
Publisher's PDF, also known as Version of record

License (if available):
CC BY-NC-SA

Link to published version (if available):
10.1016/j.socscimed.2014.06.037

Link to publication record in Explore Bristol Research

PDF-document

This is the final published version of the article (version of record). It first appeared online via Elsevier at http://www.sciencedirect.com/science/article/pii/S0277953614004055. Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available: http://www.bristol.ac.uk/pure/about/ebr-terms
1. Introduction

A concern with reducing waiting times for in-patient elective treatment in the United Kingdom's National Health Service (NHS) has, for many years, been the focus of government policies (Harrison and Appleby, 2009). In 2006 the Department of Health (DoH) introduced new guidelines outlining how patients in the NHS should wait a maximum of 18-weeks from General Practitioner (GP) referral to initial treatment in hospital (DoH and 18 Week Pathway Programme, 2006) and current policy continue to encourage the maintenance of this short waiting time (DoH, 2011; NHS Choices, 2013). Schemes to reduce the time that patients have to wait for treatment have included introduction of extra surgery lists both during the week and at weekends and trusts receiving supplementary finance to build and staff additional operating theatres (McLugh et al., 2008).

The continual drive to reduce waiting times involves monitoring and measuring the passage of time, and this highlights the need to consider the temporal landscape (i.e. how time is created, perceived and ordered) within current healthcare processes. A ‘monochronic’ (Hall, 1983) conceptualisation of time appears to underpin the organisation of the NHS: time is tangible and linear, can be broken into parts and measured by clocks. This notion of time as an objective entity contrasts with a more qualitative and subjective inner time, where time is conceived as a construction of the self, and ‘perceived time, thereafter, represents the mental status of the beholder’ (Wittmann, 2009). It is this latter conceptualisation that may have more applicability to the experiences of patients within the healthcare system.

Klingemann (2000) argues that although different conceptualisations of time have often been discussed by philosophers and novelists, ‘the sociology and psychology of time still lack theoretical coherence and sound empirical foundations’. In the
health arena, sociological work concerning the notion of time has tended to focus on how people think about and manage their illness (Morgan and Thomas, 2009). This is notable in the work of Charmaz (1991), concerned with the way in which adjustment to living with a chronic illness demands individuals to reorder temporal aspects of their daily life and to alter plans and priorities, through changing how time is organised and used. Corbin’s (2003) characterisation of different types of time in health and illness offers an alternative and comprehensive schema which can be used to help understand the changes that take place in time when an individual is faced with ill health. She suggests that time can be broken down into: clock time, historical time, biographical time, perceived time, and internal time. Here clock time is defined as relating to planned time, which for those with illness has to often be scheduled around regular medical regimens and periods when they are not in pain or experiencing fatigue. Perceived time is usually time that is ‘taken-for-granted’ where an individual may postpone activities because time is always expected to be there. However, ill health can end this assumption and time is no longer taken-for-granted.

Richardson et al. (2008) draw on Corbin’s schema to help them understand the concept of time in the lives of people with chronic widespread pain. Their findings highlight the salience of time, particularly ‘controllable time’, in the experiences of those living with this condition. Attention is drawn to the ways in which time manifests itself throughout the everyday experience for individuals with long-term pain. This impact suggests the potential importance of considering the experience of time in the lives of people living with other long-term conditions. However, the notion of time in the experiences of those with osteoarthritis (OA) has to date received little attention, yet OA is one of the most common chronic conditions. It affects around 10% of people aged over 55 years in the United Kingdom (UK) (Peat et al., 2001) and nearly 27 million adults in the United States were estimated to be living with the condition in 2005 (Lawrence et al., 2008). OA is characterised by pain and stiffness in the joints (National Collaborating Centre for Chronic Conditions, 2008), particularly affecting lower limb joints, including the hip. In the UK, exercise, weight loss and manual therapy options as well as analgesic medication are recommended as initial treatments. If these options are deemed ineffective in relieving pain or enhancing function then a person with OA may be referred by their primary care provider — their GP — to orthopaedic services (NICE, 2008). After further assessment, patients may be placed on the waiting list for a hip replacement operation (NICE, 2008). Hip replacement is one of the most common elective procedures performed in the UK with 76,448 primary total hip replacement operations taking place in England and Wales during 2012 alone (NJR, 2013).

For patients with OA, the waiting period from onset of symptoms to surgical intervention can be lengthy and complex. For instance people may initially delay seeking advice from their GP as they are reluctant to ‘bother’ them (Sanders et al., 2004). When they do, diagnosis can be delayed by months and years as patients ask for help with their pain rather than osteoarthritis (Bedson et al., 2005; Sansom et al., 2010). Therefore from initial symptoms to secondary care referral a patient may experience decline in function and the symptoms of their condition can cause distress and impact negatively on their daily life (van Dijk et al., 2006; Hirvonen et al., 2006). In addition, orthopaedic services waiting times were historically identified as problematic, and described as a ‘particularly recalcitrant problem’ (DoH, 2006). This led to the development of an integrated national strategy (The National Orthopaedic Project) which aimed to reduce waiting times, and claimed to have led to no patient having to wait over six months for their operation by the end of December 2005 (DoH, 2006). According to statistics published by NHS England, in January 2014, 86.8% of patients in the speciality of orthopaedics and trauma started treatment in hospital within 18 weeks from GP referral, with patients waiting an average time of 12.6 weeks (NHS England, 2014). This reflects current policy that encourages the maintenance of short waiting times within the NHS (DoH, 2011; NHS choices, 2013).

A growing body of research reporting on the detrimental physical and psychological impact of waiting for elective surgery reflects the significance of the issue of waiting times. During their wait for hip surgery patients have reported experiencing significant increases in pain and physical disability (Davis et al., 2008), high levels of psychological distress (Ackerman et al., 2005) and an overall deterioration in health-related quality of life (Ackerman et al., 2011). A small body of qualitative work provides more detailed insight into the waiting period for elective surgery, highlighting the need to understand who has control over waiting time. Patients awaiting coronary artery bypass (Fitzsimons et al., 2000) felt that their life was on hold and lacked influence over timing of their operation. Similarly, patients waiting for hip or knee replacement (Sjöling et al., 2005) reported powerlessness but also ‘lost dignity and frustration’. It has been suggested that an undetermined wait for surgery and associated experiences of pain and disability may impact on nearly every aspect of everyday life. However, the experience of waiting for elective surgery is multi-faceted and a systematic review of the impact of this experience from the patient perspective has highlighted a need to further explore the experience of waiting time (Carr et al., 2009).

The waiting time for hip replacement is defined by healthcare providers in the context of broader imperative to produce an acceptable waiting time. We already know a great deal about the lead up to surgery in terms of patients’ decisions to have joint replacement, the experience of disability beforehand and consequences of delay (Clark et al., 2004; Hawker et al., 2004; Hudak et al., 2002; Dosanjh et al., 2009; McHugh and Luker, 2009; Sansom et al., 2010). Despite the centrality of time to planning of healthcare around waiting for intervention, we know far less about the complexity of the impact of the period before surgery. Specifically, we know little about how patients on a waiting list for hip replacement experience and perceive time. By achieving better understanding of the experiential dimensions of time we can inform communication practices between healthcare professionals and patients in the lead-up to surgery. This is particularly important given that the rising prevalence of OA will lead to an increasing demand on secondary care resources for such surgery (McHugh et al., 2008). As such, we aimed to examine the experience of time within a longitudinal qualitative study of patients waiting for hip replacement.

2. Methods

2.1. Study design

We designed a longitudinal qualitative study involving patients undergoing hip replacement for OA. The study comprised interviewing patients after they had been placed on a waiting list for hip replacement and again at two to four weeks, six and 12 months post-operatively. The focus of the analysis described here is participants’ journeys towards surgery, and to achieve this we draw solely on data from the pre-operative and two to four week post-operative interviews.

2.2. Sampling and recruitment

Study invitation packs were mailed to 111 patients on a waiting list to undergo hip replacement at a single NHS hospital between
February and December 2011. The hospital conducts a large number of hip replacement operations, providing treatment to patients from across a region. Of those who returned a reply slip \((n = 35)\), we purposively identified a sample of men and women, who were a range of ages. Of the 29 who were invited to take part in an initial interview, 24 agreed. The remaining five were no longer eligible to take part (e.g. they had been recruited into an alternative study that precluded their inclusion; their operation date had been brought forward). Demographic information about these 24 participants (13 men and 11 women, ages 52–82 years) is displayed in Table 1. All names refer to pseudonyms.

All participants provided their written, informed consent to take part immediately prior to the initial interview. The researcher (EJ) also sought participants’ verbal agreement to ongoing participation before each follow-up interview. After interviews had been undertaken with 24 participants on the waiting list for surgery, scrutiny of the data showed that saturation had been reached, and no more patients were approached to take part (Sandelowski, 1995).

2.3. Data collection

In-depth semi-structured interviews were conducted with all 24 participants after they had been placed on a waiting list to have their affected hip replaced. We aimed to interview patients one-three weeks prior to surgery. However, this was not always possible due to patient (e.g. their availability for interview) and hospital factors (e.g. operation dates postponed or brought forward) (Table 1). Follow-up interviews were carried out with 21 of the 24 participants two to four weeks post-operatively. Three participants did not take part in post-operative interviews, two because they chose not to have surgery and one because his medical circumstances precluded a follow-up interview. Initial interviews, which lasted between 65 and 135 min, took place at participants preferred location: either in their own homes \((n = 21)\) or on University premises \((n = 3)\). Interviews undertaken two to four weeks post-operatively, which lasted from 35 to 90 min, largely took place over the telephone, other than when a participant requested a face-to-face interview in their own home \((n = 3)\). In addition, participants whose surgery was delayed by more than three months from their original admission date \((n = 2)\) were asked if they were willing to take part in an additional interview focussing specifically on their experience of delay. One participant (Mr Rayner) agreed to this additional contact in his home. All interviews were conducted by the first author (EJ). On first meeting with a participant the interviewer introduced herself as a member of a research team working for a University and explained that she had an interest in learning more about experiences of health. The interviewer made it clear that she had no medical expertise or training and was not involved in their medical care. Interview questions were guided by topic guides and aimed to elicit participants’ experiences of preparing for, undergoing and recovering from surgery. Probes were used to facilitate elaboration and to achieve depth. Specific topics were informed by existing literature and included those concerning the experience of pain over the peri-operative period (Montin et al., 2002); impact of OA on relationships and psychological wellbeing (Hall et al., 2008; Grant et al., 2009); adaptation to life with a prosthesis (Fujita et al., 2006); and sources of information about joint replacement (Hall et al., 2008). Topic guides were refined through discussion with patient representatives. Ethical approval was provided by South West – Cornwall and Plymouth NRES committee (10/H0203/44).

2.4. Data analysis

Initial analysis of transcripts began shortly after data collection started and was on-going and iterative. Analysis informed further data collection such that early findings were used to refine the topic guides and identify questions to ask in future interviews. Anonymised transcripts of audio-recordings were imported into the qualitative data management software package Atlas.ti®. Transcripts from each participant were combined and treated as one single data set and were analysed using inductive thematic analysis (Braun and Clarke, 2006). One member of the research team (EJ) first identified thematic codes which were grounded in the data. Next through identifying connections between the codes she clustered them into super-ordinate themes. To enhance analysis and enable team discussion and interpretation, team members (JH and RGH) independently coded four transcripts at each time point. A consensus about the final list of themes was reached through discussion among the research team (EJ, JH and RGH). To improve understanding of the whole data set, those aspects of data that appeared to contradict general experiences, were identified and explored. We chose to include the data from the patients who did not have hip replacement surgery because their experience of waiting for surgery in secondary care and the delays that they encountered during this period provide valuable insights.

3. Results

We explored each participant’s journey towards hip replacement surgery, with particular attention on the time from their initial referral to secondary care through to their final surgery date. We identified two superordinate themes: unavoidable changes to use and passage of time in the lead up to surgery and time in the context of healthcare. These themes do not stand alone but are interrelated and help to enhance understanding of the ways in which patients waiting to undergo elective hip replacement experience and conceptualise time.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Time from pre-operative interview to date of surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr Bedford</td>
<td>73</td>
<td>Male</td>
<td>24 days</td>
</tr>
<tr>
<td>Mrs Burton</td>
<td>70</td>
<td>Female</td>
<td>21 days</td>
</tr>
<tr>
<td>Mr Day</td>
<td>74</td>
<td>Male</td>
<td>11 days</td>
</tr>
<tr>
<td>Mr Everett</td>
<td>66</td>
<td>Male</td>
<td>10 days</td>
</tr>
<tr>
<td>Mr Foreman</td>
<td>61</td>
<td>Male</td>
<td>12 days</td>
</tr>
<tr>
<td>Mr Golding</td>
<td>62</td>
<td>Male</td>
<td>1 day</td>
</tr>
<tr>
<td>Mr Grant</td>
<td>82</td>
<td>Male</td>
<td>N/A</td>
</tr>
<tr>
<td>Mrs Hardcastle</td>
<td>71</td>
<td>Female</td>
<td>9 days</td>
</tr>
<tr>
<td>Mr Higgins</td>
<td>71</td>
<td>Male</td>
<td>4 days</td>
</tr>
<tr>
<td>Mr Horton</td>
<td>73</td>
<td>Male</td>
<td>8 days</td>
</tr>
<tr>
<td>Mrs Kade</td>
<td>73</td>
<td>Female</td>
<td>13 days</td>
</tr>
<tr>
<td>Mrs King</td>
<td>53</td>
<td>Female</td>
<td>9 days</td>
</tr>
<tr>
<td>Mrs Lovell</td>
<td>69</td>
<td>Female</td>
<td>7 days</td>
</tr>
<tr>
<td>Mr McKenzie</td>
<td>66</td>
<td>Male</td>
<td>25 days</td>
</tr>
<tr>
<td>Mrs Noble</td>
<td>74</td>
<td>Female</td>
<td>9 days</td>
</tr>
<tr>
<td>Mrs O'Brien</td>
<td>65</td>
<td>Female</td>
<td>7 days</td>
</tr>
<tr>
<td>Mrs Quinn</td>
<td>69</td>
<td>Female</td>
<td>4 days</td>
</tr>
<tr>
<td>Mr Rayner</td>
<td>79</td>
<td>Male</td>
<td>195 days</td>
</tr>
<tr>
<td>Mr Smith</td>
<td>75</td>
<td>Male</td>
<td>18 days</td>
</tr>
<tr>
<td>Mr Thomas</td>
<td>58</td>
<td>Male</td>
<td>16 days</td>
</tr>
<tr>
<td>Mr Upton</td>
<td>52</td>
<td>Male</td>
<td>14 days</td>
</tr>
<tr>
<td>Mrs Vickers</td>
<td>80</td>
<td>Female</td>
<td>3 days</td>
</tr>
<tr>
<td>Mrs Warburton</td>
<td>77</td>
<td>Female</td>
<td>N/A</td>
</tr>
<tr>
<td>Mrs Young</td>
<td>72</td>
<td>Female</td>
<td>2 days</td>
</tr>
</tbody>
</table>

a Did not have surgery – felt ‘too old’ to undergo major surgery.
b Medical circumstances precluded follow up interviews.
c Did not have surgery – reasons unknown.
3.1. Unavoidable changes to use and passage of time in the lead up to surgery

For participants, the progression of time from onset of OA towards hip replacement surgery was increasingly marked and punctuated by the experience of pain. Participants described how unrelenting pain, coupled with the functional difficulties that had arisen as a result of living with OA, meant they had to increasingly make many changes to the way in which they spent their time during the approach to surgery.

Participants spoke of how they were no longer able to engage in the hobbies that they had once enjoyed, such as cricket, bell ringing and cycling. They also had to restrict the length of time that they spent undertaking everyday activities (walking, sitting, driving, and standing) because these could result in pain and discomfort.

I'm reduced on the crosswords, reduced to what I call the boys crossword now. I can't do the cryptic one because I can't sit still long enough with the pain. (Mr Rayner)

Most of those in employment, paid and voluntary, found that they had been forced by their ill health to reduce their working hours or terminate employment altogether.

I also used to work down the community shop. Which I had to give up because I couldn't walk down the hill and walk back…. I was in the village choir. Which I gave up because I couldn't sit still for very long … so that's some of our social life wiped out. (Mr Smith)

Consequently occasions and motivations to leave their home dwindled, and in the lead up to surgery participants' accounts indicated that they found themselves progressively unable to fill their time in the ways that they had previously. For some participants, engagement in external activities outside of their home were limited to key life events and ceremonies, that in themselves were still significant markers of the passing of time.

Just stuck. I mean I haven't been anywhere apart from the doctors. I managed to get to my daughter's wedding in April and my friends funeral in May. But apart from that I just don't go anywhere. I just can't do it. (Mrs Kade)

With diminishing opportunities of how they could pass their days it was apparent that, time, for some participants, was no longer enjoyed in the same way. Instead, participants reported experiencing negative emotions, including frustration, despair and isolation. These feelings themselves could also cause participants to restrict the activities that they undertook. For example, they no longer felt the ability or desire to socialise with others and this consolidated negative emotions.

It's made me feel very isolated because of not being able to get out and go and see people and do things … it does restrict your life really to the sofa. The more, the longer it goes on before the operation the more I'm sitting on the sofa. (Mrs Burton)

In the lead up to surgery the participants spoke of how they found themselves 'sitting down and doing nothing' as opposed to actively engaging with life. They explained that they had to 'stop living' whilst time simply passes by. They talked of 'lost time' whilst waiting for their operation: of wasted months or a cancelled year. A potential consequence of this was that the perceived pace of the passage of time slowed down.

I managed to get out and I've hung towels out this morning. But that's all I do. Sit around for the rest of the day and twiddle my thumbs. (Mrs Vickers)

These feelings of lost time are in part a result of the accumulation of experiences in the lead up to diagnosis and an often long journey to secondary care (see theme 2). For example, participants described 'months and months passing by, wasted' when they experienced misdiagnosis of their symptoms and waited for test results.

It was um, anywhere from you know January 2010 to October 2011 or something like that you know. Uh, uh, we were working on the wrong lines …. I feel I wasted nearly a year of my life. (Mr Horton)

Furthermore, some participants' accounts showed that day and night merged into one another in the lead up to surgery. Daytime hours were often used to rest and participants spoke of taking regular short periods of sleep during this time. This activity was necessary to overcome and seek relief from the pain and exhaustion. Participants also spoke of experiencing daytime sleepiness related to their pain medication. Daytime hours could pass unnoticed because participants were asleep. Conversely, participants spoke of their pain either starting or becoming more intense during the night-time hours, and of this pain frequently and regularly waking them up during the night. Participants' descriptions of their experiences suggested that inability to sleep at night evoked feelings of isolation, upset and distress. It also led to a conflation of day and night.

The other night it was bad and I had to get up and move about, just to try and relieve it. I take paracetamol and sort of get back into bed and read … in the night-time everything is worse because it's so quiet and dark and there's nobody awake … it's a long night. I get up and turn the television on … but I've been forcing myself not to do that, because then I'll go and make a cup of coffee and then it sort of rolls in…. I was waking up at three o'clock and not having any sleep until I went to bed the next night. (Mrs Young)

Several participants found themselves awake for a greater number of hours in the lead up to surgery. This meaning that they felt that time passed more slowly, which seemed to prolong their wait for hip replacement. One participant, Mr Rayner, said that because of pain in his hip, he had not been to bed in the weeks before surgery instead choosing to spend the nights resting in an arm chair for comfort. Night-time provides neither escape nor relief from pain.

3.2. Time in the context of healthcare

Accounts indicated the lengthy and complicated journeys to surgery, often stretching over years. Two factors were fundamental in increasing the length of time participants had to wait from initial onset of their problems through to receiving a referral to secondary care for assessment. First, participants themselves initially delayed seeking advice and support from GPs for their problems. Reasons for this included: fear of the predicted undesirable inevitable (i.e. surgery) and other priorities (e.g. caring for an ill spouse). Second, once accessing primary care it was common for participants to
think that their GP had delayed the process of referral to secondary care. Explanations included: receiving an incorrect diagnosis of their problems and that their GP ‘discouraged’ them as they felt they were ‘not old enough’ to have a hip replacement. Two participants spoke of accessing private healthcare in order to speed up their progression to surgery, paying for a consultation to achieve a referral to the NHS secondary care system for surgery. Most had however lived for years with a painful hip and associated restrictions. It was apparent that any earlier periods of delay could influence participants’ perceptions of time and their impatience with their wait for surgery once in secondary care.

I think the doctors [GPs] could have assessed the problem quicker no doubt … initially the first doctor I saw didn’t think I needed a hip operation. Four months after another doctor decided that maybe I should get checked out in [Hospital name] … That was a long wait. It would have been nice to have gone in maybe March or so and get an assessment and said this needs doing then. I’d have had it done by now…. It’s been long enough now so … we’re ruling out most of this year. This year’s a non-entity. (Mr Smith)

After participants entered secondary care, preparatory activities relating to their admission to hospital for surgery increasingly filled their time. These included attending hospital for education sessions, assessments (e.g. blood tests) and consultations with health professionals, such as anaesthetists and radiologists. Consultations frequently involved long periods of waiting in clinics (‘for up to five hours’) to see the appropriate health professionals. Psychological, social and physical preparation also consumed increasing amounts of time during this pre-operative period. For instance, undertaking exercises as recommended by their healthcare team and making plans such as organising care for an ill spouse or cancelling normal daily commitments. The essential nature of these activities meant that blocks of time had to be taken out of daily life in order to enable participants to focus their attention on preparing for their surgery date.

They give me exercises to do at home and I’ve been doing them religiously. Well they told us to do it twice a day. So I’ve been doing it twice a day…. I would have been working today but I thought I’d take the day off. Give me a chance to get the shopping done, get myself packed, get myself in the right frame of mind to go. (Mr Golding)

Participants’ narratives also suggested that they did not always experience the passage of time before surgery as moving regularly. Two participants spoke of accessing private healthcare in order to speed up their progression to surgery, paying for a consultation to achieve a referral to the NHS secondary care system for surgery. Most had however lived for years with a painful hip and associated restrictions. It was apparent that any earlier periods of delay could influence participants’ perceptions of time and their impatience with their wait for surgery once in secondary care.

I think the doctors [GPs] could have assessed the problem quicker no doubt … initially the first doctor I saw didn’t think I needed a hip operation. Four months after another doctor decided that maybe I should get checked out in [Hospital name] …. That was a long wait. It would have been nice to have gone in maybe March or so and get an assessment and said this needs doing then. I’d have had it done by now…. It’s been long enough now so … we’re ruling out most of this year. This year’s a non-entity. (Mr Smith)

Recent NHS policy encourages the maintenance of a waiting time of less than 18-weeks for surgery once a patient has been referred to secondary care (Doh, 2011). Some participants talked of these current guidelines. Their knowledge of their right to begin consultant-led treatment within this time frame may have heightened their focus and mindfulness of the passage of calendar clock time before surgery. However, there was scepticism about whether their operation would be carried out within this period, and for a few this concern was realised.

Then I heard that the damn thing was being cancelled…. I saw my doctor… My GP last Friday I said, “Look, they’ve cancelled it and put it off.” I said, “Isn’t it funny how I got the appointment date exactly within the 18-weeks.” I said, “I bet they had no intention of doing it then, it was just to keep up the target they have to do, automatically put it back.” (Mr Upton)

Of the 24 participants, half revealed that the length of time they had to wait from referral to surgery had been affected by at least one period of delay. The delay could either be attributed to underlying health conditions (both pre-existing and those diagnosed during pre-operative health screening) or hospital factors (e.g. administrator error and equipment failure). Some learnt the news that their operation was cancelled in advance of the date but for others it was only on the day of surgery. The timing of the operation is therefore not a static entity and participants recalled how changes to it could lead to feelings of disbelief, devastation, helplessness and frustration.

Mr McKenzie: I went in on the 7th August at seven o’clock …. Half-past three in the afternoon, they said “oh your operations cancelled” … they said that the two previous operations had had problems … and so my time slot was gone.

Interviewer: So how did you feel when they told you that then?
Mr McKenzie: I was a bit peed off actually to be honest with you. I was really upset and I wasn’t very happy at all.

Although some participants were informed of their new operation date immediately upon cancellation others were left ‘living in limbo’ whilst waiting for their new appointment. Participants described how this situation extended the length of time that they, and their family, were unable to get on with their life. It meant that they had to ‘put off making decisions’ and faced an uncertain future, of which they lacked control. This was in relation to short-term plans for everyday life, such as day trips and holidays. It also concerned more significant life plans, such as, whether to make adaptations to the home to assist with everyday living (e.g. putting in a downstairs shower room) or to move into a single-storey home without the challenge of stairs.
Yeah you can never make any plans, and you’re just in limbo really – what if? (Mr Rayner)

Waiting is a bit traumatic but that’s only because it disrupts your life really. You can’t plan ahead with anything if you don’t know when you’re going to have it done. (Mrs Noble)

It was also during this wait that participants were at risk of experiencing further deterioration in their overall functional health and psychological wellbeing.

The pain is more in the knee. I can’t stand on my leg at all now .... You need some quick action because you deteriorate very quickly. (Mr Rayner)

Conversely, some participants had the opportunity to bring forward the date of their operation. For instance, they were offered an earlier date when a space appeared on an operating list due to a cancellation. Others spoke of being given the chance to change surgeons, and accepted this so to receive an earlier date. However, for several participants their surgery date did not move merely forwards or backwards in time once they had been placed on the waiting list for their operation. Instead they experienced the date of their surgery as moving both forwards and backwards. For instance, participants spoke of changing surgeons to bring forward their operation date to subsequently experience cancellation and postponement of their operation to allow for essential management of other health conditions (for instance Type 2 diabetes) prior to surgery. As a result participants were forced to once again put their lives on hold and to continue to live with the uncertainty of their situation.

4. Discussion

This study explored how patients awaiting hip replacement experienced and conceptualised time. Narratives revealed that increasing pain and deterioration in functional wellbeing altered the experience of time in the lead up to surgery. For many, the dichotomy of day and night no longer existed and participants increasingly made changes to how they spent their time. There were new restrictions and time was sometimes lost or wasted instead of spent on desirable and enjoyable activities. Accounts mirror those of people living with the consequences of stroke (Rittman et al., 2004) as participants experienced disruption to the temporal order of everyday routines and activities. This happened alongside a sense of time slowing down as there were fewer activities to choose from ‘to fill idle time’.

Corbin (2003) writes that time is precious and not taken for granted during illness. She also suggests that people living with illness watch clock time in order to organise the activities that they must perform because of illness. For people waiting for surgery, the healthcare system operates a clock that is outside their control, and time as experienced by these people is influenced both by the need to adapt their everyday activities as well as their awareness of the date of their surgery. Time, like Corbin suggests, was often no longer scheduled around usual routines or what they wanted to do. For participants in this study the time before surgery was shaped and punctuated by a consuming schedule of activities that they were required to undertake before admission to hospital, such as medical appointments. Therefore, time was no longer open-ended but driven towards and focused on a future operation date. Importantly, this date was not static. Participants described how alterations made by the healthcare system (e.g. cancellations) impacted on the date of the surgery. Changing perceptions and estimates of duration also meant that the operation date could appear further away or closer. Changes to the date made by the system and changing perceptions both had implications for wellbeing. These insights into how time is experienced by patients on a waiting list for hip replacement may help to explain potential (dis)satisfaction with healthcare.

Previous studies have identified the inconvenience caused by cancellation of surgical intervention (Ivarsson et al., 2002, 2004) and the detrimental impact on patients’ emotional wellbeing and pain status when this occurs (Eldas and Asian, 2004). Similar consequences of such events are also evident in the narratives of participants involved in our study. Accounts also mirror those of patients involved in earlier qualitative studies who talked of lives ‘on hold’ while waiting for planned surgery, that they were ‘in limbo’, not able to plan for the future and lacked influence over when their operation would take place (Fitzsimons et al., 2000; Thomas et al., 2013). However, by exploring waiting for surgery in the context of an understanding of time as experienced than as an absolute, our study shows that time itself is open to interpretation and that participants’ experiences of time may contrast with the concept of time as used by healthcare. The attempts by some participants to achieve control over the timing of surgery serve to highlight their awareness of these differences as they sought to bring the timing of healthcare into line with their own needs, for instance by seeking private consultations or changing surgeons. The opportunity for participants to have some influence over the timing of their operation reflects the current NHS system, which focuses on providing a healthcare service that places patients at the centre of decision-making (DoH, 2012). Furthermore, uncertainty is embedded in the experience of living with chronic illness (Williams, 2000) and was also evident in participants’ accounts in relation to diagnosis of OA and changes to pain and functional wellbeing. The ‘medical merry-go-round’ (Robinson 1989 cited in Williams, 2000) that living with OA brings also persists in relation to awaiting surgery.

Yet the experience of waiting to have an operation has not always been reported as undesirable: waiting can be seen instead as a chance to ‘live full lives’, even though pain and disability exists (Carr et al., 2009). Patients waiting for knee or hip surgery have previously talked of maintaining the feeling that they were ‘living a full life’ through seeking different interests and ‘contenting oneself’ with what they could still accomplish (Sjöling et al., 2005). However, findings from our work contradict these. Participant’s narratives suggest they experienced a world that was closing in and that lacked these opportunities and alternative ways of passing their time. These findings may reflect differences in healthcare context or simply the complexity of experiences during the wait for surgery. Previous work has already discussed the lengthy and complex journeys that OA patients may have to secondary care (Bedson et al., 2005; Sansom et al., 2010). However we have shown the implications that this initial period can have for later perceptions and experience of time while in secondary care. For instance, increasing a person’s impatience with their wait for surgery, even if they experience ‘usual care’, with no delays. This reinforces the importance of considering the whole wait time for patients, including that preceding referral to secondary care. It also highlights the emotional impact of waiting for surgery, even when delay and cancellation of surgery date do not take place.

Use of in-depth interviews facilitated a detailed exploration of participants’ experience of time in the lead up to hip replacement. Follow-up interviews allowed for clarification of any issues raised in earlier interviews. They also facilitated the development of a closer researcher—participant rapport, which encouraged the disclosure of personal accounts; helping to generate novel insights and richer data. In the pre-operative and two to four week post-
operative interviews, participants reflected on their experiences of waiting for surgery, which required retrospective and might have been influenced by interview timing and surgical outcome. However, we did not find any differences in accounts about the period of waiting from pre- and post-operative interviews. The use of a topic guide allowed consistent exploration of salient issues across participants but also the opportunity for additional probing and reflection in order to facilitate examination of prominent and unanticipated issues. To ensure analytic rigour, analysis was conducted by a team of experienced qualitative researchers and included double-coding and consensus to arrive at the final list of themes. A key strength of our work is the inductive nature of our approach: time emerged from the data as a key concern and over the course of our analysis it became increasingly evident how salient and relevant this concept was to participants. We do not claim that the experiences of the participants were representative of everyone awaiting hip replacement surgery, however, achievement of saturation together with the rigour of analysis helps to improve the credibility of findings.

5. Conclusion

Participants’ narratives reveal the complex, multi-dimensional nature and subjectivity of the experience and conceptualisation of time in the lead up to surgery. Their experiences do not accurately reflect the linear, monochronic conceptualisation of time clearly embedded in the healthcare system, with its policy focused on targets and measurement of (segments of) time once a patient is scheduled for surgery against the external ticking of the (medical) clock. Findings demonstrate a need for health professionals to acknowledge these differences and to recognise the fluid and dynamic nature of time and broader temporal issues embedded in the perceptions, interpretations and experiences of patients in the lead up to hip replacement. Insights generated also raise questions about how this can best be achieved.

Declaration of funding

This article presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research programme (RP-PC-0407-10070). The views expressed in this article are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The research team acknowledge the support of the NIHR through the Comprehensive Clinical Research Network.

Acknowledgements

We thank the patients who took part in the study and acknowledge the invaluable support of the RESTORE research team. Thank you also to Louise Hawkins and Catharine Elliot who transcribed the audio-recordings.

References


