codes all data were searched systematically. The data were coded initially at a latent level and then at a more abstract level. The initially identified codes were matched with data extracts, which illustrated the code for each of the participants. (iii) Searching for themes within the data; after coding all data, different codes were sorted into potential themes, for each participant. The codes were examined to detect how they

may combine to form an overarching theme. The next stage involved producing diagrams for each transcript, including a summary of potential themes and subthemes for each participant while extracts that supported each theme and subtheme were also collated. (iv) Reviewing themes; at this stage, all potential themes for each participant were examined and available extracts were reviewed in order to make sure that they described a coherent pattern. Different diagrams were compared to produce a summary diagram and defining and naming themes. At this stage, a detailed analysis of what each theme was about was produced and data were re-examined in order to ensure that there was not much overlap between themes and to examine that all important aspects of participant's world were given attention. A label was given to each theme, which aimed to be concise and provide a sense of what the theme was about. The transcripts were independently coded by two researchers (N.P. and R.D.N.) to ensure reliability of coding. There was a general agreement in terms of produced codes between the two researchers but any areas that discrepancies arose were discussed and a mutually agreed solution was reached.

## Findings

Participants offered rich descriptions of the experience of living with knee OA and of their beliefs about the illness and treatment. Six themes emerged which were shared by participants. In order to provide an in-depth account, the current article focuses on the two themes; illness representation and beliefs about medical and surgical control of pain. The choice of the two themes was determined by the lack of adequate coverage in previous literature and the potential of beliefs to be amenable to interventions. The four additional themes were; change from previous functioning, emotional impact of knee OA, managing pain and interactions with the medical team regarding OA.

## Illness representation

The theme of illness representation included a series of subthemes all of which described beliefs about key aspect of the illness and are described below.

### Pain omnipresence

Even though the intensity of reported pain differed between participants, the majority placed pain at the core of their experience. Many participants reported being always aware of the pain and presented it as something that never goes away. Their accounts revealed the central role that pain occupies in their lives and how it seems to be interwoven with their existence. It was presented as the defining feature of OA and their main source of concern:

*I don't know what it is like to be without pain. I think I'd died ... I'd go round pinching myself every five minutes! (Amanda, 59 years)*

*I feel just one mass of pain ... the pain seems to invade your very being (Amy, 72 years).*

Moreover, many participants presented pain as "unpredictable", which added to their distress:

*I never know how far I can walk and then pain comes and my knees will lock up and occasionally I fall over ... So, in a sense is not knowing ... that is frustrating ... (Britney, 65 years).*

### Factors that affect pain

Participants described a common range of factors that seemed to exacerbate their pain. For example, many participants discussed

the impact of “sitting for too long”, which tended to make their pain worse:

*You get on with it and you walk through...because it must...you know the more you sit about the worse it is...but it just...it just wears you out...(Alicia, 57 years).*

*Can't keep my legs in one position for a long time because I have to keep moving them because it helps with the pain (Tony, 62 years).*

At the same time, walking for long distances, or other weight bearing activities had a negative effect on the amount of pain that some participants experienced.

*I don't have any pain, if I'm just sitting...but when I come to then get up and move about...yeah...yeah...upstairs...downstairs...and as soon as I go any sort of distance then there is a pain there...(Sharon, 59 years).*

Additionally, some participants described how damp weather or changes to the weather also made their pain worse:

*...When the weather is changing...like cold or wet weather...that's when I feel a lot of pain...for the arthritis...(Fiona, 59 years old).*

Participants' accounts differed in the range of activities that they reported they could perform and the amount of pain they said they could tolerate. In most cases they appeared to have observed certain factors (e.g. changes in weather or weight bearing activities) that they perceived as contributing to the amount of pain they experienced and that was an additional feature of their personal representation of their illness.

### Mechanical understanding of arthritis

Most participants described a mechanical nature of arthritis, derived from an anatomical and mechanical perspective, focusing on loss of cartilage, bones rubbing against each other or bones that grow abnormally, all of which were associated with pain:

*It's just bone rubbing on bone...There is no cover at the ends of the bones...and it causes inflammation...(Brandon, 65 years).*

Another participant, in an attempt to describe what arthritis means to them mentioned:

*The bones on the joint get closer together and the bits in between isn't working as it should and it closes and closes and as it closes it get more painful...(Wendy, 62 years).*

Other participants emphasized the existence of swollen joints, which for them represented arthritis and was linked to pain:

*I think it's joint becoming swollen...and it aches...that's what I understand it a bit...I mean a lot of pain from the swollen joint...(Sharon, 59 years).*

Even though participants' accounts differed in the extent of using medical terms (e.g. OA, cartilage) and understanding of knee OA, there was an attempt in most cases to use a

mechanical model in order to “give a name” and explain their illness experience.

### Beliefs about prognosis/curability

The majority of participants discussed how they perceived their condition to progress and expressed specific expectations about the course of the illness. Almost all participants described their condition as progressively deteriorating:

*It's a lot worse and more regular the pain; you are a lot more conscious that it's there (Scot, 53 years).*

Participants reported that they tended to get more pain as time progressed, and also that they expected to get more pain in the future:

*The pain has changed...it got worse...yeah...definitely...and even when I try to do my exercises...everything seems to stiffen up when I get to bed...to roll over...yes...it has got worse...and I expect it will get even worst as I grow older...(Anna, 63 years).*

Additionally, they reported beliefs that OA is a condition that one cannot cure, is ongoing and persistent. As shown in the quotes below, participants' descriptions of their experiences suggest a link between beliefs about progression and incurability and pain related disability:

*Living with arthritis...it's a living nightmare...I wouldn't wish it on anybody...It's not like having a broken arm...it hurts at the time...but it mends...arthritis to me it does not...the last 15 years...nobody actually said oh! You will be cured...by such and such a date...so it's ongoing...and I perceive it...it only will get worse...It limits me in what I can do...very much so...which is frustrating...and sometimes all those worries about the future...really get me down...(Tom, 48 years).*

*I describe the pain as living with misery...it makes you feel miserable...makes you feel that if this is all...it is for the rest of your life...and I have always been a really independent person and now I've got to be dependent on someone else...and that's been killing me (Mary, 72 years).*

As demonstrated here, participants' accounts revealed a common set of beliefs regarding the prognosis and incurability of knee OA. Whether or not they had experienced deterioration in their condition, almost all shared a common representation of OA as having poor prognosis and being incurable. This was another defining feature of knee OA for them.

### Beliefs about causes of OA

Participants also presented a wide range of beliefs about the possible causes of knee OA. These beliefs were either internally or externally located. Some accounts were focused on placing responsibility on the individual, such as the impact of previous activities or excessive body weight that could have been avoided, while others attributed causes to factors beyond the individual's control, such as genes, weather, trauma or ageing. One participant who viewed the cause of arthritis as being biologically determined mentioned:

*I think if you've got arthritis...it is in you. I don't think it's anything that you can prevent. So, it is predetermined...It's something in the genes...(Amy, 72 years).*

Others believed that knee OA, like the deterioration described earlier, was part of a natural process of getting older:

*I think it's just because I am getting older...and my knees aren't as young as they used to be...I put it down to my ageing (Kate, 58 years).*

Many people attributed knee OA to past activities, either in terms of having been very athletic, or in terms of the conditions of their previous employment:

*I was quite an athletic person, I played a lot of sports and I realise now I probably overdid it...It's like everything, it all wears out. (Stewart, 63 years).*

Participants explored a range of possible causal factors for OA, and, in most cases, their beliefs about causation were at the core of their understanding knee OA and formed part of the illness representation.

### Beliefs about medical and surgical control of pain

Participants' narratives revealed a well defined set of beliefs about the value of the medication they were receiving and the medical control of pain. Many participants also expressed concerns and worries about medication.

#### Pain relief/partial pain relief

The majority of participants reported that they relied on medical control of pain and used analgesic tablets or patches, or received steroid injections to keep the pain at bay. However, there was diversity in terms of frequency and dosage of medication, as well as the degree of pain relief.

Most participants described partial pain relief, with medication "numbing the pain":

*I take my medication which does help...but of course it never gets rid of the pain. (Alicia, 57 years).*

*I mean, you have the painkillers and it improves it but it never goes away. It kind of numbs the situation... (Danny, 52 years).*

However, there were also some who reported very positive experiences from use of medication, which offered a sense of hope:

*...Four months ago – my doctor gave me a steroid injection...and that was wonderful...For a while...but it's wearing off now...so I mean...I suppose it varies how long it last for people...but that was really good...and in a way it has boosted me...because I know there can be a relief...: previous to that it was just pain all the time, really...but it's a nice thought that if he eventually gives me another one...that helps...definitely... (Sharon, 59 years).*

#### Worries about medication/ambivalence

Participants reported several beliefs about the impact of medication, and a sense of ambivalence towards relying on "pills" for pain relief. They expressed concerns about the side-effects of some medication and a worry about becoming dependent. At the same time, medical control of pain appeared to be a threat to their personal sense of control and they tended to express a desire to lower the dosage of pain killers or find alternative ways to control pain. The attempt to avoid painkillers was shared by almost all

participants, regardless of the amount of pain they were experiencing or the medication they were on. One participant with multiple health problems discussed his concerns:

*I have to take painkillers but I am not a great advocate...I am worried I am going to end up with ulcers...It's like a merry-go-round...one thing goes wrong and all sorts of things follow on... (Peter, 58 years).*

Another participant described a state of mixed emotions about using medication to control pain:

*The medication goes up and up on the painkilling stuff that I'm taking for pain and I'd love to be able to get off a lot of it because you get to a point where you think, "Where do I go from here?" I'm on patches and tablets and I don't want to be...I'd like to be able to get off... (Nicole, 62 years).*

Many participants regarded pain killers as their last resort and only took them when the pain got really bad. In the quote below, taking painkillers also appears as a threat to a sense of control ("give in")

*If I can think of maybe a rest can help...I try that...So, if this hasn't worked then I give in and take the painkillers... (Amy, 72 years).*

#### Beliefs about surgery

Participants also considered the impact of knee replacement surgery, and for some the prospect of a knee operation offered them a sense of hope. One participant, scheduled for a knee replacement operation, appeared cautiously optimistic:

*So I'm looking at it as there's a light at the end of the tunnel that isn't another train coming towards me! (Lisa, 61 years).*

However, many participants were not in favour of knee replacement surgery, either because they had heard stories of unsuccessful replacements or because they viewed the operation as compromising the sense of internal control:

*I wouldn't go down that road...Not in favour of things like that...No...I am careful...I'm careful...hopefully they [knees] will last me out. (Anna, 63 years).*

Another participant, having had one knee replaced, mentioned:

*This [knee] one is replaced...the other one is not yet... But I get as much pain with the one that has been replaced as I get with the one that hasn't been replaced... so there is no point... (Brandon, 65 years).*

Participants' accounts revealed a shared set of beliefs about the medical or surgical control of pain that focused around issues of dependency and concerns about possible negative effects of medication or surgery. Their descriptions showed a state of ambivalence to taking medication, since in many cases their worries about negative effects overshadowed by the possible benefits or pain relief that the drugs would potentially offer them. Similarly, the prospect of surgery, although for some offered a sense of hope, for many participants was an unattractive option.

## Discussion

The aim of the study was to explore adults' experiences of living with knee OA and to gain a better understanding of their beliefs about their condition and treatment. In the current article, the themes of illness representation and beliefs about medical and surgical control of pain are explored. Although some of the findings match those identified in previous research, it was decided that the focus should be on these two themes because they have received limited attention in the literature, and owing to their potential for change through psychological interventions. Findings appear to offer some further insights into the experience of living with knee OA.

Pain was placed at the core of the knee OA illness representation, and was for most a defining feature of OA, which is consistent with previous qualitative research on knee OA [33–37]. Even though accounts differed in terms of the intensity of reported pain, participants' stories focused on a "constant awareness of pain", while at the same time the unpredictable nature of pain was one of their main concerns. Some participants identified factors that appeared to make their pain feel worse, such as "sitting for too long", "walking for long distance" or engaging in "weight bearing activities" which is consistent with previous research [36,38]. Other research on the management of knee OA pain [39,40] found that people tend to move their joints as an important self-management approach, which was also evident in some of our participants' accounts.

Participants also discussed how they perceived knee OA to be a degenerative disease, for which there is no cure or prevention. Many people also linked a poor prognosis to getting older. Previous research on chronic illness has indicated that older adults tend to be more pessimistic about treatment options and make less use of health services [41,42], while Segall and Chappell [43] found that respondents with arthritis felt that there was no effective way to treat their condition. However, the representation of knee OA as being incurable and with a poor prognosis was also expressed by younger respondents, and points to the need to address these beliefs and inform patients of options available to better manage knee OA. Previous quantitative research using the Common Sense Model of Illness [12,13] has identified how representations about time-line, consequences and curability are related to worse illness outcomes and limitations in activity levels in OA patients [20,21,44]. The current study found that some people who expressed serious concerns about poor prognosis and curability also reported high levels of pain-related disability. Although causality cannot be claimed through such research, targeting people's beliefs about prognosis and consequences of knee OA might open a potential avenue for intervention. Previous research has also supported the hypothesis that decreased perceived control over pain is linked with increased disability and depression in chronic pain patients, while higher self-efficacy for pain control predicted lower pain and disability in arthritis patients [45–47]; findings which illuminate the impact of individuals' beliefs on illness management.

In an attempt to account for potential causes of knee OA, participants discussed beliefs about the impact of a range of factors, such as genes, previous activities, trauma, weather and a "wear and tear" explanation, while older participants tended to approach knee OA as part of a natural ageing process. Turner et al. [24], in a qualitative study of people attending primary care for OA, identified similar beliefs about causes of OA, with "wear and tear" being the most common belief. Another study of people with knee or hip OA illustrated how older respondents tended to present their symptoms as "being a normal part of ageing", which caused high disruption to daily life [48]. It appears that for some participants causes were presented as part of their personal

history, focusing more on previous activities, while others focused more on a spontaneous degenerative aspect of OA. Since there is no single known cause of knee OA, people's beliefs about the causes of their condition have important implications in terms of managing the disease. For example, presenting knee OA as a natural part of ageing might lower patients' sense of control, prevent participants from seeking medical treatment, lead to under-utilisation of services and promote a fatalistic attitude toward their condition. Furthermore, beliefs about OA as an ageing process may hold different meaning for young people than for people in later life.

Most people's accounts revealed a constant attempt to make minimal use of pain killers and find alternative ways to control pain. People's descriptions revealed a state of ambivalence, where on the one hand they had to rely on medication due to severe pain, but on the other hand they wanted to minimize use, due to worries about dependency or side-effects. There is limited research that has explored OA patients' beliefs about the use of medication. Turner et al. [24] discussed perceptions about medical control of pain, which were similar to those described by participants in the current study. Sale, Gignac and Hawker [49] studied adherence to medication in older adults with OA, and also reported that people were reluctant to take painkillers and they tried to alter the dosage and frequency or only take them when it was absolutely necessary. Medical advice is often that taking painkillers regularly is a more effective approach to controlling pain rather than waiting until the pain is bad [50]. However, evidence is not strong to support the hypothesis that regular analgesic consumption is superior to "as required" dosing for arthritis pain, either in terms of analgesic efficacy, or patient satisfaction, since many patients' related factors should be taken into account in choosing a management plan [51]. Further research is required to determine whether interventions should be developed that increase adherence to regular analgesic regimens, and whether advice should be modified to take account of factors additional to analgesic efficacy, such as impact of medication regimens on self efficacy and concerns about adverse events that were identified as important to participants in the current study.

Our findings demonstrate the common experience amongst people with OA that currently available analgesics do not adequately control pain. Research using the Common Sense Model of Illness [12] suggests that even though people with a wide range of illnesses might express a strong need for a treatment, they might also believe that the treatment is, at best, only moderately effective. Further research is urgently needed to develop more effective analgesics with less propensity for adverse effects.

There was some diversity in people's accounts regarding knee replacement, with some believing that it offered them a sense of hope for the future, while others expressed a negative view; both of which are consistent with previous research [36]. More effectively providing information about the risks and benefits of the surgical procedure may facilitate better adaptation post-operatively [52], while also allowing people to make better informed decisions.

The current study offers useful insights into the experience of living with knee OA and pain, using a sample of middle to older aged adults. The findings illustrate the power of "lay beliefs" and the impact they can exert in illness management. By understanding the complex interactions between biological, psychological and social factors and how they are all interwoven in the experience of knee OA, there is a potential to guide patients to available resources, ranging from support groups or self-management training through to orthopaedic surgery. Understanding people's beliefs and how they can affect the outcome of treatment recommendations should help healthcare

professionals to provide information and education that will assist people in managing OA. In this study it was evident that patients hold their own views about the effectiveness of medication and many expressed worries and fears about drug dependency. Healthcare professionals should strive to better address unjustified fears, while more research is needed to address realistic concerns of people with OA.

There are limitations to the current study. A small sample of purposively recruited participants was used, so the findings may not be applicable to all people with knee OA. However, there was an attempt to cover a wide age range and to include people who had experienced different treatment modalities in order to capture diverse experiences. A further limitation was that all participants were White British and therefore possible cultural differences were not accounted for. However, the fact that a previous study using a Chinese sample [37], reported similar findings, might point to potential similarities across cultures in regards to illness beliefs. Additionally, the sample consisted of motivated participants, many of whom had taken part in previous studies of knee OA, and therefore might not be representative of the wider population with knee OA. The average symptom duration was 11 years, which means that participants may have already developed a distinct set of beliefs about their condition, which may differ from patients who have had less experience of the illness. As with all qualitative research, the researcher cannot be separated from the research process and the findings presented are a personal interpretation of the data. However, different measures (such as independent data coding) were employed to increase credibility of the presented account and there was an abundance of examples in participants' own words in order to support the thematic structure presented. Despite these limitations the study offers an insight into individual beliefs about knee OA and pain, and how they operate in the context of living with a chronic illness, both of which have not previously been studied extensively from an insider's perspective. Future research might focus on using these insights into planning interventions to modify beliefs and enhance self-management skills of patients with knee OA.

## Conclusion

People with knee OA hold distinct beliefs about their illness and treatment. They placed pain at the core of the living experience, and also identified factors that impacted on the degree of pain experienced. Participants held beliefs about knee OA being an incurable disease of a progressive nature, as well as being linked to specific causal factors, such as genetics, previous activities or being part of ageing process. They expressed concerns and worries about use of medication to control pain, and were ambivalent towards relying on medical or surgical interventions to control pain, since for some this was experienced as a threat to a personal sense of control. Better understanding and addressing the beliefs and concerns of people with knee OA should help healthcare professionals to more effectively offer treatments. Participants' concerns about lack of efficacy, adverse events, dependency and lack of personal control over their OA knee pain highlight areas in need of further research aiming to develop better treatments for the future.

## Acknowledgements

Arthritis Research, UK and University of Nottingham.

## Declaration of interest

The authors report no declaration of interest. Grant supporter, Arthritis Research UK and University of Nottingham.

## References

1. Das S, Farooqi A. Osteoarthritis. *Best Pract Res Clin Rheumatol* 2008;22:657–75.
2. March LM, Bachmeier CJM. Economics of osteoarthritis: a global perspective. *Balliere Clin Rheumatol* 1997;11:817–34.
3. Hawker GA, Gignac MA, Badley E, et al. A longitudinal study to explain the pain – depression link in older adults with osteoarthritis. *Arthritis Care Res* 2011;63:1382–90.
4. Arden N, Nevitt M. Osteoarthritis: epidemiology. *Best Pract Res Clin Rheumatol* 2006;20:3–25.
5. Jones A, Doherty M. ABC of rheumatology: osteoarthritis. *BMJ* 1995;310:457–60.
6. Summers MN, Haley WE, Reveille JD, Alarc Onan GS. Radiographic assessment and psychologic variables as predictors of pain and functional impairment in osteoarthritis of the knee or hip. *Arthritis Rheum* 1988;31:204–9.
7. Creamer P, Hochberg MC. The relationship between psychosocial variables and pain reporting in osteoarthritis of the knee. *Arthritis Care Res* 1988;11:60–5.
8. Rosenstock, I. Historical origins of the health belief model. *Health Educ Monogr* 1974;2:1–8.
9. Bandura A. Exercise of human agency through collective efficacy. *Curr Dir Psychol Sci* 2000;9:75–8.
10. Bandura A. Toward a unifying theory of behavioral change. *Psychol Rev* 1977;84:191–215.
11. Fishbein M, Ajzen I. *Belief, attitude, intention and behavior*. New York: Wiley; 1995.
12. Leventhal H, Meyer D, Nerenz D. The common sense representation of illness danger. In: Rachman S, ed. *Contributions to medical psychology*. Oxford: Pergamon; 1980:7–30.
13. Leventhal H, Nerenz D, Steele D. Illness representations and coping with health threats. In: Baum A, Taylor S, Singer J, eds. *Handbook of psychology and health, V 4, social psychological aspects of health*. NJ: Erlbaum; 1984:219–52.
14. Heijmans M, De Ridder D. Assessing illness representations of chronic illness: explorations of their disease specific nature. *J Behav Med* 1988;21:485–503.
15. Scharloo M, Kaptein AA, Weinman J, et al. Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *J Psychosom Res* 1988; 44:573–85.
16. Hagger MS, Orbell S. A meta-analytic review of the common sense model of illness representations. *Psychol Health* 2003;18:141–84.
17. Schiaffino KM, Shawaryn MA, Blum D. Examining the impact of illness representations on psychological adjustment to chronic illnesses. *Health Psychol* 1998;17:262–8.
18. Sharpe L, Sensky T, Allard S. The course of depression in recent onset rheumatoid arthritis. The predictive role of disability, illness perceptions, pain and coping. *J Psychosom Res* 2001;51:713–19.
19. Graves H, Scott DL, Lempp H, Weinman J. (2009). Illness predicts disability in rheumatoid arthritis. *J Psychosom Res* 2009;67:417–23.
20. Botha-Scheepers S, Riyazi N, Kroon HM, et al. Activity limitations in the lower extremities in patients with osteoarthritis: the modifying effects of illness perceptions and mental health. *Osteoarthritis Cartilage* 2006;14:1104–10.
21. Bijsterbosch J, Scharloo M, Visser AW, et al. Illness perceptions in patients with osteoarthritis: change over time and association with disability. *Arthritis Rheum* 2009;61:1054–61.
22. Kaptein Ad A, Bijsterbosch J, Sharloo M, et al. Using the common sense model of illness perceptions to examine osteoarthritis change: a 6 year longitudinal study. *Health Psychol* 2010;29:56–64.
23. Hampson SE, Glasgow RE, Zeis AM. Personal models of osteoarthritis and their relation to self-management activities and quality of life. *J Behav Med* 1994;17:143–58.
24. Turner AP, Barlow JH, Buszewicz M, et al. Beliefs about the causes of osteoarthritis among primary care patients. *Arthritis Rheum* 2007; 57:267–71.
25. Bishop F, Yardley L. Delay in seeking help. In: Ayers S, Baum A, McManus C, Newman S, Wallston K, Weinman J, West R, eds. *Cambridge handbook of psychology, health and medicine*. 2nd ed. Cambridge: Cambridge University Press; 2007:314–18.
26. Strauss A, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks (CA): Sage; 1990.

27. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
28. Boyatzis R. Transforming qualitative information. London: Sage; 1998.
29. Giorgi, A. Concerning a serious misunderstanding of the essence of the phenomenological method in psychology. *J Phenomenol Psychol* 2008;39:33–58.
30. Smith JA, Flowers P, Larkin M. Interpretative phenomenological analysis: theory method and research. London: Sage; 2009.
31. Bhaskar, R. A realist theory of science. Brighton: Harvester Press; 1978.
32. Willig, C. Beyond appearances: a critical realist approach to social construction work. In: Nightingale D, Cromby J, eds. *Social constructionist psychology: a critical analysis of theory and practice*. Buckingham: Open University Press; 1999:37–52.
33. Keysor J, Sparline J, Riegger-Krugh C. The experience of knee arthritis in athletic young and middle aged adults: a heuristic study. *Arthritis Care Res* 1998;11:261–70.
34. Kee CC. Living with osteoarthritis: insiders' views. *Appl Nurs Res* 1998;11:19–26.
35. Maly MR, Krupa T. Personal experience of living with knee osteoarthritis among older adults. *Disabil Rehabil* 2007;29:1423–33.
36. Hall PT, Migay AM, Persad T, et al. Individuals' experiences of living with osteoarthritis of the knee and perceptions of total knee arthroplasty. *Psychother Theory Res Pract* 2008;24:167–81.
37. Chan K, Chan L. A qualitative study on patients with knee osteoarthritis to evaluate the influence of different pain patterns on patients' interpretation and coping strategies for the disease. *Rheumatol Rep* 2011;3:9–15.
38. Orbell S, Johnston M, Rowley D, et al. Cognitive representations of illness and functional and affective adjustment following surgery for osteoarthritis. *Soc Sci Med* 1998;47:93–102.
39. Morden A, Jinks C, Ong B. Lay models of self management: how do people manage knee osteoarthritis in context? *Chronic Illn* 2010; 5:1–16.
40. Grime J, Richardson J, Ong B. Perceptions of joint pain and feeling well in older people who reported to be healthy: a qualitative study. *Br J Gen Pract* 2010;60:597–603.
41. Gjørup T, Hendriksen C, Lund E, Strømgard E. Is growing old a disease? A study of the attitudes of elderly people to physical symptoms. *J Chronic Dis* 1987;40:1095–8.
42. Morgan R, Pendleton N, Clague JE, Horan MA. Older people's perceptions about symptoms. *Br J Gen Pract* 1997;47:427–30.
43. Segall A, Chappell NL. Making sense out of sickness: lay explanations of chronic illness among older adults. In: Albrecht G, Levy J, eds. *Advances in medical sociology*. Greenwich, Connecticut: JAI Press; 1991:115–33.
44. Hill S, Dziedzic K, Thomas E, et al. The illness perceptions associated with health and behavioural outcomes in people with musculoskeletal hand problems: findings from the North Staffordshire Osteoarthritis project. *Rheumatology* 2007;46:944–51.
45. Turner JA, Ersek M, Kemp C. Self efficacy for managing pain is associated with disability depression and pain coping among retirement community residents with chronic pain. *J Pain* 2005;6: 471–9.
46. Jensen MP, Turner JA, Romano JM. Changes after multidisciplinary pain treatment in patients pain beliefs and coping are associated with concurrent changes in patient functioning. *Pain* 2007;131: 38–47.
47. Pells JJ, Pells JJ, Shelby RA, et al. Arthritis self efficacy and self efficacy for resisting eating: relationship to pain, disability, and eating behaviour in overweight and obese individuals with osteoarthritic knee pain. *Pain* 2008;136:340–7.
48. Sanders C, Donovan J, Dieppe P. The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies. *Social Health Ill* 2002;24:227–53.
49. Sale JEM, Gignac M, Hawker G. How 'bad' does the pain have to be? A qualitative study examining adherence to pain medication in older adults with osteoarthritis. *Arthritis Rheum* 2006; 55:272–8.
50. NHS (2011). Available from: <http://www.nhs.uk/Conditions/Osteoarthritis/Pages/treatment.aspx> [last assessed 1 Nov 2011].
51. Jordan KM, Arden NK, Doherty M, et al. EULAR Recommendations 2003: an evidence based approach to the management of knee osteoarthritis: report of a Task Force of the Standing Committee for International Clinical Studies Including Therapeutic Trials (ESCISIT). *Ann Rheum Dis* 2003;62: 1145–55.
52. Daltroy LH, Morlino CI, Eaton HM, et al. Preoperative education for total hip and knee replacement patients. *Arthritis Care Res* 1998;11: 469–78.

## Appendix

### Interview schedule for semi-structured interview

- Can you please, tell me what is your understanding of arthritis? What does it mean for you?
- What impact has arthritis on your everyday life? Can you give me an example?
- How do you feel about that?
- How much are you bothered by pain? Can you give me an example?
- Can you please, describe how your pain feels? (If any) . . . When is it more likely that you would experience arthritis pain?
- Are there any times that you are pain free? Can you talk a bit more about this?
- Do you have any ideas in terms of what is causing you pain?/What caused you arthritis?
- Can you please, describe how your condition has progressed over time?
- Can you please, describe the effect that treatment had on your condition?
- Can you please, talk to me about what you expect from medical care for your pain/arthritis?
- Can you please, tell me what makes you satisfied with the treatment you receive?
- Can you please, tell me what makes you dissatisfied with treatment you receive?
- How would you summarise you experience of living with arthritis?