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Title: A qualitative evidence synthesis using meta-ethnography to understand the experience of living with osteoarthritis pain

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Introduction

Osteoarthritis pain affects the lives of many people around the world. It is a long-term chronic disease that is one of the most prevalent, disabling joint disorders. It is characterised by the deterioration of cartilage in joints which results in joint damage causing stiffness, pain, and impaired movement [43]. Osteoarthritis most commonly affects the joints in the knees, hands, feet, and spine and is relatively common in shoulder and hip joints. The incidence of OA increases with age, and women have higher rates than men, especially after age 50. The incidence plateaus or decreases in incidence for all joint sites around the age of 80 [85]. The Global Burden of Disease systematic reviews, conducted by the World Health Organization in 2010 and 2017, have estimated the incidence, prevalence, and disability associated with osteoarthritis in global regions and individual countries [86], suggesting that it accounts for 6.8% of disability adjusted life years and a prevalence of 10-20% in adults over 60 years.

Understanding people's experience of osteoarthritis is integral to effective care and qualitative research can have an important part to play in education and good clinical practice. There is a large body of qualitative research which explores the experience of osteoarthritis, and no comprehensive synthesis of this work. We aimed to systematically search for, identify, and synthesise qualitative research exploring the experience of living with osteoarthritis in order to incorporate this knowledge into an educational resource. The findings from this study will contribute to a short film about the experience of osteoarthritis and supporting material for clinical education.

Methods

Ethics: Ethical permissions were not required for this study as it is an evidence synthesis of published studies.

Patient and Public Involvement: in line with guidance from the National Institute of Health Research (UK) who support the involvement of patient partners in research (<https://www.invo.org.uk/>), we identified four partners to work with us on analysing themes and advising on dissemination of study findings.

We used the methods of meta-ethnography refined by Toye and colleagues, which have been used to synthesise a large number of qualitative studies in areas such as chronic pain and ageing [150-152]. We used the four domains of the GRADE-CERQual framework [84] to encourage reflection on: (1) methodological limitations, (2) relevance, (3) *adequacy* of data ('richness and quantity of data'), and (4) *coherence* ('consistency across studies'). It is currently the only framework of its kind, designed to provide guidance for assessing how much confidence to place in findings from QES. We used the recent guidelines for reporting meta-ethnography (eMERGe) which report recommendations, guidance, and good practice for conducting meta-ethnography [52].

Stage 1: Selecting meta-ethnography and getting started

Stage one involves developing the rationale and study objectives. First, to identify a need for a qualitative evidence synthesis (QES), we searched for existing reviews that aimed to explore the experience of living with osteoarthritis using the search terms shown in table 1. We identified six potential reviews [29; 37; 136; 137; 158; 165]: three reviews synthesised findings about the experience of living with osteoarthritis and included between 9-33 qualitative studies each [136; 137; 165]; two reviews included different types of arthritis [37] or the experience of carers[158]; one review presented a discourse analysis developed from primary data [29]. As our scoping review had highlighted a larger body of potential studies to synthesise, we (and our funders) concluded that the aim to undertake a comprehensive search and conceptual synthesis of qualitative research to explore the experience of living with osteoarthritis was 'worthy of the research effort'[112].

There are different methods suggested for synthesising qualitative research[51]: some aim to aggregate and summarise findings, whereas others, like meta-ethnography, aim to build on existing ideas [152]. A conceptual approach to QES is underpinned by a dialectic form of knowing where innovative ideas can develop by comparing similarities and differences across studies[51]. This comparative process allows the QES reviewer to develop new ideas. What distinguishes meta-ethnography from thematic analysis is that it goes a step further in order to pull findings together into a "story line" or "conceptual model" [112]. This is then reported as a written summary, or diagrammatically.

Stage 2: Deciding what is relevant

We included qualitative studies that explored adults' experience of living with osteoarthritis. We used thesaurus and free text terms for qualitative research, combined with thesaurus and free text terms. Table 1 reports the elements of STARLITE which outlines the standards recommended for reporting systematic searches of qualitative research [20]. One reviewer with more than 20 years of qualitative research experience screened titles and abstracts for relevance. Two reviewers

appraised full texts using the Critical Appraisal Skills Programme (CASP) questions for qualitative research [33]. The aim of this process was to identify and exclude any studies that we felt were “fatally flawed” or “irrelevant”, and to ensure that studies were at least “satisfactory”[48].

Stages 3 and 4: Reading studies and determining how studies are related

We uploaded manuscripts onto Nvivo 12 qualitative research analysis software to allow us to keep track of developing ideas. One reviewer read all studies in alphabetical order, by author. We extracted contextual information from each study to allow us to determine relevance and transferability across contexts.

Stages 5: Translating studies

The data for QES are the findings or “results” reported in the primary study. The first reviewer wrote a summary of each finding in order to capture its essence, or *essentialise*, its meaning. This reviewer then “coded” these summaries, using Nvivo software to facilitate and keep track of notes on developing ideas. Coding is a process that refines the essential meaning of data using a word or short phrase. The process of “translation” involves comparing codes across studies and sorting codes into provisional themes that make sense of the data. This process, integral to qualitative analysis, is underpinned by a dialectic view of knowledge. Dialectic reasoning aims to “define”, “discriminate”, and develop ideas through reasoned dialogue and interpretation. Similarly, in qualitative research, it is through a process of comparing similarity and difference that existing ideas “dissolve” and are “translated” into new ones [dialectic: Oxford English Dictionary]. At incremental stages the review team discussed and refined provisional themes until they **determined** the final themes. The aim of this is to develop ideas rather than to agree on a *true* version. We discussed the themes with four PPI representatives and made adaptations in line with their suggestions and ideas. To do this, one researcher discussed the findings with each PPI member individually via Microsoft Teams.

Stages 6 & 7: Synthesising translations and expressing the synthesis

Once refined, we further abstracted the themes into a diagrammatic conceptual model in order to distil the key elements. This visual aid is co-produced by researchers and PPI members through a process of comparison, thinking and dialogue: multiple draft versions of a model are made before reaching a final agreement on a diagram that synthesises findings into a whole. This process is iterative and occurs during the final weeks of the study. PPI members commented on the diagram and made comments and adjustments to the model via Microsoft Teams meetings.

Results

A summary of studies identified, screened and included is shown in an adapted PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) flow diagram [117] (figure 1). We screened 10123 titles, 548 abstracts, and 139 full texts. We excluded eight full texts on the basis of relevance [6; 15; 30; 42; 60; 108; 124; 159], and **thirteen** where we were unable to extract a coherent research finding [18; 22; 65; 68; 80; 94; 115; 118; 121; 138; 141; 161; 166]. We included findings from **118** reports (105 unique samples) published between 1998 and 2021 [1-5; 7; 9; 11-14; 16; 17; 19; 21; 23-28; 32; 34; 35; 38; 40; 41; 44-47; 49; 50; 53-59; 61; 63; 64; 66; 67; 69-79; 81-83; 87-93; 95-102; 104-106; 109-111; 113; 114; 116; 119; 120; 122; 123; 125-131; 133-135; 142-148; 153-157; 160; 162-164; 167-171]. Table 2 shows the author, year of publication, country, condition, number of participants and age. The large majority of studies explored the experience of knee and hip osteoarthritis, and 30 of these specifically aimed to understand decision making for hip or knee joint replacement surgery. The **118** studies incorporated the experience of at least **2534 people (at least 1650 female)** from around the world, although predominantly from high income countries, with 89% of studies from UK (n=30), Canada (n=21), USA (18) and Australia (n- 12) (Table 2). **Geographically, most studies were from four continents: Europe (n= 46), North America (n = 42), Australasia (17), Asia (11), with a single study from Africa, and one mixed study including participants from Europe, North America, and Australasia.** Participants' age ranged from 21 to 94 years: 12% of studies included people under the age of 40 years old; 67% included people over the age of 50 years; 5% included people over the age of 69 years.

The **118** studies reported more than 600 findings which were organised into 21 provisional themes (supplementary material) and further refined into 7 final themes (Figure 2). Table 3 lists the studies supporting each theme. We report each theme illustrated with narrative from the primary studies. Figure 3 shows the final conceptual model or "line of argument".

It is part of my life's tapestry

This theme describes osteoarthritis as integral to self: an inevitable consequence of being human, living and working. There was a sense that osteoarthritis was 'par for the course', meaning that it was a normal and integral part of getting older and bound to personal biography, rather than a disease to be cured. For some, it was described as an inevitable sign of getting old and lost youth.

[It is] wear and tear really isn't it? And probably, all the cleaning that I've done for like the last 18 years can't have helped much can it, so, you know, that's probably why it's come on I don't look at it as an illness or a disease. [59]

Well we do [accept osteoarthritis] it's just par for the course really this arthritis. It's like tennis elbow, you get that in tennis . . . I've played up to being 35-year-old. I was in the game nearly 20 years. When you've played over 600 games it takes its toll. [156]

For some, osteoarthritis was tied up with the experience of a life lived hard and to the full. There was a sense that ways of living took their "toll". Some described activities that they felt contributed, although at the same time questioned whether, in retrospect, they would have (or could have) chosen differently.

I thought possibly it was because I worked too hard in my childhood. Because my family farmed during my childhood, I had to take on the heavy labour tasks and climbing. I thought that possibly it accumulated like this, because the knee can only bear so much.[76]

[Osteoarthritis] is part and parcel of [football]. I really fully enjoyed the games I played, and I wouldn't have missed that for the world . . . many people had said to me, 'well, I wish I had been able to do what you had done—I would have given my right arm for it [156].

Interwoven with the idea that osteoarthritis as "part and parcel of life" was the question of whether it ran in the family, and was it therefore outside your control. As such, some were not surprised to have osteoarthritis and described family members who they remembered.

I wasn't surprised. I knew other people who have got it and saw my own father with it. [157]

Well, I accepted it because my mother was crippled with arthritis and all her side of the family. [157]

(Yet) it is consuming me

This theme describes the unrelenting and emotional impact of living with osteoarthritis pain that threatens a person's integrity. Pain was described as an ever-present entity that consumed and defined a person's very being: it is miserable, excruciating, threatening, and omnipresent; like a "heavy garment that I always have to wear" [10]

The pain is horrific. It's just terrible, I wish someone could . . . I would have it cut off and a false one there if they could. It's horrendous pain, it's terrible. It's driving me round the bend. I'd go for anything to get rid of this pain. [168]

I can't handle this no more . . . Pain is dominant . . . it took over everything. Your brain becomes so taken and your mind, you think pain, you see pain, you feel pain, you LIVE pain. You're just lost. It's constantly your focus in life. [90]

The unrelenting nature of pain was exacerbated by loss of sleep, fatigue, and exhaustion. There was a sense that life was circumscribed by "crippling exhaustion" [149]: an endless cycle of unrefreshing sleep that provided no relief. Day and night seemed to merge into one, and time slowed down. This

exhaustion contributed to low mood, irritability and anger that could overflow into personal, social, and work relationships.

I don't have the energy to do the things that I want to do, let alone the things that need to be done . . . Then I tend to get depressed or upset with myself and then I think it just begets more tiredness and it's a downhill slide. [123]

I'm not able . . . to focus, I'm not able to . . . work . . . that fatigue thing, it is exhaustion . . . you can't put one foot in front of the other anymore, but part of it is the exhaustion of the spirit or the exhaustion of the mind. [123]

It constrains my body and my occupations

This theme describes the profound impact of osteoarthritis on the physical body and a person's engagement in basic, necessary, and meaningful occupations. There was a sense of being let down by your own body which could no longer be relied on for even basic functions.

I'm tired of it . . . I am a very active person. My favourite comment is 'I can't.' I can't take the trash to the street. I can't cut the grass . . . I am a car salesman. I feel like a flat tire, and in my business, you can't have a flat tire. [71]

Every single day my thumb problem impacts on my daily life: biking, driving, twisting tops off jars/bottles, sewing, pincer action between thumb and forefinger, knitting and crocheting, gardening, cleaning, wringing out cloths, housework in general. [24]

For some, personal care became an ordeal which filled time that could be spent more meaningfully, or meant that you had come to rely on others.

When I have taken a shower, I have troubles drying my feet. I can't reach down, and I can hardly manage to put my socks on. I can't care for my toenails -cutting them for example - that is really difficult on this leg. [23]

Going to the toilet . . . Well, I can just about [manage], but it's very awkward . . . I've got to wash myself afterwards to make sure that I'm clean. [67]

Studies described the negative impact of osteoarthritis on looking after house and home. For some, there was profound meaning associated with being able to "keep my house in order" and a feeling of loss or defeat if you could no longer do this without help. For others, this defeat was kept at bay by relying on other people to do the more physically demanding jobs around the house. The insurmountable challenge of preparing meals and caring for others exacerbated the sense of frustration and failure.

It's so frustrating . . . I can't keep the house up the way I used to, I mean, there's a lot of things that's not being done like it used to be . . . I'll probably get used to it . . . but right now, it's so new and . . . I can't really quite handle it. [169]

I have to sort of drag my legs when I have to do something. Like sweeping . . . and it's difficult you know . . . 'You may be poor', my father used to say, 'but you don't need to be untidy'. That's what I always remember. It's a really a struggle for me. [40]

The sense of meaningful occupation was linked to a person's capacity to remain mobile and to get out of the house. Studies described loss of physical mobility, and a life more sedentary and geographically restricted. This loss of mobility had an impact on travel, sport and personal leisure, and for some, the joy and fun in life was now restricted.

That's the main thing, your lack of mobility. I mean we're both keen dancers and that's gone by the board now, we can't even do a slow waltz round the flipping 10 by 10 floor space. [156]

You no longer walk around [on the golf course] enjoying yourselves and having a laugh. Now it is just talking a little – I liked the other way better. We were a group of six men who often went skiing together . . . I can't do that anymore either. Skiing is another leisure activity that has gone [25]

Finally, the challenge of keeping in paid employment could have a significant impact on family income and on a person's sense of self. There was a sense that work was *more than* just being able to provide an income: being employed provided as sense of being valued by others and was integral to self-value.

The problem I have is, if I do not work, who will pay my bills? . . . And if I do not work . . . even if I have to drag my little leg, I'm going to work! Where am I going to [get] income for my household? [54]

You had to let part of your identity go when you had to [stop work] . . . It was almost like a process of grief, having to reduce my position.[148]

I am becoming separated, yet dependent

This theme describes the effect of osteoarthritis on a person's place in the world in relation to other people. It is underpinned by a paradoxical sense of becoming distanced from others, yet at the same becoming dependent on others. Pain and reduced mobility reduced opportunities to interact, and the motivation to overcome the challenges to get out dwindled. Studies described the experience of "living life on the side-lines" at a distance from others [79].

Sometimes I don't manage to keep up with the family; then I have to sit on some bench and tell the rest of the family that they can go into that shop . . . it shouldn't be like that. I think, 'you're going to have to sit like a pensioner on the bench. No! [120]

I did fall out with my daughter-in-law because I didn't want to go, it was the wedding of my granddaughter . . . I don't want to go with arthritis. I'm getting like that now, that's how I feel . . . Leave me alone, that's how I feel [129].

Some described loss of valued roles, altered relationships, and the fear of becoming a burden. There was a sense that reliance on others threatened a person's integrity and left them feeling useless and demoralised. Accepting help was framed as "giving up", and holding on to independence as integral to self-worth.

When you're used to being the caregiver, that's hard, having somebody take care of you. . . I went to the bathroom and I made a mess and I couldn't clean it up. . . I asked him to just leave the room and . . . I put the pillow over my head and I cried. [71]

(My 8-year-old son) is aware, I don't ask him. He just does it. He'll say pass me your socks and he puts them on. I used to dress him, now he is dressing me. We laugh about it now. But it upsets me. I am only 48, I feel like 98. [97]

I have a 19-year-old disabled son whom I used to take care of; now I sit helpless beside him; now we are both disabled. [3]

For some, the impact of osteoarthritis on intimate relationships made them feel sad and disconnected. This loss was exacerbated by a sense that others did not think that people with osteoarthritis (in particular older people) were interested in intimacy and sex.

Perhaps it's because many of us who have osteoarthritis are elderly and then maybe society de-emphasizes sexuality for the elderly, without asking, so to speak. [110]

I am 40 years old . . . it has been since two years that, that I cannot go and run into the forest . . . to go and pick mushrooms, or hike into the mountains. Even with my wife, it is not easy in bed; I cannot do all these things anymore.[46]

I accept, but will not let it define me

This theme describes how, although reluctantly accepting osteoarthritis, "I will not let it beat me".

There was a latent sense of a moral obligation to live well with osteoarthritis and to learn to live with it.

It must have something to do with the way that I was brought up . . . you don't just mire in self-pity. You can't do that . . . life is for living. I just have this really strong feeling about it, and I'm not going to bask in self-pity. [169]

It's tolerable. You learn to live with it. I'm not crippled . . . it just hurts to walk . . . Then the other knee starts acting up. It's a losing battle (laughter). But you have to be tolerant. [128]

Some described themselves as "lucky" that osteoarthritis is not as serious as other things (like cancer or heart disease), and other people as less fortunate.

I think of my sister with losing a breast, and how much she must be going through, and I complain about my knees? . . . There are so many worse things than I have. Yeah, but I can put up with a little bit of pain and hurt. [90]

You see others that hardly walk at all and you think well there for the grace of God go I . . . You just make the best of a bad thing. I say, at least I've got two legs . . . even though they might not be as new as when I first got them. [156]

Participants described themselves as stoical, strong and resilient, having been “brought up” to face adversity and get on with things, rather than giving in. This was underpinned by a sense of pragmatism whereby a person should adapt, embrace change, and adjust their expectations to be more realistic.

I come from a long line of strong women. Yeah, I think that has everything to do with it, everything to do with the way I was brought up . . . The women run everything in my family, not the men. We just put up with it. [95]

I think I'm a survivor. I've, I have come through a very good marriage and a sad marriage and I've lost my parents um and I've always moved forward . . . It never occurred to me to give up and I think it's the genes. [64]

Studies described efforts to hold onto a sense of self by finding new things to be passionate about and by holding on to an attitude of growth, learning, and curiosity.

There's more in life than just pain. I mean you get up in the morning and you can see the sun and the beautiful world and hear the birds sing . . . How could I ask for any more than that? [169]

I think you don't know what's in you until you are solely tested, that's what I tell my kids, we don't know what strengths we have and it's easy when you're cruising along but that's when you find out who you really are and how you grow I think. [64]

(Yet) this makes me feel less than the person I was

This theme describes a feeling that, despite the battle to hold onto my sense of self, I am turning into someone that I do not recognise or value. This hinged around a sense of becoming “old”, or “old before my time”.

It is tied up with me getting older . . . It's more than just the pain, it's the notification that I'm starting to get to be an older person . . . it's a kind of a holistic thing. It's the whole identify of myself . . . I'm turning into an older person. [24].

You feel a bit diminished as a person. I feel I've turned into a little old lady overnight. It takes away part of your identity, part of your personality, part of the person you used to be. [67]

Studies described the experience of feeling degraded, embarrassed, and self-conscious about physical changes and impairments associated with osteoarthritis. Some tried to present a more positive self-image by keeping quiet about it. This sense of embarrassment was exacerbated by the stigma of becoming “old”. Some felt that because osteoarthritis was conflated with old age, they were not seen as legitimately “ill” by others.

This (wheelchair) is awful! I don't accept it . . . I don't want to go out with that. Maybe it is misplaced pride but it downgrades you. People stare at you and that annoys me . . . people immediately look at you.[4]

I'm struggling with admitting it . . . other people would . . . say 'oh, what have you got bars in the toilet for', I just . . . don't know if I can get past that mentally at the moment . . . this is an emotional acceptance of something that I just don't want to accept. [155]

For some, the sense that I am no longer the person that I once was came with profound personal loss. There was a sense of desperation and impending doom: a vision of a world with little joy or hope.

Pain grinds you down and gives you that low self-esteem and no self-confidence. You can see other people your age doing things but you're not able to. It wears you down mentally . . . it's not just physical, it very much affects you mentally. [168]

I was like the leader, and then the handbrakes because they were slower than me; now I'm the handbrake. I'm just useless, just because of a daft [joint . . . It makes me feel as if I'm good for nothing, I might as well just turn it in. [168]

Please don't treat it as a trivial matter

The final theme describes the experience of being treated by others (including health professionals) as if osteoarthritis was not important. It is underpinned by a sense that because osteoarthritis is seen as either inevitable, or untreatable, that this is conflated with being unimportant, or trivial.

It's one of those things they can't do much about so they don't want to deal with it . . . there are other more important things . . . I don't know, I just feel it's not that important to him. [14]

I believe there is a hierarchy – a status related to different diseases . . . in the health care system, yeah? When I got cancer, I was sort of at the top of the pyramid. [23]

There is a sense that being taken seriously as a fellow human being with a “real” problem would alleviate the suffering of osteoarthritis.

[health professionals] are fatalists: they say that osteoarthritis is normal and that there is nothing to do. It shows clearly that physicians have a fatalistic attitude towards osteoarthritis that they are not concerned. [5]

This is my first appointment, listen to me; this is my tenth appointment, listen to me; I don't know how to express my needs, listen to me; the treatment isn't working, listen to me; I am having trouble sitting for long periods, listen to me; what should I do next, listen to me. [101]

However, experience of health professionals was variable, and some described positive examples of individual health professionals who had treated them with generosity and kindness.

The doctor was so good, he said: '... you are welcome to call me and I will try to help ... how nice, I said. Just to know that, such a nice doctor. How incredible that he listens and is interested in me. It is important to sense that. [134]

My doctor, he sorts out everything! He is really competent. He is kind and he has a real sense of humour. I do appreciate him a lot, because he is really human ... I am really pleased with him. [5]

Conceptual model

We developed a conceptual model from the final themes that can help us to understand the experience of living with osteoarthritis. Overarching the experience of living with osteoarthritis we see the person fighting to hold onto a sense of self. Our model incorporates the following tensions: (1) osteoarthritis is integral to my life story, yet at the same time it threatens my integrity (it consumes, it constrains, it separates, and it increases my dependency on others) (2). Whilst struggling to not be defined by osteoarthritis, at the same time I find that I am defined and diminished by it (it degrades me, and I feel self-conscious); (3) although osteoarthritis is an inevitable consequence of who I am and the life that I have lived inevitable should not be conflated with trivial. As such, there is an underlying sense that my suffering can be reduced if others, particularly those in health care, hear and recognise my losses: please don't treat this as a trivial matter.

Discussion

The innovation of our study is to provide a conceptual synthesis, drawn from 118 studies around the world that can help us to understand the experience of people living with painful osteoarthritis. Central to the experience is a threatened sense of self and a fight to hold onto a meaningful life.

Our findings resonate with reviews of qualitative research that highlight the profound and negative impact of osteoarthritis on people's lives [37; 136; 158; 165]. We highlight the paradox of increasing dependency alongside decreasing connection, and that a person's sense of self is inextricably linked to their place within a community. Our findings also resonate with reviews suggesting that people with osteoarthritis feel a sense of shame because of the association of osteoarthritis with getting

“old” and the stigma of ageing [136]. For example, Smith and colleagues suggest that some people pretend that nothing has changed, in order avoid negative judgements [136].

Our findings highlight the social value placed on not being “defeated” by osteoarthritis [136] and a social discourse of “healthy ageing” [29] which is underpinned by a *morally right*, and socially expected, way to be ill. Although we recognise that facing the world with a positive frame of mind is linked to health and well-being, our findings suggest that people with osteoarthritis may experience a moral obligation to face illness stoically and positively. A social discourse which demands that people perform *as if* they are “well”, when they are “unwell”, might encourage people to not complain, or not to seek care. It may be useful for health professionals to work with people with painful arthritis to resolve the tension between aligning a positive self-image (and “not complaining”) with the need for help.

Our finding that osteoarthritis is experienced as an inevitable part of living and ageing resonates with the discourse of “the body as a machine” [29]. Similarly, Chen and colleagues describe a sense of inevitability which can mean that arthritis pain is normalised, ignored or unrecognised by health professionals [37]. This conflation between “normal or inevitable”, with “unimportant or trivial” can be a “lonely path” for those with painful osteoarthritis [37]. Although reviews show that relationships with health professionals can vary, [158] they indicate that encounters where the professional hears, plays attention, and offers information and guidance about osteoarthritis can empower and reduce suffering: whereas encounters where a person is left feeling that osteoarthritis is inevitable, unimportant, insignificant, or that nothing can be done can disempower and increase suffering [137].

Qualitative research is traditionally underpinned by an *epistemology*, or way of knowing the world, that focuses on unique and idiographic experiences. As such, a methodology that synthesises primary findings could be criticised for removing us from the context, and of being an interpretation [132]. We take the position (underpinning *all* form of QES) that by comparing unique examples, QES can generate ideas that are usefully transferable beyond the unique context. Visual representations of findings add another layer of abstraction, and Lewin and colleagues recognise that GRADE-CERQual is not designed to evaluate these more conceptual findings [84].

Language translation adds yet another layer of interpretation which can raise “formidable methodological challenges” [139; 140]. Meaning is not something that straightforwardly transfers from one person to another, and all language requires interpretation. Although the studies included were undertaken in different languages, the authors did not consistently report methodological aspects relating to translation, such as who translated and at what stage translation occurred. Nasri

and colleagues highlight reporting inconsistencies related to cross-language studies and make reporting recommendations[103]: For example: are we using a qualified translator or fluent speaker to ensure “conceptual equivalence”; have we described the research setting and positionality of research team (for example, gender and ethnicity) and discussed the limitations of “socio-cultural matching”. Future studies should consider and address the issue of translation in qualitative research and how this may limit interpretations.

The GRADE-CERQual framework [84] encourages QES reviewers to report a summary of *methodological limitation*, *relevance*, *adequacy* (‘richness and quantity of data’), and *coherence* (‘consistency across studies’) and although this is a useful framework, there are some things to be considered. First (methodological limitations): it is useful to recognise that the influence of any qualitative study included in a conceptual QES hinges on the power of its ideas, and that weaker studies make minimal contribution and therefore “do no harm” [31]. As such, not all reviewers quality appraise to determine inclusion in a QES [62]. It may be that research time is better spent simply deciding if a study is “satisfactory” [48], with a low threshold for inclusion. Second (relevance): the guidance suggests that we distinguish between levels of relevance (directly, partially, indirectly, or not). However, as qualitative research is drawn from a small sample within a unique context, you could argue that each qualitative study is only ever *partially relevant* and the purpose of QES is to extrapolate the essence of ideas across a collection of unique contexts. Third (adequacy): Although we report the number of studies supporting each finding as a proxy for adequacy this tally is somewhat misleading and does not align well with an *interpretive* epistemology. In particular, a tally gives equal weight to each study and implies that more studies necessarily mean that a finding is more “true” [107]. Fourth (coherence): this refers to the consistency of an idea across studies. Again, although we have reported the number of studies as a proxy for coherence, this does not support the dialectic way in which we propose that ideas develop.

Qualitative research is *idiographic*, meaning that its focus is on unique contextual experience, and we recognize that the nuances within studies are (necessarily) sacrificed in the abstraction of ideas across studies. However, we feel that this can be framed as a weakness or a strength of QES which aims to abstract ideas that can be useful for healthcare improvement. **The GRADE-CerQual framework is useful for framing confidence in review finding. However, it is important to acknowledge that the framework is embedded in an interpretive epistemology and its intention is to develop understanding, rather than make “truth” claims. Future QES reviewers might consider the concepts of adequacy in relation to current debates about data saturation in qualitative research**

[39; 107]. It might also be useful to frame “low confidence” as highlighting under-researched or marginalised experiences that challenge given knowledge, and which might direct future research efforts.

The innovation of our study is to synthesise 118 qualitative studies. We only identified one study from Africa, and eleven from Asia (the continent with the largest population): we did not identify a single study from South American. Future studies focusing on the experience of osteoarthritis in a range of socio-economic, geographic, and cultural contexts would contribute to our understanding. Similarly, most studies explored the experience of knee and hip osteoarthritis, and further qualitative research might build on this knowledge by focusing on osteoarthritis affecting other joints, or multiple joints. For example, there were only eight studies exploring the experience of hand osteoarthritis, and although the final themes were drawn from these eight studies, nuanced differences are likely. Future studies could use the findings from this QES as a framework to explore the experience in other samples. This framework approach has been used in a primary study of living beyond the age of [151]. Similarly, studies exploring the relevance of these findings in specific groups, such as minoritised populations, specific age groups, or social contexts might increase our understanding of what it means to live with osteoarthritis, and therefore contribute to improvements in healthcare.

Our findings highlight that, for some, osteoarthritis is framed as part and parcel of life. However, this does not negate the profound impact that osteoarthritis can have on people’s lives and their sense of self. Findings highlight the unrelenting and emotional impact of pain (“like a heavy garment”) which can constrain meaningful occupations, social roles, personal relationship, and working lives. Our conceptual model illustrates the tension between holding onto a sense of self, yet at the same time accepting changes to self. For some, life becomes deplete of joy and hope for the future. There are some important implications for clinical practice: inevitable, or untreatable, should not be conflated with being unimportant, or trivial: (2) being taken seriously as a fellow human being with a real problem can alleviate the suffering of osteoarthritis even if we have no treatment to offer. Charon highlights that in modern medical practice, “The impulse to roll up our sleeves and do something is irresistible” and that other aspects of caring, such as hearing and treating others with generosity, can be side-lined [36]. Listening and hearing is integral to the effective treatment of osteoarthritis pain: “this is my first appointment, listen to me; this is my tenth appointment, listen to me” [49]. These findings have an implication for pain education and practice that may be transferable to other health conditions.

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Conflict of interest statement

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Figure legends.

Figure 1: Search Flow diagram: This adapted PRISMA flow diagram [112] shows the number of studies identified, screened, and included in this QES.

Figure 2: Provisional themes organised into final themes: this shows 21 provisional themes distilled into the final 7 themes

Figure 3: Conceptual model: this illustrates the final analytical stage of meta-ethnography where the themes are organised into a conceptual model.

Table 2: Descriptive details of included studies:

Author (year of publication), country, condition/topic, number of participants (number of women)
age range (mean age)

AUTHOR (YEAR)	COUNTRY	BODY PART/CONTEXT	NUMBER (WOMEN)	AGE RANGE (OR MEAN)
ACKERMAN, LIVINGSTON, & OSBORNE 2016 [1]	AUSTRALIA	KNEE/HIP	33 (21)	58–71
AGALLOTIS ET AL. 2018 [2]	AUSTRALIA	KNEE	11 (7)	51–77
ALAMI ET AL. 2011[5]	FRANCE	KNEE	81 (59)	nk
ALI, WALSH & KLOSECK 2018 [7]	CANADA	MIXED	20 (16)	67-83
AL-KHLAIFAT ET AL. 2020[4]	JORDAN	KNEE	14 (13)	43-77
AL-TAIAR ET AL. 20132013[3]	KUWAIT	DM: KNEE	39 (39)	(63)
BAIRD 2000 [9]	USA	MIXED	18 (18)	65-92
BAIRD 2003[11]	USA	MIXED	5 (5)	72-91
BAIRD, YEHLE, & SCHMEISER 2007[12]	USA	MIXED	23 (23)	73-94
BALLANTYNE, GIGNAC & HAWKER 2007[13]	CANADA	DM: KNEE/HIP	29 (nk)	59-86
BARBER ET AL. 2019[14]	CANADA	KNEE	5 (3)	57-72
BARLOW ET AL. 2018[16]	UK	DM: KNEE	22 (10)	57-82
BOOKER & HERR 2021 [17] ^a	USA	MIXED	18 (9)	(68)
BOOKER, HERR & TRIPP-REIMER 2019[19] ^a	USA	MIXED	18 (9)	(68)
BOWER ET AL. 2006[21]	CANADA	MIXED	9 (nk)	nk
BREMBO ET AL. 2016[23]	NORWAY	HIP	13 (7)	59-88
BÜHLER ET AL. 2021[24]	NEW ZEALAND	HAND (THUMB)	30 (19)	(65)
BUKHAVE & HUNICHE 2014[26] ^b	DENMARK	HAND	34 (30)	38-89
BUKHAVE, LA COUR & LOTTE HUNICHE 2014[25] ^b	DENMARK	HAND	31 (29)	38-89
BUNZLI ET AL. 2019[27]	AUSTRALIA	DM: KNEE	20 (10)	(72)
BUNZLI ET AL. 2020[28]	AUSTRALIA	DM: KNEE	27 (13)	(67)
CARMONA-TERÉS ET AL. 2017[32]	SPAIN	KNEE	10 (7)	58-85
CEDRASCHI ET AL. 2013[34]	FRANCE	KNEE/HIP/HAND	14 (10)	40-75
CHAN & CHAN 2011[35]	HONG KONG	KNEE	20 (15)	(58)
CLARK ET AL. 2004[38] ^c	CANADA	DM: KNEE/HIP	17 (9)	59-81
COETZEE, GILJAM-ENRIGHT & MORRIS 2019[40]	SOUTH AFRICA	KNEE	18 (15)	49-84
CONNER-SPADY ET AL. 2014[41]	CANADA	DM: KNEE/HIP	65 (43)	28-89
DAMAR & BILIK 2017[44]	TURKEY	DM: KNEE	17 (16)	(68)
DARLOW ET AL. 2018[45]	NEW ZEALAND	KNEE	13 (7)	50-84
DEMIERRE, CASTELAO, & PIOT-ZIEGLER 2011[46]	SWITZERLAND	DM: KNEE/HIP	24 (15)	(60)
DICKSON & KIM 2003[47]	USA (KOREAN)	MIXED	7 (7)	63-80
DOSANJH, MATTA, & BHANDARI 2009[49]	USA	DM: HIP	18 (8)	52-79
FIGARO, WILLIAMS RUSSO, & ALLEGIANTE 2004[50]	USA	DM: KNEE/HIP	94 (79)	50-89
FRANKEL ET AL. 2012[53]	CANADA	DM: KNEE/HIP	58 (46)	(72)
GASKIN ET AL. 2020[54]	USA	KNEE (PAIN)	21 (21)	45-nk
GIBBS & KLINGER 2011[55]	CANADA	KNEE/HIP	11 (11)	60-75
GIGNAC ET AL. 2006[56]	CANADA	MIXED	90 (53)	39-88
GOOBERMAN-HILL ET AL. 2010 [57] ^d	UK	DM: KNEE/HIP	26 (14)	46-86

GOOBERMAN-HILL ET AL. 2007 [58]	UK	KNEE/HIP	28 (14)	57-89
GRIME, RICHARDSON & ONG 2010[59]	UK	MIXED (PAIN)	27 (15)	56-87
HALL ET AL. 2008[61]	CANADA	KNEE	15 (5)	52-80
HARRIS ET AL. 2015[63] ^e	AUSTRALIA	MIXED	19 (19)	(63)
HARRIS ET AL. 2016[64] ^e	AUSTRALIA	MIXED	19 (19)	(63)
HILL, DZIEDZIC & ONG 2011[66] ^f	UK	HAND	29 (25)	50-84
HILL, DZIEDZIC & ONG 2010[67] ^f	UK	HAND	29 (25)	50-84
HSU ET AL. 2018[69]	CHINA	DM: KNEE	79 (59)	60-87
HUDAK ET AL. 2002[70] ^c	CANADA	DM: KNEE/HIP	17 (9)	59-81
JACOBSON ET AL. 2008[71]	USA	DM: KNEE	27 (14)	45-83
JINKS, ONG & O'NEILL 2010 [72]	UK	KNEE	28 (8)	53-86
JOHNSON, HORWOORD, & GOOBERMAN-HILL 2014[73]	UK	HIP	24 (11)	52-82
JOLLY ET AL. 2017[74]	NEW ZEALAND	KNEE/HIP	23 (20)	52-86
KAMSAN ET AL. 2020[75]	MALAYSIA	KNEE	16 (13)	61-89
KAO & TSAI 2012[76] ^g	CHINA	KNEE	17 (14)	40-55
KAO & TSAI 2014[77] ^g	CHINA	KNEE	17 (15)	40-55
KEE 1998[78]	USA	MIXED	20 (17)	62-92
KEYSOR, SPARLING AND RIEGGER-KRUGH 1998[79]	USA	KNEE	4 (3)	25-43
KROLL ET AL. 2007[81] ^h	USA	DM: KNEE	37 (23)	(64)
LARSSON ET AL. 2020[82]	SWEDEN	HAND (WRIST)	13 (5)	38-75
LEOV ET AL. 2017[83]	NEW ZEALAND	DM: KNEE/HIP	20 (12)	55-82
MACKAY ET AL. 2014[87] ⁱ	CANADA	KNEE	41 (26)	35-65
MACKAY ET AL. 2016[88] ⁱ	CANADA	KNEE	41 (26)	35-65
MALY & COTT 2009[89]	CANADA	KNEE	26 (15)	41-65
MALY & KRUPA 2007[90]	CANADA	KNEE	3 (2)	62-87
MAN ET AL. 2017[91]	CANADA	KNEE	8 (4)	46-80
MANN & GOOBERMAN-HILL 2011[92]	UK	KNEE/HIP	16 (9)	56-81
MARTIN ET AL. 2012[93]	USA	MIXED	37 (31)	50-90
MCGRUER ET AL. 2019[95]	NEW ZEALAND	KNEE/HIP	7 (7)	44-71
MCHUGH & LUKER 2009[96]	UK	DM: KNEE/HIP	27 (18)	49-89
MCHUGH, SILMAN & LUKER 2007[97]	UK	KNEE/HIP	21 (16)	48-86
MIKHAIL ET AL. 2007[98]	AUSTRALIA	KNEE/HIP/HAND	20 (10)	54-85
MILDER ET AL. 2011[99] ^j	AUSTRALIA	MIXED	15 (8)	nk
MILDER ET AL. 2011[100] ^j	AUSTRALIA	MIXED	15 (8)	nk
MILLER ET AL. 2016[101]	CANADA	MIXED	25 (17)	nk
MILLER, OSMAN & MANWELL 2020[102]	USA	KNEE/HIP	11 (7)	(69)
MORDEN, JINKS, & ONG 2014[104] ^k	UK	KNEE	22 (13)	56-90
MORDEN, JINKS, & ONG 2017[105] ^k	UK	KNEE	22 (13)	56-90
MORDEN, JINKS, & ONG 2011[106] ^k	UK	KNEE	22 (13)	56-90
NASCIMBEN ET AL. 2019[109]	DOMINICAN REPUBLIC	KNEE/HIP	17 (15)	32-86
NILSING-STRID & EKELIUS HAMPING 2020[110]	SWEDEN	KNEE/HIP	20 (13)	52-77

NIU ET AL. 2011[111]	DOMINICAN REPUBLIC	KNEE/HIP	18 (13)	21-80
NYVANG, HEDSTRÖM, & GLEISSMA 2016[113]	SWEDEN	KNEE	12 (7)	47-77
O'BRIEN ET AL. 2019[114]	AUSTRALIA	DM: KNEE	27 (13)	52-80
ONG & JINKS 2006[116]	UK	KNEE	10 (nk)	nk
PARKS ET AL. 2014[119]	USA	DM: KNEE/HIP	36 (29)	(68)
PARSONS, GODFREY, & JESTER 2009[120]	UK	KNEE/HIP	6 (3)	60-76
POULI ET AL. 2014[122]	UK	KNEE	24 (17)	48-84
POWER ET AL. 2008[123]	CANADA	KNEE/HIP	46 (28)	56-88
PROFFITT, ABRAHAM, & HUGHES 2019[125]	USA	HAND OA/RA	4 (4)	62-74
RICHARDSON, GRIME & ONG 2014[126]	UK	MIXED	27 (nk)	55-90
ROSEMANN ET AL. 2006[127]	GERMANY	MIXED	20 (12)	40-78
SALE, GIGNAC & HAWKER 2006[128]	CANADA	KNEE/HIP	10 (10)	67-92
SANDERS, DONOVAN & DIEPPE 2002[129] ^l	UK	KNEE/HIP	27 (17)	51-91
SANDERS, DONOVAN, & DIEPPE 2004[130] ^l	UK	DM: KNEE/HIP	27 (17)	51-91
SANSOM ET AL. 2010[131] ^d	UK	DM: KNEE/HIP	26 (14)	46-86
SELTEN ET AL. 2016[133]	THE NETHERLANDS	DM: KNEE/HIP	24 (16)	35-79
SJOLING ET AL. 2005[134]	SWEDEN	KNEE/HIP	18 (9)	51-82
SMITH ET AL. 2020[135]	UK	DM: KNEE	31 (17)	50-nk
SUAREZ-ALMAZOR ET AL. 2010[142]	USA	DM: KNEE	37 (23)	(64)
SWÄRDH ET AL. 2021[143]	INDIA	KNEE/HIP	24 (15)	49-85
SWIFT ET AL. 2002[144]	UK	MIXED	5 (5)	63–89
TEO ET AL. 2021[145]	AUSTRALIA	KNEE	24 (18)	49-81
THOMAS ET AL. 2013[146]	UK	FOOT//ANKLE	11 (6)	56-80
THUMBOO, WU, & LEUNG 2017[147]	SINGAPORE	HAND	26 (23)	52-78
TOLLEFSRUD & MENGSHOEL 2020[148]	NORWAY	KNEE/HIP	12 (10)	45-65
TOYE ET AL. 2006[153]	UK	DM: KNEE	18 (6)	54-77
TRAUMER ET AL. 2019[154]	DENMARK	DM: KNEE	11 (5)	57-77
TSINDOS ET AL. 2020[155]	AUSTRALIA	KNEE/HIP	20 (18)	52-84
TURNER ET AL. 2007[157]	UK	MIXED	31 (14)	56-84
TURNER, BARLOW, & ILBERY 2002[156]	UK	KNEE	12 (0)	45-76
WEBSTER ET AL. 2013[160]	CANADA	KNEE/HIP	33 (17)	38-79
WOOD, CONNELLY, & MALY 2009[162]	CANADA	KNEE	5 (3)	68-79
WOOLHEAD ET AL. 2010[163]	CANADA, USA, AUSTRALIA, UK	KNEE/HIP	130 (80)	47-92
WOOLHEAD ET AL. 2002[164]	UK	DM: KNEE	25 (14)	40-84
YEH ET AL. 2017[167]	CHINA	DM: KNEE	26 (20)	61-86
YEOWELL ET AL. 2021[168]	UK	FOOT//ANKLE	9 (1)	30-70
YORGASON ET AL. 2010[169]	USA	MIXED	28 (15)	(68)
ZAIDI ET AL. 2013 [170]	UK	FOOT//ANKLE	14 (8)	41-83
ZAMANZADEH ET AL. 2017 [171]	IRAN	MIXED	17 (12)	39-75

Studies marked ^{a-l} report findings from a shared sample

DM = decision making for joint replacement

Table 3. List of studies supporting each theme

IT IS PART OF MY LIFE'S TAPESTRY	[2; 13; 23; 27; 34; 35; 38; 40; 45; 47; 50; 56; 59; 63; 66; 70; 74-77; 81; 83; 88; 89; 105; 111; 116; 122; 126; 129; 130; 142; 143; 148; 156; 157]
(YET) IT IS CONSUMING ME	[2] [4] [9] [11] [12] [23] [34] [35] [40] [45] [47] [55] [56] [58] [61] [63] [73] [75] [76] [77] [79] [83] [87] [90] [89] [91] [97] [95] [102] [105] [109] [113] [120] [122] [123] [126] [129] [134] [145] [148] [155] [156] [160] [162] [163] [169] [3] [44] [46; 49] [49] [53] [69] [71] [81] [96] [130] [133] [153] [26] [24] [67] [82] [147] [146] [168] [170] [38; 41] [128] [143]
IT CONSTRAINS MY BODY AND MY OCCUPATIONS	[2] [4] [9] [11] [12] [14] [23] [34] [35] [40] [45] [47] [54] [55] [56] [61] [63] [73] [75] [76] [79] [83] [90] [89] [91] [97] [105] [106] [109] [111] [113] [120] [122] [126] [129] [134] [142] [148] [156] [160] [162] [3] [44] [46] [49] [53] [69] [71] [81] [96] [114] [133] [135] [153] [154] [25] [26] [67] [82] [125] [147] [146] [168] [170] [24] [27] [38; 41] [143]
I AM BECOMING SEPARATED, YET DEPENDENT	[2] [4] [9] [11] [12] [23] [34] [35] [40] [45] [47] [54] [56] [61] [63] [73] [75] [77] [78] [79] [83] [90] [91] [97] [95] [105] [109] [110] [111] [113] [120] [122] [129] [142] [160] [44] [46] [49] [53] [69] [71] [81] [114] [153] [154] [25] [26] [67] [82] [147] [146] [168] [24] [41] [143]
I ACCEPT, BUT WILL NOT LET IT DEFINE ME	[2] [9] [11] [12] [23] [34] [35] [45] [47] [55] [56] [59] [63] [64] [75] [78] [79] [88] [90] [104] [105] [106] [109] [111] [113] [126] [134] [142] [144] [156] [169] [3] [49] [71] [81] [147] [146] [67] [82] [128]
(YET) THIS MAKES ME FEEL LESS THAN THE PERSON I WAS	[2] [4] [11] [23] [34] [35] [40] [45] [47] [56] [61] [63] [73] [75] [79] [83] [88] [90] [91] [97] [95] [105] [106] [113] [120] [122] [129] [134] [142] [148] [155] [156] [157] [160] [3] [16] [46] [49] [69] [71] [81] [114] [135] [153] [67] [82] [147] [146] [168] [24] [41]
PLEASE DON'T TREAT IT AS A TRIVIAL MATTER	[1] [4] [5] [7] [14] [17] [23] [32] [34] [40] [45] [47] [56] [73] [79] [83] [88] [87] [90] [92] [95] [98] [101] [102] [104] [109] [120] [127] [134] [134] [145] [71] [81] [96] [114] [130] [131] [135] [142] [66] [146] [168] [170]