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A synthesis of qualitative research to understand the complexity behind treatment decision-making for osteoarthritis

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ABSTRACT

Objective: Osteoarthritis is the most common joint disease with treatment involving a multidisciplinary approach with pharmacological, physical therapies and surgery as options. Qualitative research can help us to understand the complexity of managing health conditions and this understanding plays a role in good clinical practice. We aimed to systematically search for, identify, and synthesise qualitative research exploring the experience of living with osteoarthritis, including decision making about joint replacement.
Methods: We comprehensively searched 4 bibliographic databases and used the methods of meta-ethnography to synthesise qualitative research findings. We screened 10 123 titles, 548 abstracts, and 139 full texts. We included findings from 118 reports (105 unique samples) of at least 2534 adults living with osteoarthritis around the world.
Results: We developed 7 themes: Becoming your own expert can be hard work; Living has become a careful balancing act; Medication is a double-edged sword; I have other things in my life to consider; You have to weigh up the odds of surgery; Surgery is the only effective option; and Surgery will give me a chance to live now. These findings have been drawn into a conceptual model reflecting a complex balancing act with tensions underpinning treatment decision making.
Conclusions: Osteoarthritis is framed as a world where patients become their own expert about their management and healthcare choices. Our conceptual model highlights key tensions underpinning treatment decision-making. These findings provide clinicians with insight of the complex nature of these decisions and how they can help patients through shared decision making.

1. Introduction

Osteoarthritis is the most common joint disease resulting from deterioration of the joint structure. It can occur in any joint, but is commonest in the hips and knees [1]. Prevalence increases with age and becomes more significant in the context of ageing populations. Treatment involves a multidisciplinary approach with pharmacological, physical therapies and surgery as options. The National Institute for Health and Care Excellence (NICE) guidelines recommend a stepped approach reserving surgical interventions for those who fail to respond to treatments [2]. Whilst regarded as a last resort, hip and knee arthroplasty have good evidence of cost-effectiveness and improved quality of life with end stage disease [3]. Shared decision-making, also recommended in the NICE guidelines, leads to improvements in health outcomes, particularly for knee arthroplasty [4]. In addition, whilst joint replacement can be effective, patients willingness to consider it varies with sex, ethnicity and socioeconomic status, and expectations and self-efficacy are important predictors of satisfaction with outcome [5].

Qualitative research can help us to understand the complexity of managing health conditions and this understanding plays a role in good clinical practice. There is a large body of qualitative research exploring the experience of osteoarthritis, including the decision for joint replacement surgery, and no comprehensive synthesis. We aimed to systematically search for, identify, and synthesise research exploring the experience of osteoarthritis. This study reports the findings related to the management of osteoarthritis, including the complex decision to undergo joint surgery. Findings related to the experience of living with osteoarthritis are reported separately [6].

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2. Methods

This qualitative evidence synthesis (QES) was registered prospectively on the PROSPERO database CRD42021250292 [7].

Ethics: Ethical permissions are not required for evidence synthesis.

We used meta-ethnography for synthesising qualitative research and followed published reporting guidelines [8]. We used the GRADE-CERQual framework to assess confidence in findings and report this assessment in the recently developed interactive summary of Qualitative findings software (iSQF) [9].

Stage 1: *Selecting meta-ethnography and getting started*. The stage incorporates the aims and selection of methodology. To determine whether a QES was 'worthy of the research effort' [10], we identified six existing reviews (using search terms designed for this purpose [11,12]) that explored the experience of living with osteoarthritis [13,14], or knee osteoarthritis [15,16], or the experience of decision-making for joint replacement surgery [17,18]. These reviews were neither comprehensive, nor conceptual in design, and the innovation of our study is to comprehensively review and analyse findings using the conceptual approach of meta-ethnography [10]. There are different methods for synthesising qualitative findings: some aim to amalgamate and describe findings: others aim to build on findings through comparison, and to make 'a whole' that is greater than the sum of its parts [10].

Stage 2: *Deciding what is relevant*. One reviewer searched four bibliographic online databases (Medline, Psychinfo, Cinahl, Embase) from inception until March 2021, to identify studies published in English that explored adults' experience of living with osteoarthritis, including decision-making for joint replacement surgery. We combined thesaurus and free text terms for qualitative research (Table 1) with broad condition specific thesaurus terms (exp ARTHRITIS/; exp ARTHROPLASTY). We excluded studies with mixed samples where we were unable to decipher experience of OA from other experiences, or other people's experiences. One experienced reviewer screened titles and abstracts. Two reviewers read and appraised full texts, using the Critical Appraisal Skills Programme [19] to ensure that studies were at least *satisfactory*, excluding studies that did not meet the inclusion criteria, or which were *fatally flawed* [20]. A fatal flaw for the purposes of QES is a qualitative judgement regarding the study merits. In this case a decision that a study was fatally flawed, made by two reviewers, meant that the findings lack a coherent idea that it was possible to compare and synthesise: for example, the findings were descriptive or organised into topics summaries rather than themes.

Stages 3 and 4: *Reading studies and determining how studies are related*. One reviewer read all studies in alphabetical order, by author, and extracted descriptive information to allow us to determine transferability of findings to other contexts: publication year, country, condition or topic, gender, and age.

Stages 5: *Translating studies*. The data for QES are the findings from primary qualitative research. The first reviewer summarised each finding in order to capture its meaning, and coded these summaries, using Nvivo software for qualitative research. Coding is a process that captures the essence of meaning in a few words. Translation involves comparing codes and sorting them into themes. At several stages of analysis, the review team discussed and refined themes until they determined the final QES findings. The aim of this is to develop ideas rather than to agree on a *"true"* version. We discussed the themes with four PPI representatives, via Microsoft Teams, and made adaptations to incorporate their ideas.

Stages 6 & 7: *Synthesising translations and expressing the synthesis*. Once refined, we organised the QES findings into a conceptual model. This is an iterative process where multiple versions of a model are refined and distilled into a final version.

3. Results

Fig. 1 shows the flowchart of studies identified and included. We included 118 reports (105 unique samples) [21–138], incorporating the experience of more than 2534 people from around the world, aged between 21 and 94. The author, publication year, country, condition, number of participants and age are shown in Table 2. Forty-four percent of studies (n = 52) explored the experience of hip or knee osteoarthritis; 21% (n = 25) included a range of joints affected by OA; 25% (n = 30) explored decision making for joint replacement surgery; 7% (n = 8) explored wrist or hand OA; 2% (n = 2) explored foot or ankle OA (Fig. 2).

We organised the findings into 16 provisional themes, which we refined into seven QES findings (Fig. 3). Our assessment of confidence in findings are reported in a GRADE-CERQual interactive summary of Qualitative Findings (iSQF) (supplementary material). Two reviewers assessed their confidence in findings 1–6 as high, meaning that they had either no, or very minor concerns regarding methodological limitations, coherence, adequacy and relevance. Both reviewers had moderate confidence in finding 7, with minor concerns regarding the adequacy of data supporting this finding. The studies underpinning each finding are listed in Table 3. We report each finding with narrative exemplars, and our conceptual model is shown in Fig. 4.

Table 1
Qualitative search terms.

Qualitative methods - thesaurus term	Medline: exp "Focus groups"/OR exp "Anthropology, Cultural"/OR exp "Qualitative research"/OR exp "Nursing Methodology Research"/OR exp "Interviews as topic"/ Psychinfo: exp "Thematic Analysis"/OR exp "Semi-structured Interview"/OR exp "Narrative Analysis"/OR exp "Interpretative Phenomenological Analysis"/OR exp "Grounded Theory"/OR exp "Focus Group"/OR exp "Qualitative Methods"/OR exp Phenomenology/OR exp Ethnography/OR exp "Group Discussion"/ Cinahl: exp "Phenomenological Research"/OR exp "Grounded Theory"/OR exp "Ethnonursing Research"/OR exp "Ethnological Research"/OR exp "Ethnographic Research"/OR exp "Action Research"/OR exp "Naturalistic Inquiry"/OR exp "Qualitative Studies"/OR exp "Anthropology, Cultural"/OR exp "Focus Groups"/OR exp "Discourse Analysis"/OR exp "Constant Comparative Method"/OR exp "Purposive Sample"/ Embase: exp Hermeneutics/OR exp "Qualitative Research"/OR exp Phenomenology/OR exp "Personal Experience"/
Qualitative methods – free text	Qualitative ADJ5 (theor* OR study OR studies OR research OR analys*)).ti,ab OR (ethnog*).ti,ab OR (phenomenolog*).ti,ab OR (hermeneutic* OR heidegger* OR husserl* OR colaizzi* OR giorgi* OR glaser OR strauss OR (van AND kaam*) OR (van AND manen) OR ricoeur OR spiegelberg* OR merleau).ti,ab OR (constant ADJ3 compar*).ti,ab OR (grounded ADJ3 (theor* OR study OR studies OR research OR analys*)).ti,ab OR (narrative ADJ3 analys*).ti,ab OR (discourse ADJ3 analys*).ti,ab OR (conversation ADJ3 analys*).ti,ab OR ((lived OR life) ADJ3 experience*).ti,ab OR ((theoretical OR purposive) ADJ3 sampl*).ti,ab OR ((field ADJ note*) OR (field ADJ record*) OR fieldnote*).ti,ab OR (participant* ADJ3 observ*).ti,ab OR (action ADJ research).ti,ab OR ((digital ADJ record) OR audiorecord*).ti,ab OR ((((co AND operative) AND inquir*) OR co-operative) AND inquir*).ti,ab OR ((semi-structured OR semistructured OR unstructured OR structured) ADJ3 interview*).ti,ab OR (feminis*).ti,ab OR (humanistic OR existential OR experiential).ti,ab OR (social AND construct*).ti,ab OR (poststructural* OR post structural* OR post-structural*).ti,ab OR (postmodern* OR post modern* OR post-modern*).ti,ab OR ('appreciative inquiry').ti,ab OR ('interpretative phenomenological analysis').ti,ab OR (face ADJ3 interview*).ti,ab OR ((depth OR in-depth) ADJ3 interview*).ti,ab OR (abductive ADJ analys*).ti,ab)

3.1. Becoming your own expert can be hard work

This finding describes the burden of responsibility to be proactive in managing osteoarthritis, to keep learning, and to become your own advocate. Studies described the need to do your "own research" and seek your own solution. This involved a process of trial and error where people monitored the effects of a range of treatments. There was a sense that it was your job to be proactive, persistent, and assertive to get what you need.

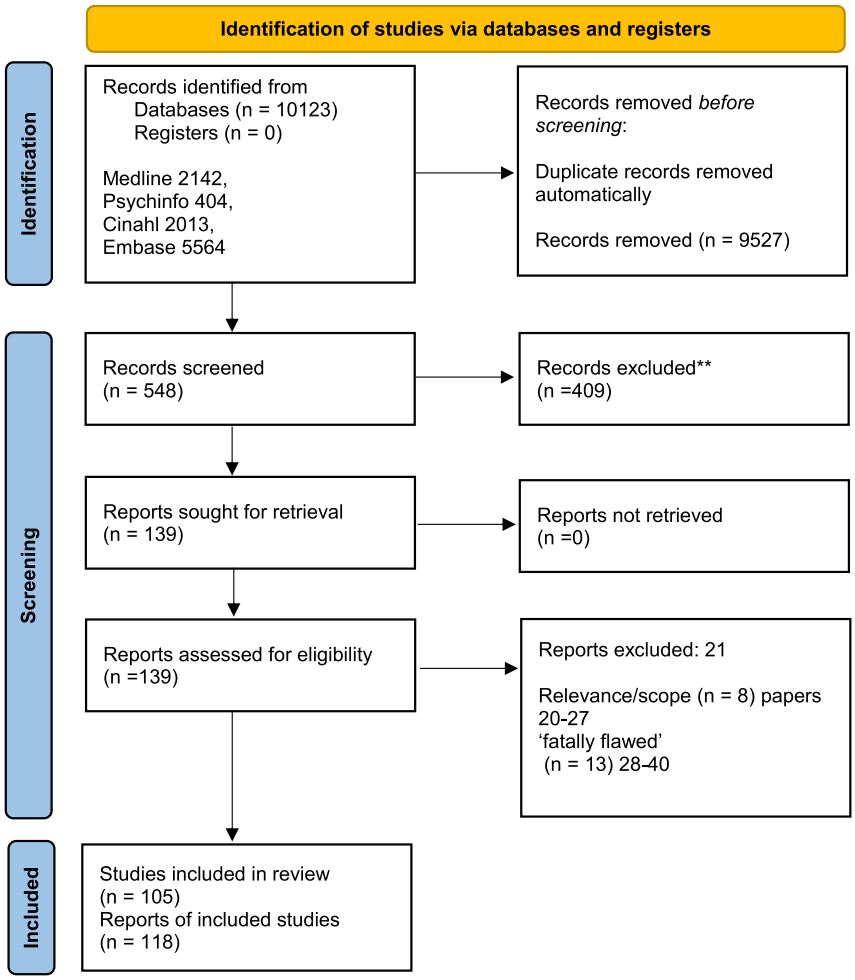

Fig. 1. Search Flow diagram: This PRISMA flow diagram shows the number of studies identified, screened and included in this QES.

> A lot of people … choose to take the attitude 'well, I'd rather somebody else take the responsibility for what I should be doing myself', but I just don't happen to believe that [69]. (Knee OA)

> There is no help nowhere … this is when I decided I'm responsible for my health, doesn't look like he [my family doctor] wants to help, to heck with it [83]. (Knee OA)

The hard work of becoming your own expert was underpinned by a struggle to find accurate and non-conflicting sources of knowledge. People were constantly on the lookout for new information, and drew on a range of sources from inside and outside healthcare. Some did not feel confident in information, either because it was inconsistent, or because it did not match their own experience.

> I've always been sceptical about the knowledge and the interest of the care providers for osteoarthritis. They always gave me vague information; they are not able to precise the evolution of osteoarthritis [25]. (Knee OA)

> The best possible place to get information for your medical assistance is in the barber shop [35]. (Mixed OA)

3.2. *Living has become a careful balancing act*

This finding describes a tension between (a) battling on, or (b) limiting or adapting activities. There was a sense that you must weigh up the costs and benefits of maintaining versus limiting activity: "keeping going" was not necessarily an unwavering adherence to the past, but rather, it could be a pragmatic approach where you made choices in order to prioritise valued and important activities. This might mean avoiding, adapting, "being careful", not "overdoing thing", or being vigilant in order to avoid flare-ups.

> It's always kind of there … 'I can come back and hurt you … if you don't watch what you're doing … I could just all of the sudden be hurting you again … [and you] won't be able to do what you want to do again.' It's kind of there in the back of your mind, that you have to be careful [82]. (Knee OA)

> Pace yourself. I mean I go bull mad at things sometimes. It's like this lecture I went to on Monday evening. And I enjoyed it. But I realized I'd done too much the next day. But you've got to adjust your life to what you can do. I'm not saying it's easy [120]. (Mixed OA)

3.3. *Medication is a double-edged sword*

This finding describes the paradoxical position of medication, which was simultaneously framed as both a "last resort" and a "daily companion" that you cannot survive without. Studies described fears of addiction, medication tolerance, and potential long-term noxious side-effects. Some felt that medication was dangerous because it masked pain and therefore increased the risk of further damage.

> [Medication is] a necessary evil. I mean it doesn't make your pain go away completely but you sure as hell notice it if you don't take them … I tell you; you need them to get through the day 79. (Decision-Making for joint replacement)

> Without medication I would be really limited, maybe 60%. I am afraid when I take the medication, if the medication is so helpful to cover the

Table 2
Study characteristics: condition/context, author, year of publication, country, number of participants, and age.

JOINTS/CONTEXT	AUTHOR (YEAR) & COUNTRY	NUMBER (WOMEN)	AGE RANGE (OR MEAN)
KNEE OA	AGALIOTIS ET AL. 2018 [22] AUSTRALIA	11 (7)	51–77
	ALAMI ET AL. 2011 [25] FRANCE	81 (59)	NKK
	AL-KHLAIFAT ET AL. 2020 [23] JORDAN	14 (13)	43–77
	BARBER ET AL. 2019 [31] CANADA	5 (3)	57–72
	CARMONA-TERÉS ET AL. 2017 [42] SPAIN	10 (7)	58–85
	CHAN & CHAN 2011 [44] HONG KONG	20 (15)	(58)
	COETZEE, GILJAM-ENRIGHT & MORRIS 2019 [46] SOUTH AFRICA	18 (15)	49–84
	DARLOW ET AL. 2018 [49] NEW ZEALAND	13 (7)	50–84
	HALL ET AL. 2008 [61] CANADA	15 (5)	52–80
	JINKS, ONG & O'NEILL 2010 [69] UK	28 (8)	53–86
	KAMSAN ET AL. 2020 [72] MALAYSIA	16 (13)	61–89
	KAO & TSAI 2012 [73] CHINA	17 (14)	40–55
	KAO & TSAI 2014 [74] CHINA	17 (15)	40–55
	KEYSOR, SPARLING AND RIEGGER-KRUGH 1998 [76] USA	4 (3)	25–43
	MACKAY ET AL. 2014 [80] CANADA	41 (26)	35–65
	MACKAY ET AL. 2016 [81] CANADA	41 (26)	35–65
	MALY & COTT 2009 [82] CANADA	26 (15)	41–65
	MALY & KRUPA 2007 [83] CANADA	3 (2)	62–87
	MAN ET AL. 2017 [84] CANADA	8 (4)	46–80
	MORDEN, JINKS, & ONG 2014 [95] UK	22 (13)	56–90
	MORDEN, JINKS, & ONG 2017 [96] UK	22 (13)	56–90
	MORDEN, JINKS, & ONG 2011 [97] UK	22 (13)	56–90
	NYVANG, HEDSTRÖM, & GLEISSMA 2016 [101] SWEDEN	12 (7)	47–77
	ONG & JINKS 2006 [103] UK	10 (nk)	nk
	POULI ET AL. 2014 [106] UK	24 (17)	48–84
	TEO ET AL. 2021 [121] AUSTRALIA	24 (18)	49–81
	TURNER, BARLOW, & ILBERY 2002 [128] UK	12 (0)	45–76
	WOOD, CONNELLY, & MALY 2009 [131] CANADA	5 (3)	68–79
KNEE (PAIN)	GASKIN ET AL. 2020 [55] USA	21 (21)	45-nk
	ACKERMAN, LIVINGSTON, & OSBORNE 2016 [21] AUSTRALIA	33 (21)	58–71
	GIBBS & KLINGER 2011 [56] CANADA	11 (11)	60–75
	GOOBERMAN-HILL ET AL. 2007 [59] UK	28 (14)	57–89
	JOLLY ET AL. 2017 [71] NEW ZEALAND	23 (20)	52–86
	MANN & GOOBERMAN-HILL 2011 [85] UK	16 (9)	56–81
	MCGRUER ET AL. 2019 [87] NEW ZEALAND	7 (7)	44–71
	MCHUGH, SILMAN & LUKER 2007 [89] UK	21 (16)	48–86
	MILLER, OSMAN & MANWELL 2020 [94] USA	11 (7)	(69)
	NASCIMBEN ET AL. 2019 [98] DOMINICAN REPUBLIC	17 (15)	32–86
	NILSING-STRID & EKELIUS HAMPING 2020 [99] SWEDEN	20 (13)	52–77
	NIU ET AL. 2011 [100] DOMINICAN REPUBLIC	18 (13)	21–80
	PARSONS, GODFREY, & JESTER 2009 [105] UK	6 (3)	60–76
	POWER ET AL. 2008 [107] CANADA	46 (28)	56–88
	SALE, GIGNAC & HAWKER 2006 [111] CANADA	10 (10)	67–92
	SANDERS, DONOVAN & DIEPPE 2002 [112] UK	27 (17)	51–91
	SJOLING ET AL. 2005 [116] SWEDEN	18 (9)	51–82
	SWÄRDH ET AL. 2021 [119] INDIA	24 (15)	49–85
	TOLLEFSRUD & MENGSHOEL 2020 [124] NORWAY	12 (10)	45–65
	TSINDOS ET AL. 2020 [127] AUSTRALIA	20 (18)	52–84
	WEBSTER ET AL. 2013 [130] CANADA	33 (17)	38–79
	WOOLHEAD ET AL. 2010 [132] CANADA, USA, AUSTRALIA, UK	130 (80)	47–92
HIP OA	BREMBO ET AL. 2016 [36] NORWAY	13 (7)	59–88
	JOHNSON, HORWOORD, & GOOBERMAN-HILL 2014 [70] UK	24 (11)	52–82
KNEE/HIP/HAND OA	CEDRASCHI ET AL. 2013 [43] FRANCE	14 (10)	40–75
	MIKHAIL ET AL. 2007 [90] AUSTRALIA	20 (10)	54–85
MIXED OA	ALI, WALSH & KLOSECK 2018 [26] CANADA	20 (16)	67–83
	BAIRD 2000 [27] USA	18 (18)	65–92
	BAIRD 2003 [28] USA	5 (5)	72–91
	BAIRD, YEHLE, & SCHMEISER 2007 [29] USA	23 (23)	73–94
	BOOKER & HERR 2021 [33] [USA]	18 (9)	(68)
	BOOKER, HERR & TRIPP-REIMER 2019 [34] USA	18 (9)	(68)
	BOWER ET AL. 2006 [35] CANADA	9 (nk)	nk
	DICKSON & KIM 2003 [51] USA (KOREAN)	7 (7)	63–80
	GIGNAC ET AL. 2006 [57] CANADA	90 (53)	39–88
	HARRIS ET AL. 2015 [62] AUSTRALIA	19 (19)	(63)
	HARRIS ET AL. 2016 [63] AUSTRALIA	19 (19)	(63)
	KEE 1998 [75] USA	20 (17)	62–92
	MARTIN ET AL. 2012 [86] USA	37 (31)	50–90
	MILDER ET AL. 2011 [91] AUSTRALIA	15 (8)	nk
	MILDER ET AL. 2011 [92] AUSTRALIA	15 (8)	nk
	MILLER ET AL. 2016 [93] CANADA	25 (17)	nk
	RICHARDSON, GRIME & ONG 2014 [109] UK	27 (nk)	55–90
	ROSEMANN ET AL. 2006 [110] GERMANY	20 (12)	40–78
	SWIFT ET AL. 2002 [120] UK	5 (5)	63–89

(*continued on next page*)

Table 2 (*continued*)

JOINTS/CONTEXT	AUTHOR (YEAR) & COUNTRY	NUMBER (WOMEN)	AGE RANGE (OR MEAN)
	TURNER ET AL. 2007 [129] UK	31 (14)	56–84
	YORGASON ET AL. 2010 [136] USA	28 (15)	(68
	ZAMANZADEH ET AL. 2017 [138] IRAN	17 (12)	39–75
	GRIME, RICHARDSON & ONG 2010 [60] UK	27 (15)	56–87
SURGICAL DECISION MAKING: HIP	DOSANJH, MATTA, & BHANDARI 2009 [52] USA	18 (8)	52–79
SURGICAL DECISION MAKING: KNEE	AL-TAIAR ET AL. 2013 [24] KUWAIT	39 (39)	(63)
	BARLOW ET AL. 2018 [32] UK	22 (10)	57–82
	BUNZLI ET AL. 2019 [40] AUSTRALIA	20 (10)	(72)
	BUNZLI ET AL. 2020 [41] AUSTRALIA	27 (13)	(67)
	DAMAR & BILIK 2017 [48] TURKEY	17 (16)	(68)
	HSU ET AL. 2018 [66] CHINA	79 (59)	60–87
	JACOBSON ET AL. 2008 [68] USA	27 (14)	45–83
	KROLL ET AL. 2007 [77] USA	37 (23)	(64)
	O'BRIEN ET AL. 2019 [102] AUSTRALIA	27 (13)	52–80
	SMITH ET AL. 2020 [117] UK	31 (17)	50-nk
	SUAREZ-ALMAZOR ET AL. 2010 [118] USA	37 (23)	(64)
	TOYE ET AL. 2006 [125] UK	18 (6)	54–77
	TRAUMER ET AL. 2019 [126] DENMARK	11 (5)	57–77
	WOOLHEAD ET AL. 2002 [133] UK	25 (14)	40–84
	YEH ET AL. 2017 [134] CHINA	26 (20)	61–86
SURGICAL DECISION MAKING: KNEE/HIP	BALLANTYNE, GIGNAC & HAWKER 2007 [30] CANADA	29 (nk)	59–86
	CLARK ET AL. 2004 [45] CANADA	17 (9)	59–81
	CONNER-SPADY ET AL. 2014 [47] CANADA	65 (43)	28–89
	DEMIERRE, CASTELAO, & PIOT-ZIEGLER 2011 [50] SWITZERLAND	24 (15)	(60)
	FIGARO, WILLIAMS RUSSO, & ALLEGRANTE 2004 [53] USA	94 (79)	50–89
	FRANKEL ET AL. 2012 [54] CANADA	58 (46)	(72)
	GOOBERMAN-HILL ET AL. 2010 [58] UK	26 (14)	46–86
	HUDAK ET AL. 2002 [67] CANADA	17 (9)	59–81
	LEOV ET AL. 2017 [79] NEW ZEALAND	20 (12)	55–82
	MCHUGH & LUKER 2009 [88] UK	27 (18)	49–89
	PARKS ET AL. 2014 [104] USA	36 (29)	(68)
	SANDERS, DONOVAN, & DIEPPE 2004 [113] UK	27 (17)	51–91
	SANSOM ET AL. 2010 [114] UK	26 (14)	46–86
	SELTEN ET AL. 2016 [115] THE NETHERLANDS	24 (16)	35–79
FOOT/ANKLE OA	THOMAS ET AL. 2013 [122] UK	11 (6)	56–80
	YEOWELL ET AL. 2021 [135]UK	9 (1)	30–70
	ZAIDI ET AL. 2013 [137] UK	14 (8)	41–83
HAND/THUMB/WRIST OA	BUKHAVE & HUNICHE 2014 [39] DENMARK	34 (30)	38–89
	BUKHAVE, LA COUR & LOTTE HUNICHE 2014 [38] DENMARK	31 (29)	38–89
	HILL, DZIEDZIC & ONG 2011 [64] UK	29 (25)	50–84
	HILL, DZIEDZIC & ONG 2010 [65] UK	29 (25)	50–84
	KJEKEN ET AL. 2012 [143] NORWAY	125 (122)	(65)
	THUMBOO, WU, & LEUNG 2017 [123] SINGAPORE	26 (23)	52–78
	BÜHLER ET AL. 2021 [37] NEW ZEALAND	30 (19)	(65)
	LARSSON ET AL. 2020 [78] SWEDEN	13 (5)	38–75
HAND OA/RA	PROFFITT, ABRAHAM, & HUGHES 2019 [108] USA	4 (4)	62–74

Studies marked [a-l] report findings from a shared sample.
DM = decision-making for joint replacement.

pain, I might do something wrong, you know, overuse or something [83]. (Knee OA)

3.4. *I have other things in my life to consider*

This finding describes contextual factors that played a role in treatment decision-making. Studies described a complex and evolving hierarchy of needs which altered with age and stage of life: commitments, personal circumstances, caring roles, and other priorities might influence decisions.

> We had a family meeting. My son will take care of me after the surgery. I'm still afraid of adding pressure on top of his responsibilities to his own family. I'll wait until he can take his annual leave [134]. (Decision-Making for joint replacement)

> I have postponed (joint surgery) firstly because my husband was not well … I had to take care of him, so I could not find time for [joint surgery] [50]. (Decision-Making for joint replacement)

Similarly, some described other health conditions that might influence their decisions and saw osteoarthritis as just one thing in a competing hierarchy of concerns. Some found it hard to separate and prioritise one part of the body from another. This complexity was exacerbated by age-related changes, and some wondered whether treatment was "worth it at my age?"

> I have many serious chronic diseases, such as heart and renal problems. I'm not sure if my body can tolerate the surgery. If complications occur, what can I do? I need to think more before making the decision 134. (Decision-Making for joint replacement)

> After you reach a certain age, you say: "What's the point?" I'm not gonna be kicking around … I'll be gone in a couple years … Especially with my health. … I'm overweight, I have high blood pressure, [I'm a] borderline diabetic … is it worth [it]? You kind of weigh it [up] [45]. (Decision-Making for joint replacement)

3.5. *You have to weigh up the odds of surgery*

This finding describes the challenge of weighing up the odds for and against surgery. It is underpinned by a reluctance to opt for surgery because of potential risks, and surgery was not framed as a decision to be taken lightly. The decision was complicated by receiving conflicting opinions and inconsistent information. Some felt that the best knowledge

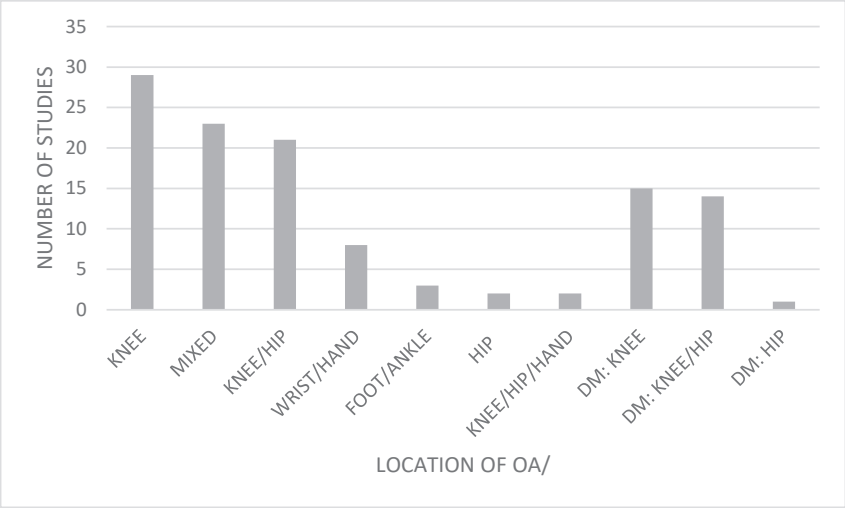

Fig. 2. Provisional themes organised into final QES findings: this shows 16 provisional themes distilled into the 7 findings.

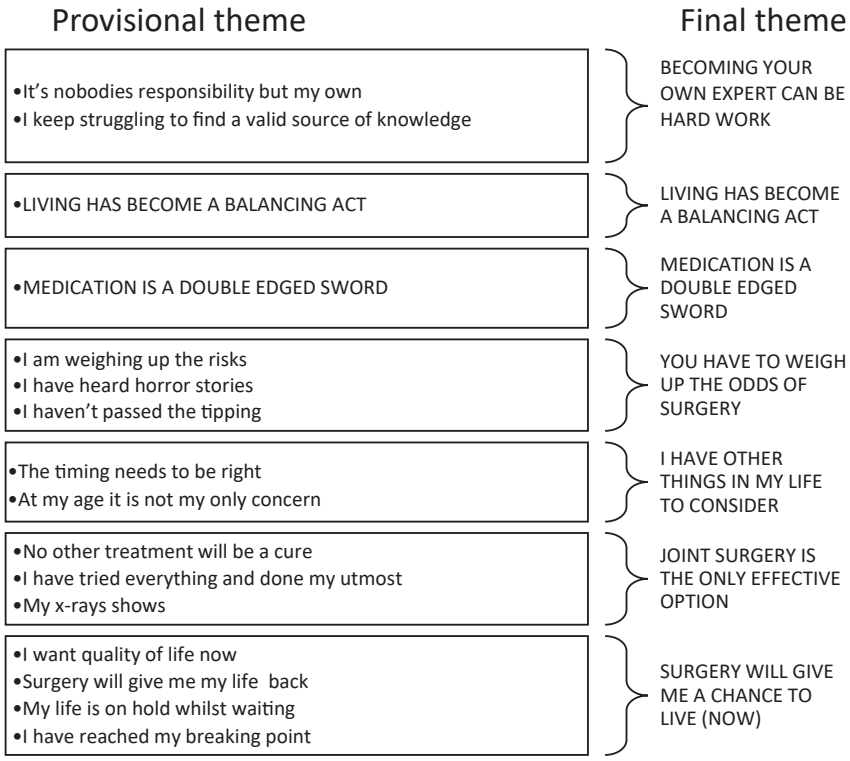

Fig. 3. Conceptual model.

came from someone who had experienced surgery first-hand, there was a recognition that you tend to only hear things that you want to hear.

> it's really hard to internalize how rare those complications are … you keep saying to yourself, 'yes, I know it's a long shot, but it did happen to someone' … so it's a teeter totter … yes, you can hear a hundred good stories, but that [bad] one stays there 47. (Decision-Making for joint replacement)

> I worry about negative accounts of joint replacement and try to avoid hearing them. I only want to hear the positive stuff. It would be useful to talk to more people [68]. (Decision-Making for joint replacement)

Some described horror stories told about surgery: some were worried about the procedure itself, and others were worried about not "waking up" after anaesthetic: patients did not want to trade a "known" problem for an "unknown" one.

> I am not frightened with the surgery … I am frightened with the anaesthesia simply because I have had two members in the family who did not come out of anaesthesia and that's frightening 104. (Decision-Making for joint replacement)

> [my surgeon] showed me a picture of the prosthesis … it was like pieces of artillery…it confronts you to the fact that you will miss a piece of your bones, so I was struck by this image of a sawn bone … tears came up to my eyes in rebellion and then … in fear [50]. (Decision-Making for joint replacement)

Although some framed surgery as "the last resort", the option was not ruled out for the future, once you had passed a "tipping point".

Table 3
Primary studies underpinning findings.

Becoming your own expert can be hard work	21–26,28,30,31,34–36,42,44,46,49–51,55,60,63–65,69,71–77,79,80,82,83,85–90,93–98,100,103,105,107,110,113,118,121,124,126,129,135–137
Living has become a careful balancing act	22,28–30,32,36,38,39,41,44,49–51,56,57,59,61,62,64,65,68,70,72,74–76,80–82,84,86,97,99,101,105,108,109,117–120,123,124,130,132,136
Medication is a double-edged sword	22–28,34–36,42,44,46,50,57,61,64,68,72,74,75,79,80,83,89–92,94,95,98,100–102,105,106,110,111,115,117,119,122,126,130–132,138
I have other things in my life to consider	22,23,30,32,36,37,43,45,47,50,59,60,66,70,88,97,98,102–105,109,113,115,117,122,125,130,131,134,136
You have to weigh up the odds of surgery	21–25,30,32,36,41,42,44–50,52–55,58,61,66–68,70,72,77,78,81,84,88,94,101,102,104–106,113–115,117,118,123,125,126,131,133,134,137
Joint surgery is the only effective option	21,32,36,40,41,43,48–50,52,54,61,66,67,70,72,74,78,79,83–85,89,101,104–106,112,114–117,125,126,130,133,137
Surgery will give me the chance to live (now)	21,24,30,36,40–42,47,50,61,66,70,79,88,102,113–116,125,129,130,133

I just persevere … [my knees are] bad but not bad enough … they're not hanging off in stubs like … you know. I take them as they hurt … They hurt. … They're both swelled up … But you … live and learn 45. (Decision-Making for joint replacement)

To me surgery is the last resort. If I'm at a point where I can't walk no more and I have to crawl, then I might consider surgery 118. (Decision-Making for joint replacement)

3.6. Joint surgery is the only effective option

This finding describes surgery as the only effective solution. Some had tried and exhausted all other treatment options, and felt that surgery was the only real "cure". Treatments had been tried and failed, and there were concerns that things could get worse.

Hell before surgery if someone had told me to put a poached egg on my head and run around the block I would have. I'll try anything but nothing really worked [79]. (Decision-Making for joint replacement)

What's the point in trying to do something when something's worn out? I believe in nuts and bolts; if something's worn out, you pull it out and put a new part in Ref. [40]. (Decision-Making for joint replacement)

Whilst some had done their utmost to follow advice to be active and lose weight, they described this as a vicious circle: pain limited activity, weight was gained, and pain increased. Again, some saw surgery as the only way out of this cycle.

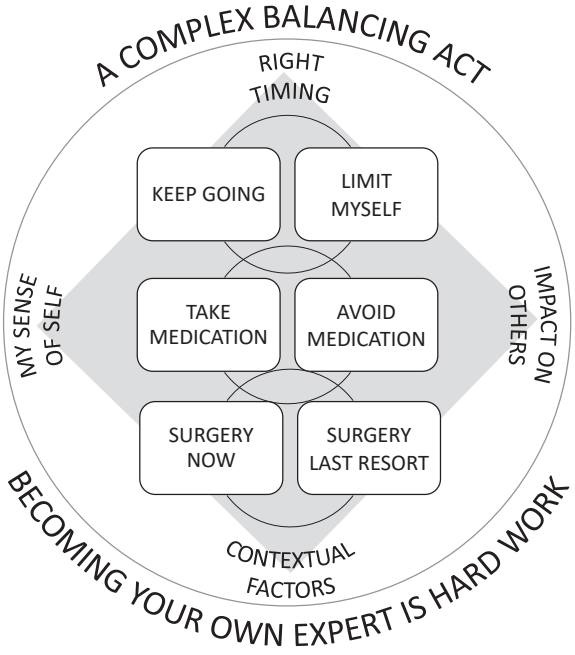

Fig. 4. Conceptual model of themes.

I was told was to lose a bit of weight and come back again … They tend to look at you as though it is your own fault … Problems I have got have not been caused by being overweight … I'm overweight because of the problems that I've got133. (Decision-Making for joint replacement)

I also thought, this could be because I'm overweight, and the doctors insist on that, I'm 110 kilos, each of my knees manage 55. It's a form of guilt that is imposed on us, of course it's for our own good, we should lose weight, but vexation aside, it's not that simple [43]. (Knee, hip and hand OA)

There was also a sense that a medical diagnosis of osteoarthritis, confirmed by x-ray, meant that surgery was the only solution.

[The surgeon] looked at the x-rays, he showed me the left-hand side is just bone on bone, there's nothing there. He said 'it's not going to get any better, as a matter of fact it's going to get worse' 40. (Decision-Making for joint replacement)

The X-rays told it all … it was obvious … [the doctor] said it had just wore out [133]. (Decision-Making for joint replacement)

3.7. Surgery will give me the chance to live (now)

This finding describes a desire to undergo joint surgery and to live life to the full *now*, even if this meant negative consequences later. Some described challenging interactions with health professionals who said that their symptoms were not "bad enough", or that they are "too young" for surgery.

[I have] just been waiting, putting up with the pain, because all the doctors say I'm too young. But everyone in my family dies before 70. So, what, am I going to live for the rest of my life in pain? 40(Decision-Making for joint replacement)

Quality of life is more important now than when I'm 70 or 80. Give me the chance now and then if we have to go through it again when I'm in my 80's or 70's, okay, then do it again, but why waste the good years when you still have them? [47](Decision-Making for joint replacement)

For some already listed for surgery, the journey had been arduous, and life was "on hold" whilst they waited. Some felt that it had been a constant battle, where they had felt reduced to a "number" in healthcare.

The nurse told me there was a whole bundle of people ahead of me, I don't know how many there are in a bundle … I felt so neglected, you get treated … worse than an animal … nobody listens. I feel so powerless 116. (Knee and hip OA)

Unfortunately, by the time we feel that we need to have the surgery, then we're faced with a wait list. Or a waiting time. So, we feel like our lives are on hold [47]. (Decision-Making for joint replacement)

Some felt that surgery would give them a chance to get back to "normal" and to restore their former self. Although not all expected a "100% recovery", there remained cautious optimism for a better life.

> I don't even remember if the doctor said there was a risk of an unfavourable result … I think I was just so ready for the surgery that I may not have heard other things … I just went in thinking 'I'm going to have my life back'47. (Decision-Making for joint replacement)

> [The surgeon] said 'I cannot promise you 100% because nothing is 100%. But you will be 100% better than now … I said, 'Oh, God, that's good news for me, just take away 50% of it so I can move just half a day, not all day' [61]. (Knee OA)

There was a sense that the person had reached the limit of what they could bear, and that without surgery, this was the end of the road.

> You're ready. You are desperate. Your pain, your quality of life, it's intolerable and you're willing to do anything. You have no other avenue [47]. (Decision-Making for joint replacement)

> I am not going to be any bloomin' good if I don't have it done, if I am going to sit indoors, I might as well be in my box, I can understand people taking an overdose. I mean the value of life's gone [125]. (Decision-Making for joint replacement)

3.7.1. Conceptual model

Our findings indicate that managing osteoarthritis can become a complex balancing act where the landscape constantly changes, and where becoming your own expert can be hard work. Our conceptual model highlights key tensions that underpin treatment decision-making: do I fight to keep going or do I limit myself by altering, adapting, stopping and pacing; do I take medication and live with side effects, or do I avoid medication and live with pain; and (for those with a surgical option), am I ready to take the risks or surgery now or will surgery be my last resort. Our model highlights factors that interplay in treatment decision-making: what are the potential effects of my decision on (a) my quality of life and sense of self, and (b) other people (family, friends, colleagues); (c) are there other contextual factors which must take priority; (c) is this the right time to do this (for example, am I too old, or too young).

4. Discussion

Our findings highlight the complexity of decision-making for managing osteoarthritis, and the need for evidence-based information and support to assist this. We highlight the tensions at play: do I keep fighting it, or do I embrace change: how do I balance the pros and cons of medication; how do I weigh up the odds of surgery? The findings indicate that whilst there are those that see surgery as the only effective option, there are also those who do not want to take the risk, or who have higher priorities.

Although viewed by many as the ultimate solution, 10–15% of patients remain dissatisfied after their joint replacement surgery because of persistent pain or ongoing functional limitations [139,140]. Klem and colleagues suggest that patients with "unrealistically high hopes" for complete symptom resolution after joint replacement surgery may be more likely to experience dissatisfaction. As such, support is needed to "reconceptualise" overly high expectations [141]. In contrast, there are those who seem "perfect for the procedure" but who make the decision not to undergo surgery [67]. A robust process in healthcare to help people to make the right decision, and to support them in shared decision-making would facilitate good decisions: our findings suggest areas to focus on in supporting patients.

The support needed by patients to manage their osteoarthritis and to make an informed decision about the choice of conservative or surgical interventions needs to be tailored and individualised to patients as advocated in the recent UK NICE guidelines for diagnosis and management of osteoarthritis [2]. This could mean focusing on therapeutic exercise, weight management and pharmacological management as appropriate and should be a precursor to any consideration about surgery.

Our study highlights methodological considerations for future systematic reviews of qualitative research. First, although there are agreed screening approaches for quantitative reviews, the merits of dual screening are less clear for QES. Secondly, qualitative research is underpinned by an interpretive epistemology and not all QES reviewers agree that it is useful to quality appraise for QES [142].

Most of these studies explored the experience of knee and hip osteoarthritis, and further qualitative research might focus on osteoarthritis affecting other joints, or osteoarthritis in joints where surgery is not a routine treatment option. Similarly, studies exploring the transferability of our findings to minoritised populations, certain age groups (such as those who are much younger or older), or a range of socio-economic contexts, might increase our understanding of decision-making. For example, decision-making conversations with older and younger patients might be very different. The innovation of our study is to provide a conceptual synthesis, drawn from 118 studies that can help us to understand the complexity of this process. Our findings suggest areas that could be usefully explored in shared decision-making. In particular, exploring a person's knowledge base, the impact of osteoarthritis on their life, the context in which they are making their decisions, and their understanding of the potential costs and benefits of particular approaches would enhance shared decision-making for osteoarthritis.

4.1. Conclusions

Our findings highlight that, for some, osteoarthritis is framed as a world in which they have to become their own expert. The challenge of decision-making about their own management and healthcare choices can have a profound impact on people's lives. Our conceptual model highlights key tensions that underpin treatment decision-making. These findings provide clinicians with better understanding of the complex nature of these decisions for many patients and how they can help them through shared decision making.

Author contributions

FT, KS and KB madesubstantial contributions to the conception and design of the study, and the collection, analysis and interpretation of data.

FT drafted the manuscript, and KS and KB revised the article for important intellectual content.

FT, KS and KB approved the final version to be submitted.

Declaration of competing interest

This project was funded by the EFIC and Pfizer- Lilly Alliance Grant on Education in Pain Associated with Arthritis. There are no further conflicts to be declared.

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Appendix A. Supplementary data

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