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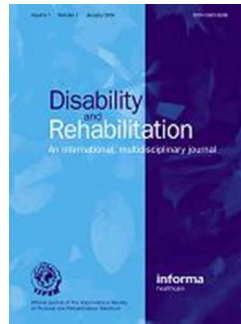
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Trajectories of need: Understanding patients' use of support during the journey through knee replacement

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Trajectories of need: Understanding patients' use of support during the journey through knee replacement

Abstract

Purpose: To explore how the process of undergoing and recovering from knee replacement surgery alters patients' experiences and use of their support networks.

Methods: Ten patients having knee replacement surgery for osteoarthritis were invited to take part in in-depth interviews prior to surgery and two-four weeks, six and 12 months postoperatively.

Transcripts were analysed using ~~i~~Interpretative ~~p~~Phenomenological ~~A~~analysis.

Results: Three superordinate themes were identified: (1) Relationships with health professionals over the knee replacement journey; (2) Implications for informal relationships and support networks and (3) Providing support to others.

Conclusions: Transformation from a person with osteoarthritis to someone recovering from a surgical intervention can lead to alterations in the source, type and level of support people receive from others, and can also change the assistance that they themselves are able to offer. Findings highlight the value of the concept of interdependence to our understanding of participants' experiences. Activity undertaken by informal support networks assists participants to cope with the consequences of osteoarthritis and surgery, and fills in the gap when more formal support is lacking.

However, it is essential that provision of care is individually tailored and that formal support is adequate at times when informal support networks are unavailable.

Introduction

Osteoarthritis is one of the most common long-term conditions, estimated to affect a third of people aged over 45 years in the United Kingdom (UK) [1]. Pain and stiffness in a person's joints, including knees, are common features of osteoarthritis [2]. Osteoarthritis of the knee can have considerable consequences for daily life, including detrimental impact on social life, sleep, activity levels and overall quality of life [3-5]. Strategies recommended for management of knee osteoarthritis include exercise, weight loss and manual therapy options as well as analgesic medication. If these are not sufficiently effective in enhancing function and relieving pain then knee replacement surgery may be considered [6]. Knee replacement is a major operation that involves surgical removal of an affected joint, and its replacement with an artificial prosthesis made from metal and plastic.

Knee replacement has become a common procedure in developed countries. In the UK over 676,000 primary knee replacement procedures took place in England, Wales and Northern Ireland between 2003 and 2013 [7]. Numbers of joint replacement operations undertaken, including knee replacements, are increasing globally [8-10] and with an ageing population, demand is predicted to rise [11]. People who have had a knee replacement need a period of care and rehabilitation after the operation [12], and healthcare systems vary in their rehabilitation practices [13, 14]. In the UK's National Health Service (NHS) many patients experience a short hospital stay, often returning home three to four days after their joint replacement [15, 16].

Osteoarthritis and its treatment present challenges to everyday life and bring about changes in support arrangements. Those living with osteoarthritis may engage with formal support in order to help them cope with pain and functional limitations associated with the condition. This might include input from social services and contact with health professionals, including surgeons, nursing staff, and physiotherapists [17]. Family and friends may assist with everyday activities, including help

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2
3 around the home [18, 19]. Although this can mean that people with osteoarthritis feel that they are
4
5 a burden on others [20, 21] this support from family and friends has been described as valuable [21],
6
7 with positive implications for mental and physical health [22, 23]. Once a decision is made to have
8
9 surgery, social support continues and formal services such as outpatient appointments and
10
11 education sessions may help people to prepare for the operation. However, people with
12
13 osteoarthritis who are waiting for joint replacement receive little active management and support
14
15 for their osteoarthritis at this time [19].
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19
20 In the NHS patients tend to be admitted to hospital on the day of their operation, which is usually
21
22 performed under general or spinal anaesthetic or a combination of the two. After surgery patients
23
24 spend some time in the recovery room before they move to the orthopaedic wards where nursing
25
26 staff and physiotherapists play a significant role in encouraging patients to get up and walk as soon
27
28 as possible [24]. In the weeks after surgery, patients who have had a knee replacement may
29
30 experience post-surgical pain, impaired mobility and novel restrictions that affect daily life (e.g.
31
32 unable to drive). At this time, there may be little contact with health professionals [25] and family
33
34 are particularly important in provision of support, including personal care [12, 25]. The value of this
35
36 type of support is well documented [25-27] but can also evoke mixed reactions including gratitude
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38 and frustration towards family, feelings of isolation, and concern about placing burden on others
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40 [12, 28, 29].
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46 Throughout the experience of osteoarthritis, treatment, surgery and recovery, interaction with
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48 others, including support, takes place but is not necessarily stable or continuous. This is highlighted
49
50 in a study with people who had hip replacement surgery, in which it is argued that people
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52 experience decreasing independence before surgery and increasing independence afterwards [26].
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54 Independence may have positive connotations of 'freedom of choice and autonomy' [30], be highly
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56 regarded [31, 32] and upheld as an indicator of healthy ageing [33]. Conversely, dependence may
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3 connote negative aspects of ageing [30]. However, independence and dependence are blunt
4
5 instruments through which to understand long-term conditions, social and formal support, and
6
7 recovery from treatment. Instead, we need to consider that the majority of people live within social,
8
9 political and economic contexts and 'within complex webs' of shared dependence [34]. This
10
11 interdependence is evident in the concept of 'linked lives' proposed by Elder [35]. In linked lives
12
13 people are interdependent, reciprocal connection occurs on different levels, and relationships have
14
15 the potential both to support and control an individual's behaviour. Therefore it may be possible to
16
17 further our understanding of the human experience of health and healthcare through examination
18
19 of the experience of shared dependence (i.e. interdependence) and reciprocity [33, 36]. This concern
20
21 is in keeping with the epistemological underpinning of our study, phenomenology, with its
22
23 foundation in understanding human experiences and how people gain knowledge of the world
24
25 around them [37]. Phenomenology originated from the ideas of Edmund Husserl in the early 20th
26
27 century [38], who rejected the idea that empirical science is the basis for attaining an understanding
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29 of the world and instead emphasised the salience of the life world or lived experience [39].
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38 A phenomenological lens can help to illuminate the humanness that is intrinsic to the changing
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40 illness experience ~~Both~~ that is brought about both by -living with, and undergoing surgical treatment
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42 for osteoarthritis. It offers a means to explore, and gain a deeper understanding of, how the
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44 disability and restrictions imposed by this experience change an individual's perception of their
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46 social world and need to depend on others. ~~-can result in disability and restrictions that can alter a~~
47
48 person's need to depend on others. Recent work has already provided us with some understanding
49
50 of the function of support for people living with osteoarthritis. Insights into the experiences of
51
52 support around the time of joint replacement have also been generated from the retrospective
53
54 accounts of participants who have undergone and recovered from surgery [19, 21, 25, 26]. However,
55
56 this work has not addressed how people's relationships with others alter as they move from
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3 disability, through to postoperative recovery and to functional independence; and the complexity of
4
5 their social networks (i.e. who they rely on) during this time. Understanding these elements of
6
7 recovery, with particular attention to the detail and subjectivities of the lived experience, provides
8
9 the basis for the future development of interventions to optimise outcome after surgery. Given that
10
11 people recovering from surgery are embedded in social relationships with people who provide
12
13 support, understanding how this changes over time means that interventions can seek to include or
14
15 involve those people as and when it may be most appropriate. Using inductive qualitative methods,
16
17 our study aimed to explore how the process of undergoing and recovering from knee replacement
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19 surgery alters patient's lived experiences and use of their support networks.
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27 **Methods**

31 *Study design*

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33 The study was a longitudinal qualitative interview study with patients undergoing total knee
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35 replacement surgery for osteoarthritis. In-depth interviews were conducted with patients prior to
36
37 surgery and between two-andfour weeks, six and 12 months after their operation. We used
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39 Interpretative Phenomenological Analysis (IPA), a well-established approach to qualitative research
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41 [40], that has been employed successfully in previous work involving people living both with
42
43 osteoarthritis and those undergoing orthopaedic surgery [12, 41]. to explore participants' lived
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45 experiences and how they make sense of them [37, 38]. The dual epistemological underpinnings of
46
47 this approach are phenomenology and hermeneutic inquiry. IPA itself is phenomenological in that it
48
49 is concerned with the premise of 'attending to the way things appear to us in experience': how
50
51 individuals perceive and provide accounts of objects and events (Smith and Eatough, 2006, p.324)
52
53 [42]. Ultimately, as a method, IPA attempts to provide a detailed exploration of participants' lived
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55 experiences and how they make sense of their personal and social world. A key concern is with the
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3 meanings that experiences hold for individuals. However, IPA also acknowledges that the researcher
4 plays a central, significant and dynamic role in making sense of that personal experience. Therefore
5 this method has a strong connection with the interpretative or hermeneutic tradition [40, 42]. Smith
6 and Osborn (2004) suggest that IPA is a particularly appropriate method when a researcher is
7 interested in learning about 'process and change' (p.231) [43]. Using IPA will therefore enable the
8 in-depth individualised examination of the process of change and adjustment over time as patients
9 undergo and recover from knee replacement surgery. Smith and Eatough (2006) highlight the fact
10 that studies employing IPA are usually concerned with 'big issues, issues of significant consequence
11 for the participant either on an ongoing basis or at a critical juncture in her or his life' (p.327) [42].
12 Living with a debilitating condition such as osteoarthritis, and undergoing and recovering from major
13 surgery, can be perceived as a big issue appropriate for examination with IPA.
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31 *Sampling and recruitment*

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33 As the study was concerned with the process of undergoing and recovering from knee replacement
34 surgery, potential participants were individuals who were waiting to undergo this elective
35 procedure. Potential participants were approached within a large UK NHS hospital where a high
36 number of knee replacements take place annually. Locating the research at this hospital enabled the
37 study to include sufficient participants, and a diverse sample (from across a large geographical area,
38 for example). Study invitation packs were mailed to 68 patients listed to undergo total knee
39 replacement ~~at a single NHS hospital~~ between February and November 2011. ~~The hospital conducts~~
40 ~~a large number of knee replacement operations, providing treatment to patients from across a~~
41 ~~region.~~ Of those who returned a reply slip (n=17), we purposefully identified a sample of men and
42 women, who were a range of ages. WW contacted 12 potential participants and of them 10 agreed
43 to take part in an initial interview. The remaining two were no longer eligible to take part. One had
44 been recruited into an alternative study that precluded their inclusion and another had had their
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3 operation date brought forward which meant that there was insufficient time to undertake an initial
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5 interview. These 10 patients reflect the original sample of 68 in terms of age and gender. Small
6
7 sample sizes are typical in IPA studies, with many having samples of 5-10 participants [40]. This is in
8
9 part because during the process of analysis 'subtle inflections of meaning' can potentially become
10
11 lost if the data set is too large [3944]. We considered our sample size of 10 appropriate to enable us
12
13 to undertake a 'detailed, nuanced analysis' which would facilitate an in-depth understanding of each
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15 participants' lived experience [3740, 45-49]. All participants provided their written, informed consent
16
17 to take part immediately prior to the first interview. The researchers (WW and XX) also sought
18
19 participants' verbal agreement to ongoing participation before each follow-up interview.
20
21 Demographic information about the 10 participants (six men and four women, ages 61-78 years) is
22
23 displayed in table 1. All names are pseudonyms.
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30 ***[Insert table 1. Participant demographics]***
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33

34 *Data collection*

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36 In-depth semi-structured interviews were conducted with all 10 participants after they had seen a
37
38 hospital consultant and were placed on the waiting list for knee replacement. Follow-up interviews
39
40 were carried out with 8 of the 10 participants at each of the three follow-up points. Two
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42 participants did not take part in postoperative interviews, one because he chose not to have surgery
43
44 and one because the date of her surgery moved beyond the time constraints of this study.
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46
47 Preoperative interviews, which lasted between 74 – 102 minutes, took place at participants'
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49 preferred location: either in their own homes (n=7) or on University premises (n=3). The first author
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51 (WW) carried out all preoperative interviews. Postoperative interviews, which lasted from 40-84
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53 minutes were undertaken by either WW or XX, who worked between them and with other members
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55 of the study team to ensure consistency of approach. These interviews and largely took place over
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57 the telephone, other than when a participant requested a face-to-face interview in their own home
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3 (n=1). The first postoperative interviews took place between two and four weeks after surgery so
4 that participants were able to recall their time in hospital but had also had sufficient time since their
5 operation to allow for some postoperative recovery. The time window enabled some flexibility so
6 that interviews could take place at the convenience of participants. Further interviews took place at
7 six and twelve months as key points when recovery was likely to be underway or relatively complete.

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16 Interview questions were guided by topic guides developed by WW, YY and ZZ and were initially
17 informed by existing literature and through discussion with patient representatives. We also used
18 the findings of early interviews to help us further refine the topic guides.~~Interview questions were~~
19 ~~guided by topic guides, informed by existing literature and through discussion with patient~~
20 ~~representatives.~~ Core qQuestions aimed to elicit participants' experiences of preparing for,
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undergoing and recovering from surgery. The core topics covered included: pain and function [3, 4,
21, 46]; support whilst preparing for/recovering from surgery [17-19]; hopes for, and knowledge of,
surgery and recovery [25, 47]; and experiences of rehabilitation and recovery [15, 20, 48]. Use of
topic guides helped to ensure consistent issues were addressed across participants, but we used
open-ended questions and detailed probing to encourage participants to talk about their
experiences and to tell their story in their own words, in keeping with methods of IPA [4149]. This
enabled generation of rich data and exploration of issues that emerged as important to each
individual. With consent of participants, interviews were audio-recorded and participants also
provided their consent to the publication of anonymised quotations. Research ethics approval for
this study was provided by [name removed for peer review].

Data analysis

Audio-recordings were transcribed verbatim, checked for accuracy and anonymised. Using IPA, we
started with the detailed examination of case studies. This involved reading the preoperative
interview transcript from the first participant several times. During initial readings we made notes on

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2
3 the transcript of important and interesting aspects of the data and developed these preliminary
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5 notes into more explicit phrases and themes as we became more familiar with the data. We then
6
7 aimed to make connections between these ideas in order to establish superordinate themes for the
8
9 case; again returning to the transcript to check them against the data. The transcript of the first
10
11 interview was put to one side and the transcript from the subsequent interview with that participant
12
13 was then analysed in the same way as the first. This pattern was repeated until all transcripts for the
14
15 case had been analysed. It was at this point that an attempt was made to identify patterns between
16
17 the themes from different time points, with the aim of establishing the superordinate themes for the
18
19 complete case. Once a table of superordinate themes had been compiled for a case we began the
20
21 analysis process for the next participant. Once the process was completed for each case we aimed to
22
23 identify patterns between cases with the key objective of formulating a list of superordinate themes
24
25 for the complete group. We then 'transformed' the superordinate themes into a narrative account
26
27 with the aim of drawing out the patterns in participants' experiences; discovering the similarities and
28
29 differences in their stories [4250]. Taking this approach we were able to illuminate patients' lived
30
31 experiences and their process of preparing for, undergoing and recovering from surgery. In
32
33 particular it enabled us to discover and capture the meaning that alterations to social support
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35 systems had for patients as they navigated this lived experience.
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42 During the process of analysis we remained mindful of the principle, as suggested by Smith et al
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44 (1999), that themes should not be chosen only on how often they appear in accounts, but rather,
45
46 should be influenced by additional factors. These factors include how well passages exemplify
47
48 themes and the way in which the theme provides illumination of the account. We also worked to
49
50 immerse ourselves in the data as much as possible during analysis and embraced the flexibility of IPA
51
52 that allows unanticipated ideas and themes to emerge concerning participants' lived experience
53
54 during analysis [3740]. During analysis and while writing the manuscript, we were mindful of the
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56 idea that a 'good IPA study' narrative will allow the reader to find out something about both the
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3 salient generic themes in the analysis, and also gain an insight into the 'narrative lifeworld', the
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5 world as lived, of each of the participants [3842].
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11 WW undertook analysis of the data and other members of the research team (YY and ZZ)
12 commented on interpretations made during the process of analysis and within the drafts and final
13 accounts provided. Situating results and interpretations within current literature, comparing findings
14 with existing work, and triangulating participants' experiences during analysis, all serve to increase
15 the credibility of the findings.
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24 Results

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28 We were interested in exploring participants' experiences of support during their journey through
29 knee replacement surgery. To achieve this we explored interview transcripts at all time-points
30 (before surgery, two-four weeks, six and twelve month's post-surgery) together to provide as
31 complete a picture as possible about the journey through knee replacement. From our analysis, we
32 identified three superordinate themes that relate to dependence and interdependence: (1)
33 Relationships with health professionals over the knee replacement journey; (2) Implications for
34 informal relationships and support networks and (3) Providing support to others.
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45 Theme 1. Relationships with health professionals over the knee replacement journey

46 1a. 'I've got faith in him': trust and confidence in the surgical team

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3 Participants explained how the pain and impaired mobility they increasingly faced before surgery
4
5 meant that they felt the need to rely on medical opinion and expertise, and that surgery was an
6
7 inevitable need rather than a choice.
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9

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11 *It's not like having cosmetic surgery. I don't have to have it done, I got to have it done to*
12
13 *get, to keep moving otherwise I'm gonna seize up. I'll get to the stage where I won't be*
14
15 *able to walk at all. Practically a cripple. (Mr Ings, 1)*
16
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19
20 There was considerable 'faith' (Mrs French) and 'total trust' (Mrs Evans) in surgical teams. This was
21
22 rooted in previous positive encounters in consultations as well as experiences (their own and others)
23
24 of successful outcomes after other types of surgery. For instance, Mr Jackson's confidence in his
25
26 surgeon's ability was enhanced because he thought that his brother had a good outcome after
27
28 surgery performed by the same, 'experienced', surgeon. Accounts however also indicated that
29
30 participants' trust was tempered by recognition that surgeons 'are only human' and that outcome
31
32 was not guaranteed.
33
34

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37 *he [has] done my brother's leg, both legs, about six years before me, and he's had – you*
38
39 *know, brilliant. I asked for him. And he's been there for a long time as well, he's not a*
40
41 *new chap. (Mr Jackson, 3)*
42
43

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45
46 *all these Consultants they're fantastic guys but they can't guarantee anything 100%. It's*
47
48 *just common sense isn't it? They do the best they can but you don't know whether, you*
49
50 *know, how good your op's going to be. No two people are the same so, you know. You*
51
52 *just keep your fingers crossed. (Mr Clark, 1)*
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3 Alongside awareness that outcome was not guaranteed, participants were also aware that surgery
4
5 entailed considerable risks. They expressed a sense of vulnerability that focused on relinquishing
6
7 control to the surgical team when under general anaesthetic in the operating theatre.
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9

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11 *So every time you have an operation you're putting yourself at risk. Especially with a big*
12
13 *operation and that side of it always, I watch too much Holby City. (Mr Cook, 1)*
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18 However, after surgery, even if complications occurred, participants were still confident in the
19
20 surgical team. For instance, Mr Armstrong retained faith in his surgeon despite a setback when in
21
22 the operating theatre, this may have related to the surgeon taking responsibility and providing a
23
24 solution.
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29 *A little bit of the cement has squeezed out through the joint and it was a slither of it and*
30
31 *they could see it on the x-ray and it was inside the knee still. ... [Surgeon] his words were*
32
33 *"I'm taking the responsibility, I'll be doing it" ... [Surgeon] gives a lot of confidence to you*
34
35 *with what he's doing. He knows what he's doing and he took responsibility and he said*
36
37 *he would put it right and that's what's happened. (Mr Armstrong, 2)*
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40 41 42 1b. Contact with secondary care team 43 44

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46 After undergoing surgery, participants' contact with secondary care health professionals shifted
47
48 from the surgical team to a team of nurses, physiotherapists and auxiliaries. Relationships with
49
50 health professionals at this time subtly changed: participants wanted health professionals to provide
51
52 support and guidance rather than the total control that had been the expectation of surgical teams.
53
54 Although experiences were underpinned by a sense of frustration, participants' accounts indicated
55
56 willingness to depend on support from staff while recovering in hospital (e.g. for self-care) as there
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3 was little alternative. The perception that staff were 'caring' may have also served to reduce
4
5 resistance to relying on others during this time for some participants.
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10 *They were caring. ... they'd be available anytime um. ... the only trouble was then I*
11 *wasn't allowed to walk at all for that intervening more or less a week like, four days, five*
12 *days. That was a pain that was. ... if I wanted to go to the loo I had to call for a nurse to*
13 *come with a wheelchair to take me there, oh it was a right, that was the biggest chore*
14 *of it that was. (Mr Armstrong, 2)*
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22 However, some participants also thought that support with personal care and recovery during their
23 hospital stay was lacking. Instead they felt staff would: 'leave you to do whatever you can do' (Mrs
24 Biggs). This encouragement of independence was unexpected and Mr Cook described the distress he
25 experienced when he was not offered the assistance with personal care that he felt he needed.
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33 *I was sitting there and uh, this woman said "what you sitting there for?" I said "oh I was*
34 *waiting to be washed". She said "we expect people to wash themselves" really abruptly.*
35 *I thought "you horrible woman" ... it was in front of other people, I felt really small. (Mr*
36 *Cook, 2)*
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44 Post-discharge all participants had some contact, although often infrequent, with secondary care
45 professionals: predominantly consultants and sometimes physiotherapists. They were 'keen' to
46 receive follow-up appointments and eager to obtain clinical opinion about when they should drive
47 again, terminate use of walking aids and return to formal exercise. Interactions bolstered confidence
48 and offered reassurance. They were also a useful forum to discuss postoperative goals and beneficial
49 in equipping participants with knowledge and skills to enhance recovery. However, although
50 consultations were important in informing expectations for recovery, accounts suggested that the
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3 information provided by their medical team was not always perceived to facilitate the formulation of
4
5 accurate expectations; much to Mr Ings' regret.
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10 *I'd say, but be prepared, you will be restricted in what you can and can't do. This is not*
11 *what you're told, you know, you're not told this at the time. ... I think then you should be*
12 *told it is not a quick fix, it is a slow recovery. (Mr Ings, 3)*
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18 1c. 'You were sort of cut adrift': Unmet support needs during the recovery process
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22 Accounts highlighted the detrimental implications of unmet support needs during the recovery
23
24 process. At time point two Mrs French expressed irritation that she had not received a
25
26 physiotherapy outpatient's appointment, despite being told in hospital that everything was in place
27
28 for her to receive this service. Instead she was left to chase this contact, something that contributed
29
30 to the stress of a 'difficult few weeks'.
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35 *I rang them week before last. ... he [physiotherapist] said "Of course we are very busy at*
36 *the moment, but I will be in touch with you again, but there is a two to three week*
37 *wait". ... But I was quite annoyed ... I felt like saying to him well don't bother. I mean*
38 *they say I can drive within six to seven weeks ... I wouldn't even of had any physio by*
39 *then. ...I know everybody is very busy and you're only one of a number really aren't you,*
40 *but this physio thing really that did annoy me, because they stress about you having*
41 *physio and making sure you bend your knee and all this and then nobody comes. ... it*
42 *don't make sense to me. (Mrs French, 2)*
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55 Her experiences are mirrored by others, who at time point two had also not received the anticipated
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57 physiotherapy appointment. There was a sense that input from physiotherapists was often received
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3 too late after surgery and that earlier involvement would have helped to reduce feelings of
4 abandonment, enhanced motivation to exercise and facilitated earlier recovery. Instead, unless
5 paying for private care, patients are reliant on waiting their turn to receive an appointment.
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11 *After I'd got home, there was about six weeks before I saw a physiotherapist and you*
12 *were sort of cut adrift there and if some assistance could be given in that short time for*
13 *people I'm sure it would help a lot. (Mr Armstrong, 4)*
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20 When physiotherapy was offered it tended to be on a short-term basis; for a few weeks. Participants
21 disclosed at the 6 and 12 month interviews that they would have appreciated long-term support
22 from health professionals and an 'aftercare service at the hospital'. Instead they were in a sense of
23 limbo and did not know where or who to turn to receive support for continuing difficulties,
24 particularly long-term postoperative pain.
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33 *Interviewer: And was there any other support you would have liked to have received*
34 *from health professionals during your recovery?*
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36

37 *Mr Ings (4): Probably a little bit more either a physio, or a check-up from the physio*
38 *say after, about six to eight months or something like that, just to see*
39 *how it is moving and that.*
40
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46 *I would have liked to have kept on going [to physiotherapy] because I was putting more*
47 *and more pressure on my knee and it was bending more and more, from my perspective,*
48 *but they [the physiotherapist] put their measuring tool on it and it was so tiny the*
49 *difference. It wasn't worth their time. (Mr Cook, 4)*
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3 *It's a pity they haven't got like an after – an aftercare service at the hospital, whatever*
4 *they call it, I don't know um, you know, that you could probably go up and see. 'Cos they*
5 *were very good these physios, they know what they're doing [...] an ideal world, just to*
6 *go and be able to phone, you know, perhaps the person – I seen a chappie in the um – I*
7 *went to the swimming department [means hydrotherapy ... I wish I could go back and*
8 *see him, if you see what I mean. Um 'cos he would put me on the right track perhaps.*
9 *[...] I don't want painkillers. I want to know if there's something I could do, like some*
10 *sort of exer – different exercises or something I don't even know about, that um – that*
11 *everybody goes through and I don't know about it and, you know, they might be able to*
12 *cure it or whatever. (Mr Jackson, 4)*
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27 Postoperative aftercare in the community was also seen to be lacking. After discharge from hospital
28 Mrs Evans, a widow who lives alone, lacked the support of a district nurse. Instead, she was left to
29 struggle with self-care activities, such as changing her surgical stockings, and had to implement her
30 own support by paying for help.
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37 *I think that would have been helpful, somebody you know, at least every other day, just*
38 *to make sure that you could get them [surgical stockings] on, because they are dreadful.*
39
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41

42 *(Mrs Evans, 4)*
43
44
45

46 Mrs Evans is concerned how the 'lack of backup' may affect others more 'fragile' than her or without
47 financial resources to seek postoperative support. She appears frustrated that her experience of the
48 perceptions of hospital ward staff about the availability of postoperative care in the community do
49 not reflect the reality, and, suggests that receiving this support could offer reassurance and reduce
50 isolation.
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3 *If you lived on your own, you know, if you were elderly, and you couldn't afford*
4 *somebody, then that would be a problem. ... especially when they keep on talking about*
5 *care in the community.I do think that really it's no good talking about it, it's got to be*
6 *there. How we provide it, I don't know. But it would be a dreadful worry for somebody.*

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11 *(Mrs Evans, 2)*
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16 1d. Differing perceptions of expertise: primary versus secondary care health professionals
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20 As described in theme 1a, confidence in secondary care professionals was consistently high amongst
21 participants. However, their trust in, and willingness to seek support from, primary health care
22 professionals was more mixed. Perceptions of support on offer, and received, from primary care
23 practitioners during the postoperative period was influenced by the quality and continuity of care
24 received prior to surgery. This is illustrated by Mr Clark's description of the confidence he has in his
25 GP, something that lends him to depend upon him during his journey through knee replacement.
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35 *They are a seriously good crowd. So my doctor, it's been the same GP that I've been*
36 *seeing for a quite a long time now ... if I felt the need to see him, he's always there for*
37 *me. ... you see the same guy each time. ... he obviously gets to know you and you know*

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40
41 *vice versa. (Mr Clark, 1)*
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46 In contrast, Mr Jackson's account indicates his dissatisfaction and frustration with the impersonal
47 and inconsistent care and contradictory advice he received from GPs before surgery. Like others, he
48 perceives consultations to be too short to address adequately address his concerns; feels guilty
49 about taking up too much of the GP's time, and believes that GPs lack the specialist knowledge
50 required to provide appropriate input. Consequently in the lead up to surgery he feels unable to rely
51 on GPs to support him with effective pain management.
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5 Interviewer: Do you feel there's anywhere you could go to get those answers?
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7 Mr Jackson (2): Not really, I'm afraid we are very poor at the moment... we've had the
8
9 same doctor for about 40 years and he retired and at this practice we
10
11 got now we get a different doctor every week, they seem to be coming
12
13 and going. If you go to see anybody, they don't know nothing about
14
15 you. ... I had an experience with them, one doctor give me these tablets
16
17 for pain killers, something I'd never tried before and then when I went
18
19 back a couple of... I don't know three or four weeks later I said "Oh your
20
21 colleague gave me these" and she said "He shouldn't of never give you
22
23 them" and chucked them in the waste bin. I thought blimey... they can't
24
25 even trust each other.... So that's put me off a bit.
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31 This early dissatisfaction underpins Mr Jackson's postoperative experience. Six months after surgery
32
33 he again chooses not to seek the advice of his GP about the pain he is experiencing; seeing little
34
35 value in doing so.
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42 **Theme 2. Implications for informal relationships and support networks**

43 2a. Changes in level and type of assistance

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50 During the preoperative period the changes in function and pain that participants experienced
51
52 impacted on the level and type of assistance provided by their informal support networks. Before
53
54 surgery most became increasingly reliant on family to undertake activities such as fetching groceries
55
56 and household chores. With increasing pain and functional decline participants progressively turned
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3 to others to undertake the roles they traditionally assumed within a family unit or partnership. For
4
5 example, Mr Ings needed his family to help him undertake gardening activities and to carry heavy
6
7 objects. It was striking to hear a man, a manual worker who had such a solid/substantial appearance,
8
9 tell me this.
10

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12
13
14 *Interviewer: Have the way that your wife and your son and your daughter support*
15
16 *you, has that changed at all?*

17
18 *Mr Ings (1): Yeah it has a bit. The daughter ... she helped me plant the garden yes.*
19
20 *She's been down this week and I said I got some cabbage plants I want*
21
22 *to get in. ... I clears it with the long handled tools, yeah and she*
23
24 *actually bends down and puts it in for me.*

25
26
27 *Interviewer: And is there anything else that's changed, any different ways that your*
28
29 *wife or your children are helping out now?*

30
31 *Mr Ings (1): Yeah, shopping. Carrying stuff, yeah quite a bit.*
32
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38 However, there were individual differences in the support that participants chose, or needed, to
39
40 seek from those around them. For instance, Mr Jackson described how during the progression to
41
42 surgery, despite experiencing functional decline, he remained independent and able.
43
44
45

46
47 *Interviewer: Has the support that your wife or other people offer to you changed at*
48
49 *all over the last twelve...*

50
51 *Mr Jackson (1): No not really because I've never asked for any. No I've never, I can still*
52
53 *do all the things I want to do just not as far or not as easily, not as well.*
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3 During the immediate postoperative period, participants' reliance on those around them sharply
4 increased. They now called on others to help them with even small practical tasks of daily living,
5 such as carrying a drink. Undergoing surgery also led to novel changes in the roles that participants
6 played within their relationships. This could evoke negative emotions, including dependency and
7 helplessness. For example, when recovering from surgery Mr Cook was often looked after by his
8 children who were 'running errands and things' and he felt that his wife was 'treating him like a
9 baby'. The temporary change in his role within the family unit was evident.
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20 *Interviewer: What about your wife then and the rest of your family, how have they*
21 *been supporting you since you've come out of hospital?*
22
23

24 *Mr Cook (2): Well my wife has been working like a trooper you know. I mean, trouble*
25 *is she won't let me do stuff. ... going to the shop. Um, you know getting a*
26 *magazine, treating me like a baby. Um, I mean just doing extra. ... I mean*
27 *I cannot drive a car so, you know, I used to do virtually all the driving.*
28
29 *Now my wife is doing all the driving.*
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37 This dependency for most however steeply decreased as their recovery accelerated.
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42 *Without [name of wife] being here I would have struggled at home. It would have been*
43 *very difficult. Uh, the first couple of days, just getting out to make any food for yourself*
44 *or put a kettle on you know, that was an effort. Whereas now I can put the kettle on*
45 *with no problems no like, you know, I'm back to normal virtually. (Mr Armstrong, 2)*
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55 2b. 'She's always there you know when I want her': the assumption that family will help
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3 Married participants explained that they initially turned to their spouses for assistance during the
4 journey through knee replacement (all married participants lived with their spouses). They were
5 usually comfortable in accepting the help they offered, a support that was implicit and
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8
9 unconditional.
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13
14 *And she's always there you know when I want her so yeah. (Mr Clark, 1)*
15
16

17
18 After surgery, spouses assumed increased responsibility for tasks relating to everyday living and
19 functioning and also took on additional caring responsibilities, including personal care (e.g. helping
20 to bathe). They also played a role in medical aspects of the recovery process. For example Mr
21 Armstrong's wife administered postoperative anti-clotting injections and Mr Clark's wife, a retired
22 nurse, removed his stitches. Mr Clark also asked his wife for advice about pain management. He
23 preferred to discuss medical issues with her rather than 'bothering' health professionals.
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33 *Interviewer: And where did you have that done, having the staples out?*
34

35 *Mr Clark (3): Er now um [laughs] um my wife, [name], is a nurse. And um well she*
36 *retired about a year ago. And um we thought rather than, you know, um*
37 *– she knew the people in um – in the hospital, and they gave her a thing*
38 *for taking them out, um she's ever so good and ever so careful, rather*
39 *than go into hospital. Um she took them out at home for me.*
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50 Although many participants appeared comfortable in accepting that their spouse was occupying a
51 new role as carer, two felt 'awkward' and embarrassed at asking spouses to undertake duties that
52 they felt should be provided by paid professionals. However, such aftercare services were not
53 available to them and they were compelled to ask their spouse for help. There was a perception
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3 amongst participants that there was an expectation that caring responsibilities should, and would,
4
5 be provided within families, even if this had detrimental consequences on the dyad (e.g. spouse
6
7 having health problems of their own).
8
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10
11 *My wife who had, she has got a problem with a disc in her neck, there is no support. I*
12 *was stuck in bed at that point, where I had just come out of the hospital, I couldn't lift*
13 *my leg off the bed and I couldn't put my nylon stockings on, couldn't take them off, she*
14 *was giving me, my wife used to work in [Hospital name], she was giving me a bed bath,*
15 *which is you know, which I think is a bit wrong really. When someone is in a predicament*
16 *like that. I think there should be a district nurse, just policy that they have taken them*
17 *away. (Mr Cook, 4)*
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33 2c. Use of extended informal support networks

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37 When participants did not live with a spouse, participants looked outside to extended family
38 (children, grandchildren, siblings) and friends to meet their postoperative support needs. For
39 instance, several were the only driver in a household. As a consequence of postoperative restrictions
40 both they and their spouse had to rely on others for lifts to fulfil a function that they could no longer,
41 albeit temporary, undertake.
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50 *Interviewer: What sort of things have they [friends and extended family members]*
51 *been doing?*
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54 *Mr Jackson (2): Lifts everywhere, my wife can't drive ... so to and from hospital for any*
55 *appointments or to do the shopping, anything.*
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5 Those who were widowed had to call on extended family to fulfil the roles that spouses traditionally
6 performed; something particularly evident in the early postoperative period. As a widow, Mrs
7 French's family and friends provided her with 'anything that she want[ed]' before surgery;
8 something that continued during the postoperative period when she received regular visits, was
9 provided with meals and clean laundry. Again this illustrates how the need for support from health
10 professionals can sometimes diminish during the postoperative period when family and friends
11 instead fulfil support needs.
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22 *I can't say I've wanted support from the professionals, I've got very good family, they*
23 *come in every day. My son has been in this morning. Um ... and they bring me a meal*
24 *every day... I think I've only cooked one meal since I've been home. (Mrs French, 2)*
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31 Mrs Evans, also a widow, received offers of support from her son and daughter-in-law, whose visits
32 to her increased during the postoperative period. However, these were limited to the weekends. She
33 made use of paid help such as taxi services, rather than asking for help from friends and family
34 members as other participants did.
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42 *I am fortunate, in the sense that actually I can take a taxi down town and a taxi back.*
43
44

45 *And to get to the doctor's, um this is what I have to do as well. (Mrs Evans, 3)*
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47

48 2d. 'I'm lucky': willingness to accept help
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52 Mixed emotions were expressed about the help participants received from their social network
53 around the perioperative period. Several viewed it positively; as 'helpful' and 'invaluable'. They felt
54 fortunate to be 'spoilt' by friends and family who 'rallied' around them and reflected how difficult it
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3 would be for individuals who lacked this support. They often felt minimal discomfort in depending
4
5 on others and were accepting of the situation; perhaps because it was a time limited period.
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10 *Interviewer: What sort of support have you had?*

11
12 *Mr Ings (4): Well I've been lucky like that; the wife and the kids are pretty good, you*
13
14 *know, I've had the support of them around me. I suppose if it was*
15
16 *somebody living on their own it might be a bit different.*

17
18 *Interviewer: Yeah, what in particular are you thinking of?*

19
20
21 *Mr Ings (4): Oh loneliness and getting to do things.*
22
23

24
25 Some participants who were widowed were reluctant to burden ('put others out') and call on their
26
27 extended support networks; unwilling to disclose the extent of their problems to others. This could
28
29 have negative consequences such as increased pain and exhaustion.
30
31

32
33 *[Name of son] and [name of daughter-in-law], that's his wife, have to come from [name*
34
35 *of town]. You know, when they've had a full week, uh and they're both, she's as busy as*
36
37 *he is. ... So by the time they drive down here I feel guilty because it's the only spare time*
38
39 *they have ... I don't think it's fair to burden them. I really don't because they got their*
40
41 *lives to lead and you know, I think somebody complaining you know. I mean they always*
42
43 *ask and I say "I'm fine, I'm fine". (Mrs Evans, 1)*
44
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49 'Valuing' their independence and the opportunity to 'carry on and look after myself, rather than
50
51 have to depend on other people' (Mrs French) were key motivations to undergo surgery. Yet
52
53 following their operation participants were initially forced to increase their reliance on others. A
54
55 desire to return to independence underpinned early postoperative experiences and participants
56
57 craved a return to self-sufficiency. Reliance was associated with ageing; something they were
58
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2
3 attempting to halt by having a new knee joint. However undergoing surgery did ultimately enable
4
5 most participants to experience increased mobility and to regain the independence they were
6
7 beginning to lose by the time they had their operation: a positive outcome of having surgery.
8
9

10
11 *Interviewer: And how do you feel about the outcome?*

12
13 *Mrs Biggs (4): Oh yes, yes, I mean to have a nice straight leg, to be able to get back into*
14
15 *a car and drive. Be independent that was, you know wonderful. ... I mean*
16
17 *I'm a very independent person really and I, you know to rely on people is*
18
19 *not you know, I know what being very elderly is like. [laughs] ... you can't*
20
21 *just do things when you want to. You have to then consult with other*
22
23 *people, ask them if they can take you places or get things for you. ... of*
24
25 *course I had to uh you know, really be a bit uh um a bit more reliant on*
26
27 *people until I could actually get back into um what I call my normal life.*
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35 **Theme 3. Providing support to others**

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39 Although not a shared experience, a striking feature in the accounts of two participants was the
40
41 impact that undergoing knee replacement had on the support they provided to others, and how
42
43 caring responsibilities influenced their journey through joint replacement. Mrs Biggs, a widow and
44
45 sole provider of support for her mother and brother-in-law, was particularly articulate about the
46
47 reliance of others on her and the impact of surgery on this. Due to her caring responsibilities, and
48
49 despite limitations and pain imposed on her by osteoarthritis, she strived to maintain her role and
50
51 not let others down. As a result she increasingly used her car and mobility aids to undertake
52
53 everyday tasks. Undergoing surgery forced Mrs Biggs to pass over the caring responsibilities that she
54
55 traditionally assumed to her sister as she was no longer at that time able to undertake them.
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3 Keeness and determination to decrease 'burden on others' as soon as possible and to return to her
4
5 original role supporting others served to drive and motivate Mrs Biggs in her recovery from the
6
7 operation.
8
9

10
11 *Interviewer: Are you where you thought you'd be six months ago in terms of*
12 *recovery?*
13

14
15 *Mrs Biggs (4) Um, yes I think I, because things moved so well after. Yeah, yeah. But I*
16 *was determined any way that I wouldn't be a burden to anyone.*
17

18
19 *Interviewer: No, and does that make a difference do you think?*
20

21
22 *Mrs Biggs (4) Yes, oh yeah. ... Well for me mentally it does because of course uh, you*
23 *know I feel I got a lot of responsibility here to keep the home running and*
24 *I don't want uh, to feel any one else has to come in and um, you know*
25 *take over from me. ...it certainly encouraged me to get going, yes, yes.*
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33 The positive health benefits of having her knee replaced left Mrs Evans feeling that she was now
34
35 able to assume a new role and offer support and care to others; something which she felt was
36
37 impossible to undertake prior to surgery.
38
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40
41
42 *Yesterday, we got a little local, uh, pamphlet or whatever you'd like to call it down*
43 *[Town name] it was looking for volunteers actually to help families that might be in,*
44 *were going through different kinds of troubles ... so I'm going to ring them. ...I wouldn't*
45 *have done it twelve months ago. I wouldn't have been physically able to just go out and*
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48 *be confident enough to walk. (Mrs Evans, 4)*
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Discussion

This study explored how undergoing knee replacement surgery impacts on patients' experiences and use of informal and formal support networks over time. Transformation from a person living with osteoarthritis to a person recovering from a surgical intervention led to alterations in the assistance participants received from others, including source, type and level. Participants accepted the need to depend on health professionals over the perioperative period and this contact usually facilitated the recovery process (e.g. offered reassurance and enhanced confidence) and ultimately helped to minimise the potential interruption of this period of rehabilitation on participants' lived experience.

Conversely, when participants wanted to, but were not offered the support of health and social professionals to aid recovery, negative consequences ensued (e.g. distress and feelings of abandonment).

Findings suggest the need for long-term follow-up and on-going advice and support from secondary care specialists, something which-that could help to limit these feelings. Interestingly, despite a high level of trust in secondary care professionals across participants, this was not the case for primary care practitioners. Nevertheless, confidence, or lack of, remained stable over time for both groups and undergoing surgery did little to alter preoperative notions. For most, progression towards surgery was marked by increasing use of informal support networks, something which-that increased further during the postoperative period and sharply decreased as participants recovered from surgery. Although participants valued their independence, and this was a key motivation to have surgery, most accepted the need to rely on family and friends. There was a sense that participants perceived themselves to have layers of support around them: spouses were called upon first for assistance and when they were unable to fulfil support needs participants would seek out extended family and friends. There was a sense of willingness to accept others' awareness of their impaired function and readiness to integrate these public and visible changes in function into their daily

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2
3 experiences. Undergoing surgery also altered the support that participants were able to offer to
4
5 others and caring responsibilities affected the surgical experience and recovery. Both living with OA,
6
7 and undergoing knee replacement surgery, can be associated with threatened, or actual, loss in role
8
9 of helper and supporter to others. However, successful surgery can equate to a reverse of these
10
11 losses, and there is a reduction in interruption to lived experience.
12
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16 Findings support previous literature that has documented the reliance of people with osteoarthritis
17
18 on family and friends for tasks of everyday living [18, 19]. The often short hospital stay and relatively
19
20 rapid discharge after knee replacement means the intensive support offered by health professionals
21
22 is for a time limited period only and responsibility for rehabilitation falls mainly on the patient and
23
24 their spouse, wider family or friends. After surgery, in addition to providing practical assistance and
25
26 personal care, spouses sometimes provided aspects of medical care, ~~which had the potential to~~
27
28 ~~affect roles and relationships within a family unit.~~ There was a sense that for some dyads it was
29
30 particularly during the early postoperative period that recovery from surgery had the potential to
31
32 threaten and interrupt their lived experience and adversely impact on their relationship with their
33
34 spouse. At times there was a need to renegotiate roles and relationships and to take on
35
36 new/changed responsibilities. This adds to previous work involving patients who had undergone hip
37
38 replacement surgery whose family primarily provided support to them during this period [25] and
39
40 lower limb surgery whose family were described as providing unpaid care [12]. However, earlier
41
42 work involving the family carers of people living with long-term chronic illness suggests that this
43
44 group do not see themselves as 'carers'; instead the roles that they undertake are seen as natural
45
46 and a part of normal family relationships [4351], and that older people living with mobility
47
48 difficulties rarely describe their relationships with significant others as 'carer' and 'cared for' [4452].
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55 Furthermore, aside from one participant, even those living alone saw themselves to have solid and
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57 willing support networks who they felt comfortable depending upon after surgery. This insight is not
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3 in keeping with the experiences of participants who had undergone hip surgery; This group who
4 talked of, although hypothetically, being 'adamant' that they would not be happy about returning
5 home without the support of family; feeling that they would not be able to manage [28]. Our
6
7 analytic approach, as one that helps to illuminate the diversity and variability of human experience,
8 may in part explain this discrepancy. Literature has also described the negative implications of
9 reliance on others over the perioperative period in relation to feelings of burden [20, 21].
10
11 Interestingly, this emotion was only described by those participants in our sample who were
12 widowed and therefore lacked the apparently implicit support of a spouse. It is possible that this
13 finding may relate to Heine and colleagues' (2004) interpretation concerning different views about
14 support between older and younger patients who had undergone hip surgery. They report that
15 younger participants in their study felt more of a burden on their family whereas older participants
16 had a different attitude; feeling like they had already looked after their spouse previously so it was
17 now their turn [28].
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34 The notion of independence has arisen previously in work involving patients who have undergone
35 orthopaedic surgery [29] and also underpinned the experiences of those involved in our study.
36 Feelings concerning loss of independence were, for most, tempered by a sense of acceptance that
37 dependency on others was for a discrete period. Literature suggests that independence as a key
38 feature of positive ageing can mean that older people hide signs of decline and refuse care and
39 support [53, 54, 45, 46]. Participants in our study were all over 60 years; however only one said that
40 they hid their difficulties from family and resisted support. This is perhaps because patients, and
41 indirectly their families, had been provided with sufficient information on recovery after knee
42 replacement that allowed them to expect that it would be necessary to depend initially more heavily
43 on others whilst recovering from major surgery. This does however suggests the limitations of this
44 notion and the relevance of interdependence instead to participants' experiences. Furthermore, the
45 way in which less support from formal support networks is accompanied by additional support from
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3 informal networks suggests a type of interdependence with the absence of one relationship being
4 filled with another. This is an idea previously suggested in relation to interdependence of horizontal
5 family relationships and friendships [4755]. It is also apparent that informal care can facilitate the
6 use of formal care, for instance, both pre- and post-surgery participants were reliant on family and
7 friends for lifts to medical appointments. Participants' discourse highlights the dynamic connections
8 between people within their social networks in the context of health and wellbeing. It also highlights
9 participants' flexibility towards acceptance of changes in their relationships with others, with this
10 acceptance perhaps serving the function of preserving the normality of their lived experience.

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14 A large body of work has established the need to consider the role and function of patients'
15 expectations around the perioperative period [56-58]. Our work has highlighted the major role that
16 health professionals can play in informing expectations for recovery. Findings suggest the
17 importance of them providing accurate information to patients concerning postoperative recovery,
18 and the need for them to check their patients understanding of this. Ultimately this may help
19 patients to formulate accurate expectations and limit disappointment. This links to previous
20 qualitative work which suggests that patients should have the opportunity to discuss their
21 expectations of joint replacement in order to limit 'false optimism' [25].

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43 Employing a longitudinal design and use of in-depth interviews facilitated a detailed exploration of
44 participants' experiences of their support networks as they underwent and recovered from knee
45 replacement. Through the use of IPA, we have been able to gain an insider's perspective and
46 increase our understanding of how people electing to undergo knee replacement surgery perceive
47 and experience their support networks as they at first prepare for, and then recover from, their
48 operation. It is hoped that the in-depth understandings generated by inclusion of multiple patient
49 perspectives will also have relevance for how we make sense of recovery from, and subsequently
50 design support, for patients experiencing other types of elective surgery. This detailed exploration

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3 has been facilitated by employing a longitudinal design, use of in-depth interviews, and fine-grained
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5 analytic processes specified by IPA. To ensure analytic rigour we engaged in several validation
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7 strategies: discussion of findings with patient representatives, reflexivity, seeking out and paying
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9 attention to negative cases and have aimed to produce stories that are 'realistic' and 'believable' so
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11 that they are an accurate portrayal of 'all the complexities that exist in real life' (Creswell, 2007,
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13 p.46) [4859].

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20 Qualitative researchers have traditionally chosen to meet face-to-face with participants when
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22 carrying out in-depth interviews. However research in the area now indicates that the mode of
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24 interview may have little impact on the amount, character and depth of data generated during an
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26 interview [4960]. However, in light of this, we designed the study such that initial interviews took
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28 place in person to build rapport, and consider it likely that this enabled the generation of even richer
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30 data during subsequent interviews that were conducted by telephone. Although we did not have
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32 ethical approval to access information about specific characteristics of the 58 patients who did not
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34 take part in the study (for example, marital status, length of stay in hospital), we do not feel that this
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36 knowledge would have influenced our analysis or interpretations. In addition, while the focused
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38 nature of our study may mean that it is difficult to transfer our findings directly to other healthcare
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40 contexts, the depth achieved in the data described, sampling strategy and the inclusion of
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42 participants from a standard, all be it large, NHS hospital, should mean that key findings have
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44 resonance for patients in other healthcare contexts.
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52 All participants in our study returned to their own home after a hospital stay of 3-10 days. Future
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54 research could explore the experiences of those who take a different postoperative pathway (e.g.
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56 when patients experience extended hospital stays or are not discharged to their own home).
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3 Findings also suggest that future work could address the specific impact of age, gender (i.e. gender
4 differences) and cohabitation status on patients' use of support networks.
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10 In sum, we have gained novel perspectives on the trajectories of support used by patients over the
11 journey through knee replacement for osteoarthritis. Patients rely extensively on, and value, both
12 informal and formal support networks over the perioperative period; with use of this support
13 peaking in the weeks following surgery. The ongoing and active role of informal support networks in
14 helping participants cope with the consequences of osteoarthritis and surgery may reduce their
15 need to request or arrange formal support. Although formal support is not necessarily available or
16 accessible it is important that health and social care systems do not assume that patients have
17 family and friends willing or able to undertake caring responsibilities. Findings highlight, from
18 patients' own perspectives, the potential value of postoperative physiotherapy received soon after
19 surgery and the possible role of long-term follow-up after surgery. Findings also show that missing
20 or ill-timed support may have detrimental psychosocial consequences for patients going through
21 joint replacement. Provision of appropriate and adequate care to patients recovering from knee
22 replacement should consider these issues. Finally, development and evaluation of interventions for
23 such patients, and related recommendations for practice, should recognise the importance of
24 informal support and take steps to ensure that support is tailored to individuals and is adequate
25 when informal support networks are not available.
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Or Peer Review

References

- [1] Arthritis Research UK [Internet]. July 2013. Osteoarthritis in general practice. Data and perspectives [cited October 25 2014]. Available from: <http://www.arthritisresearchuk.org/arthritis-information/data-and-statistics/osteoarthritis.aspx>
- [2] National Collaborating Centre for Chronic Conditions. Osteoarthritis: national clinical guideline for care and management in adults. London: Royal College of Physicians; 2008.
- [3] 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. *Sociology of Health & Illness* 2002; 24:227–53.
- [4] Woolhead G, Gooberman-Hill R, Dieppe P, Hawker, G. Night pain in hip and knee osteoarthritis: a focus group study. *Arthritis Care & Research* 2010; 62(7): 944-9.
- [5] Cook C, Pietrobon R, Hegedus E. Osteoarthritis and the impact on quality of life health indicators. *Rheumatology International* 2007; 27(4): 315-21.
- [6] National Institute for Health and Clinical Excellence. The care and management of osteoarthritis in adults. NICE clinical guideline 59. London: National Institute for Health and Clinical Excellence; 2008.
- [7] National Joint Registry for England and Wales [Internet]. 2014. 11th Annual Report 2014 [cited November 5 2014]. Available from: <http://www.njrcentre.org.uk>

1
2
3 [8] Australian Orthopaedic Association [Internet]. 2014. Lay Summary 2014 Annual Report Hip and
4
5 Knee Replacement [cited October 24 2014] Available from:

6
7 <https://aoanjrr.dmac.adelaide.edu.au/annual-reports-2014>
8
9

10
11 [9] Kurtz SM, Ong KL, Lau E, Widmer M, Maravic M, Gómez-Barrena E, de PinaMde F, Manno V,
12
13 Torre M, Walter WL, de Steiger R, Geesink RG, Peltola M, Röder C. International survey of primary
14
15 and revision total knee replacement. International Orthopaedics 2011; 35:1783–9.
16
17

18
19
20 [10] Norwegian Arthroplasty Register [Internet]. 2010. Annual Report. [cited October 24 2014].
21
22 Available from: <http://nrlweb.ihelse.net/eng/>
23
24

25
26 [11] Kurtz S, Ong K, Lau E, Mowat F, Halpern M. Projections of primary and revision hip and knee
27
28 arthroplasty in the United States from 2005 to 2030. Journal of Bone and Joint Surgery [Am] 2007;
29
30 89:780–5.
31
32

33
34 [12] Perry MA, Hudson S, Ardis K. “If I didn't have anybody, what would I have done?”: Experiences
35
36 of older adults and their discharge home after lower limb orthopaedic surgery. Journal of
37
38 Rehabilitation Medicine 2011; 43(10): 916-22.
39
40

41
42 [13] Waddell J, Johnson K, Hein W, Raabe J, FitzGerald G, Turibio F. Orthopaedic practice in total hip
43
44 arthroplasty and total knee arthroplasty: results from the Global Orthopaedic Registry (GLORY).
45
46 American Journal of Orthopedics 2010; 39(9): 5-13.
47
48
49

50
51
52
53
54

1
2
3 [14] Lingard EA, Berven S, Katz JN, Kinemax Outcomes Group. Management and care of patients
4
5 undergoing total knee arthroplasty: variations across different health care settings. *Arthritis Care &*
6
7 *Research* 2000; 13(3):129-36.
8
9

10
11 [15] Jimenez J, Romero, N, Keyson D. Capturing patients' daily life experiences after total hip
12
13 replacement. *Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops.*
14
15 2011; 226-29.
16
17

18
19
20 [16] North Bristol NHS Trust. *Knee Replacement: A guide for patients*; North Bristol NHS Trust; May
21
22 2014.
23
24

25
26 [17] Gustafsson BÅ, Heikkilä K, Ekman SL, Ponzer S. In the hands of formal carers: older patients'
27
28 experiences of care across the perioperative period for joint replacement surgery. *International*
29
30 *Journal of Orthopaedic and Trauma Nursing* 2010; 14(2): 96-108.
31
32
33

34
35 [18] Montin L, Suominen T, Leino-Kilpi H. The experiences of patients undergoing total hip
36
37 replacement. *Journal of Orthopaedic Nursing* 2002; 6(1): 23-9.
38
39
40

41
42 [19] McHugh GA, Silman AJ, Luker KA. Quality of care for people with osteoarthritis: a qualitative
43
44 study. *Journal of Clinical Nursing* 2007; 16(7b): 168-176.
45
46
47

48 [20] Koyama Y, Miyashita M, Irie S, Takatori Y, Yamamoto M, Karita T, Kazuma K. A study of the
49
50 reality of daily life among patients with osteoarthritis of the hip undergoing conservative treatment.
51
52 *Journal of Orthopaedic Nursing* 2007; 11(2): 81-90.
53
54
55

1
2
3 [21] Parsons GE, Godfrey H, Jester RF. Living with severe osteoarthritis while awaiting hip and knee
4 joint replacement surgery. *Musculoskeletal Care* 2009; 7(2):121-35.
5
6

7
8
9 [22] Sherman AM. Social relations and depressive symptoms in older adults with knee osteoarthritis.
10 *Social Science & Medicine* 2003; 56(2): 247-57.
11
12

13
14
15 [23] Evers AW, Kraaimaat FW, Geenen R, Bijlsma JW. Psychosocial predictors of functional change in
16 recently diagnosed rheumatoid arthritis patients. *Behaviour Research and Therapy* 1998; 36(2):179-
17 93.
18
19
20

21
22 [24] NHS Choices [Internet]. 2014 [cited 26 October 2014]; Available from:
23 <http://www.nhs.uk/Conditions/Knee-replacement/Pages/Recovery.aspx>
24
25
26
27
28

29
30 [25] McHugh GA, Luker KA. Individuals' expectations and challenges following total hip replacement:
31 a qualitative study. *Disability and Rehabilitation* 2012; 34(16): 1351-57.
32
33
34
35

36
37 [26] Grant S, St John W, Patterson E. Recovery from total hip replacement surgery: "it's not just
38 physical". *Qualitative Health Research* 2009; 19(11): 1612-20.
39
40
41
42

43 [27] McHugh GA, Luker KA. Influences on individuals with osteoarthritis in deciding to undergo a hip
44 or knee joint replacement: A qualitative study. *Disability and Rehabilitation* 2009; 31(15): 1257-66.
45
46
47
48

49 [28] Heine J, Koch S, Goldie P. Patients' experiences of readiness for discharge following a total hip
50 replacement. *Australian Journal of Physiotherapy* 2004; 50(4): 227-33.
51
52
53
54
55
56
57
58
59
60

1
2
3 [29] Perry MA, Hudson HS, Meys S, Norrie O, Ralph T, Warner S. Older adults' experiences regarding
4 discharge from hospital following orthopaedic intervention: a metasynthesis. Disability and
5 Rehabilitation 2012; 34(4): 267-78.
6
7
8
9

10
11 [30] Plath D. International Policy Perspectives on Independence in Old Age. Journal of Aging & Social
12 Policy 2009; 21(2): 209-23.
13
14
15
16
17

18 [31] Plath D. Independence in old age: The route to social exclusion? British Journal of Social Work
19 2007; 38(7): 1353-69.
20
21
22
23

24 [32] Wilken CS, Walker K, Sandberg JG, Holcomb CA. A qualitative analysis of factors related to late
25 life independence as related by the old-old and viewed through the concept of locus of control.
26 Journal of Aging Studies 2002; 16(1): 73-86.
27
28
29
30
31
32

33 [33] Breheny M, Stephens C. Negotiating a moral identity in the context of later life care. Journal of
34 Aging Studies 2012; 26(4): 438-47.
35
36
37
38
39

40 [34] Robertson A. Beyond apocalyptic demography: Towards a moral economy of interdependence.
41 Ageing and Society 1997; 17: 425-46.
42
43
44
45

46 [35] Elder GH. Time, human agency, and social change: perspectives on the life course. Social
47 Psychology Quarterly 1994; 57: 4-15.
48
49
50
51

52 [36] Breheny M, Stephens C. "I sort of pay back in my own little way": Managing independence and
53 social connectedness through reciprocity. Ageing & Society 2009; 29(8): 1295-1313.
54
55
56
57
58
59
60

1
2
3 [\[37\] Willig C. Introducing qualitative research in psychology: Adventures in theory and method.](#)
4
5 [Berkshire: Open University Press; 2001.](#)
6
7

8
9 [\[38\] Husserl, E. The Crisis of European Sciences and Transcendental Phenomenology. Euanston:](#)
10 [Northwestern University Press; \(1936; trans. 1970\).](#)
11
12

13
14
15 [\[39\] Fade S. Using interpretative phenomenological analysis for public health nutrition and dietetic](#)
16 [research: a practical guide. Proceedings of the Nutrition Society 2004; 63\(4\): 647-53.](#)
17
18
19

20
21
22 [\[4037\]](#) Smith JA. Reflecting on the development of interpretative phenomenological analysis and its
23 contribution to qualitative research in psychology. *Qualitative Research in Psychology* 2004; 1(1): 39-
24
25
26
27 54.
28
29

30
31 [\[41\] Turner A, Barlow, J, Ilbery, B. Play hurt, live hurt: Living with and managing osteoarthritis from](#)
32 [the perspectives of ex-professional footballers. Journal of Health Psychology 2002; 7\(3\): 285-301.](#)
33
34
35

36
37
38 [\[4238\]](#) Smith JA, Eatough V. Interpretative Phenomenological Analysis. In: Breakwell GM, Hammond
39 S, Fife-Schaw C, Smith JA, eds. *Research methods in psychology*. 3rd ed. London: SAGE; 2006. p. 322-
40
41
42
43 41.
44

45
46
47 [\[43\] Smith JA, Osborn M. Interpretative Phenomenological Analysis. In: Breakwell GM, ed. Doing](#)
48 [social psychology research. Oxford: The BPS and Blackwell Publishing Ltd; 2004, p. 229-254.](#)
49
50
51

52
53
54 [\[4439\]](#) Collins K, Nicolson P. The meaning of 'satisfaction' for people with dermatological problems:
55 Reassessing approaches to qualitative health psychology research. *Journal of Health Psychology*
56
57
58 2002; 7: 615–29.
59
60

1
2
3
4
5 [4540] Smith JA, Flowers P, Larkin M. Interpretative Phenomenological Analysis. Theory, Method and
6
7 Research. 1st ed. London: Sage Publications Ltd; 2009.
8
9

10
11 [\[46\] Gooberman-Hill R, Woolhead G, Mackichan F, Ayis S, Williams S, Dieppe P. Assessing chronic](#)
12 [joint pain: lessons from a focus group study. Arthritis & Rheumatology 2007; 57\(4\): 666-71.](#)
13
14
15
16
17
18
19

20
21
22 [\[47\] Hall M, Migay AM, Persad T, Smith J, Yoshida K, Kennedy D, Pagura S. Individuals' experience of](#)
23 [living with osteoarthritis of the knee and perceptions of total knee arthroplasty. Physiotherapy](#)
24 [theory and practice 2008; 24\(3\): 167-81](#)
25
26
27
28
29

30
31 [\[48\] Woolhead GM, Donovan JL, Dieppe PA. Outcomes of total knee replacement: a qualitative](#)
32 [study. Rheumatology \(Oxford\) 2005; 44: 1032-7.](#)
33
34
35
36
37

38 [4941] Smith JA, Jarman M, Osborn M. Doing interpretative phenomenological analysis. In: M.
39 Murray M, Chamberlain, K, eds. Qualitative health psychology: Theories and methods. 1st ed.
40
41 London: Sage, 1999. p. 218-40.
42
43
44
45

46
47 [5042] Millward LJ. The transition to motherhood in an organizational context: An interpretative
48
49 phenomenological analysis. Journal of Occupational and Organizational Psychology 2006; 79(3): 315-
50
51 34.
52
53
54

55 [5143] Adamson J, Donovan, JL. 'Normal disruption', South Asian and African/Caribbean relatives
56
57 caring for an older family member. Social Science & Medicine 2005; 60(1): 37-48.
58
59
60

1
2
3
4
5 [5244] Gooberman-Hill R, Ebrahim S. Informal care at times of change in health and mobility: a
6 qualitative study. Age and Ageing 2006; 35(3): 261-66.
7
8
9

10
11 [5345] Kemp CL, Denton M. The allocation of responsibility for later life: Canadian reflections on the
12 roles of individual, government, employers and families. Ageing & Society 2003; 23(6): 737-76.
13
14
15

16
17 [5446] Perkins, MM, Ball MM, Whittington FJ, Hollingsworth C. Relational autonomy in assisted
18 living: A focus on diverse care settings for older adults. Journal of Aging Studies 2012; 26(2): 214-25.
19
20
21
22

23
24 [4755] Wrzus C, Wagner J, Neyer FJ. The interdependence of horizontal family relationships and
25 friendships relates to higher well-being. Personal Relationships 2012; 19(3): 465-82.
26
27
28

29
30
31 [\[56\] Mancuso CA, Jout J, Salvati EA, Sculco TP. Fulfillment of patients' expectations for total hip
32 arthroplasty. The Journal of bone and joint surgery. American volume. 2009; 91: 2073-8.](#)
33
34
35

36
37 [57] Mahomed NN, Liang MH, Cook EF, Daltroy LH, Fortin PR, Fossel AH, et al. The importance of
38 patient expectations in predicting functional outcomes after total joint arthroplasty. Journal of
39 Rheumatology 2002; 29: 1273-9.
40
41
42
43

44
45 [58] Noble PC, Conditt MA, Cook KF, Mathis KB. Patient expectations affect satisfaction with total
46 knee arthroplasty. Clinical Orthopaedics and Related Research 2006; 452: 35-43.
47
48
49
50

51
52 [5948] Creswell JW, Clark VLP. Designing and conducting mixed methods research. 1st ed. London:
53 Sage; 2007.
54
55
56
57
58
59
60

1
2
3 [6049] Sturges JE, Hanrahan KJ. Comparing telephone and face-to-face qualitative interviewing: a
4
5 research note. Qualitative Research 2004; 4(1): 107-18.
6
7
8
9
10
11
12
13
14
15
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For Peer Review

Table 1. Participant demographics

Pseudonym	Age at first interview	Gender	Co-habitation status	Length of stay in hospital
Mr Armstrong	70	Male	Lives with spouse	10 days
Mr Cook	64	Male	Lives with spouse	8 days
Mrs French	76	Female	Lives alone	10 days
Mr Ings	64	Male	Lives with spouse	5 days
Mr Jackson	68	Male	Lives with spouse	4 days
Mr Clark	65	Male	Lives with spouse	3 days
Mrs Evans	74	Female	Lives alone	6 days
Mrs Biggs	61	Female	Lives with mother and brother-in-law	4 days
Mr Ostafew	78	Male	Lives with spouse	Did not have the operation
Mrs Parker	67	Female	Lives with spouse	Unknown (operation delayed)

Implications for rehabilitation

- Activity undertaken by informal support networks can help patients who undergo knee replacement cope with the consequences of their operation; filling the void when support from health professionals is lacking
- Contact with health professionals after surgery enhances confidence and offers reassurance; helping to facilitate the recovery process from knee replacement
- Findings highlight, from patients' own perspectives, the potential value of postoperative physiotherapy received soon after surgery and the possible role of long-term follow up
- Missing or ill-timed support from health professionals can have negative psychosocial consequences for patients going through joint replacement