Title:

Misconceived expectations. Patient reflections on the total knee replacement journey

Author Manuscript

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as doi: [10.1002/msc.1475](https://doi.org/10.1002/msc.1475)

Abstract:

Introduction: Fifty percent of patients consent for total knee replacement (TKR) with unrealistic expectations about what it involves and can achieve. A framework is needed to help surgeons identify key knowledge gaps and misconceptions that can be targeted during the informed consent process. In this qualitative study we explored knowledge gaps and misconceptions by asking patients to reflect on their expectations along the TKR journey. **Methods:** Eligible adults were ≥ 18 years, 12-months post-TKR and had completed a validated expectations questionnaire pre-TKR as part of a joint replacement registry. To capture a variety of perspectives, people with a range of pre-TKR expectations scores were invited. In interviews, participants reflected on anticipated and actual experiences, and unexpected experiences they had along the way. Transcripts were analysed through inductive thematic analysis. Recruitment ceased when thematic saturation was reached. **Ethics Approval:** St Vincent's Hospital Melbourne Ethics Committee (LRR 077/18). **Results:** In the final sample ($n=20$; 50% female; median age=72 years; contralateral TKR=11); all participants described instances where their anticipated and actual experiences diverged including; high expectations of improvements in pain/function (*Pre-surgical optimism*); lacking awareness about anaesthetic procedures (*Peri-operative misunderstandings*); feeling unprepared for the length of the recovery period (*Post-operative misestimations*); and trying to make sense of ongoing functional limitations (*Long-term misattributions*). **Discussion and Conclusion:** These findings are captured in a preliminary framework of therapeutic misconception. While future research is needed to test this framework prospectively in larger more generalisable samples, surgeons can consider these key knowledge gaps and misconceptions when consenting for TKR.

Keywords:

Total knee replacement; Knee arthroplasty; Patient expectations; Informed consent; Qualitative research

Introduction:

Expectations have long been known to play a key role in treatment outcomes. Neurobiological models have shown that expectations influence changes at the biochemical, anatomical and cellular level, which can modify the course of a symptom and/or a disease (Colloca & Benedetti, 2005). Marketing theory proposes that a discrepancy between expected and experienced treatment outcomes can lead to patient dissatisfaction (Scott et al., 2012), which has turned attention to the importance of 'realistic' expectations. 'Realistic expectations' is consistent with the ethical principles of informed consent, which state that care providers have an ethical, legal and regulatory obligation to ensure that patients accurately weigh up the risks and benefits of proposed treatments to make informed decisions about their own care (J. W. Jones, McCullough, & Richman, 2007).

In the context of Total Knee Replacement (TKR) for osteoarthritis, evidence suggests that most patients overestimate the expected benefit of TKR. While most expect to be pain-free post-TKR, only around 40% of patients report no knee pain two years later (Mannion, Kampfen, Munqinger, & Kramers-de Quervain, 2009). Symptoms including residual pain, stiffness, crepitus and difficulties with functional tasks such as stair climbing and squatting, persist in up to a third of patients one year post-TKR (Nam et al., 2016; Parvizi et al., 2014). Despite objective signs of surgical success, 20-40% of patients report a level of dissatisfaction with the surgical outcome (Bourne, Chesworth, Davis, Mahomed, & Charron, 2010).

Currently 50% of patients wait-listed for TKR have discordantly high expectations compared to that of their surgeons (Ghomrawi et al., 2011), suggesting that patients are consenting for surgery with unrealistic expectations about what surgery can achieve. To help understand this discrepancy, we have previously conducted qualitative research with twenty orthopaedic surgeons at one of Australia's largest public joint replacement services (Bunzli et al., 2017). According to the surgeons, 'realistic' expectations for TKR were the removal of diseased tissue in the knee, with some corresponding improvement in pain and function post-TKR. All surgeons believed that it was common for patients to present with 'unrealistic' expectations for TKR and that, left unaddressed, these could lead to dissatisfaction post-surgery. However many, particularly less experienced surgeons, reported difficulties assessing the

range of expectations that patients present with pre-TKR, especially in patients with psychosocial factors such as lower health literacy and high anxiety.

To assist in identifying and targeting patient expectations for TKR, surgeons may benefit from a framework to draw on (Mulsow, Feeley, & Tierney, 2012). To be clinically useful, such a framework should be grounded in the needs of patients and draw attention to knowledge gaps and misconceptions that may be targeted during the informed consent process (C. Jones & Suarez-Almazor, 2017). Towards such a framework, in this qualitative study we explored knowledge gaps and misconceptions by asking patients to reflect on their expectations along the TKR journey.

Methods:

Study approval was granted by the St Vincent's Hospital Melbourne Human Research Ethics Committee (LRR 077/18).

Aims and design: The theoretical approach underpinning this qualitative study was Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2019). Reflexive thematic analysis was selected as the researchers played an active role in the construction of meaning of the participants experiences via their 'world view' as clinician/researchers with backgrounds in physiotherapy, orthopaedic nursing, orthopaedic surgery and rheumatology and common interests in optimising patient selection and patient outcomes from orthopaedic surgery. Data was collected through semi-structured interviews with participants 12-months post-surgery. Previous research has shown that patients' expectations continue to be shaped after TKR surgery (Goldsmith et al., 2017) and while the recall of expectations is inherently biased, this design provided insight into the 'unformed expectations' that patients are unable to articulate pre-surgery due to not knowing what to expect (Bowling et al., 2012) . Through analysis of participants reflections' our objective was to develop a preliminary framework which could then be applied prospectively to a pre-operative sample.

Inclusion criteria: Eligible individuals were English-speaking, aged ≥ 18 years who had undergone a primary, elective TKR for knee osteoarthritis at one public hospital in Australia 12 months prior, and who had completed the Hospital for Special Surgery (HSS) Knee Replacement Expectations Survey

(Mancuso et al., 2008) as part of routine pre-surgical data collected for a joint replacement registry. The 12-month time frame was chosen as expectations tend to stabilize as symptoms stabilize in the 12 months post-surgery (Levinger et al., 2018).

Measures: The HSS was developed to evaluate expectations related to different aspects of recovery from TKR, including pain relief and functional abilities. It has 17 items when the walking items are considered collectively and 19 items when the walking items are considered separately (Mancuso et al., 2008). For each item, respondents indicate how much improvement they expect on a scale of: 0 (I do not have this expectation); 1 (a little improvement); 2 (a moderate amount of improvement); 3 (a lot of improvement) and; 4 (complete improvement/back to normal). The total raw score is transformed $[(\text{raw score}/76) \times 100]$ to yield a score out of 100, with higher scores indicating higher expectations (Mancuso et al., 2008). While the HSS is reliable, valid (Mancuso et al., 2008) and commonly used in TKR research, cut-offs scores for high and low expectations have not been reported (Zywiell, Mahomed, Gandhi, Perruccio, & Mahomed, 2013).

Recruitment: To capture a broad range of perspectives and experiences, we employed maximum variation sampling (Leopold, 2019), purposely selecting a sample which represented a range of scores on the HSS, a range of ages and an equal representation of gender. To do this, we identified candidates with a range of scores on the HSS and sent invitation letters out in batches of twenty; to ten candidates with lower expectations (scores of 0 or 1 on at least two items) and ten with higher expectations (scores of 3 or 4 on all items) who represented a range of ages and an equal representation of gender. Individuals received a follow-up phone call one week later inviting them to participate. Data collection and analysis were conducted in parallel. This enabled us to check that we were capturing a range of voices in our sample. For example, after ten interviews we had not captured older females with higher scores on the HSS, so we specifically reached out to eligible individuals who fit this profile and invited them to participate. This also enabled us to adapt our interview schedule to pursue and challenge emerging themes in subsequent interviews. For example, in early interviews, participants described being unaware that they would receive a regional rather than general anaesthetic for surgery. We therefore added a question in our interview schedule to explore participants awareness of what type of anaesthetic

they would receive. We conducted 'theoretical testing' of the emerging theme 'anaesthetic surprise' by including participants in our sample who had previously received a contralateral TKR and comparing their awareness of peri-operative procedures with those who had undergone TKR for the first time. Interviews continued until sufficient patterns could be identified in the data to fulfill the research aim, at which point the research team deemed saturation had been reached and recruitment ceased.

Invitation letters were sent to 40 people. Twelve opted-in by contacting the researchers. An additional 10 were recruited through follow-up phone calls. One person declined at the time of interview citing poor health and one was subsequently unable to be contacted for interview. Twenty people gave informed consent and participated.

Data collection: Individuals received a study information sheet, a verbal explanation and had the opportunity to ask questions before consenting. Age, gender and history of contralateral TKR were recorded for each participant. Participants had the choice of a face-to-face interview at the orthopaedic clinic, or a phone interview to accommodate potential limited mobility. Interviews were conducted by one of two experienced qualitative researchers (a post-doctoral researcher (SB) and research assistant (PO)). None of the research team was previously known to the participants or involved in their care.

In semi-structured interviews, participants described their expectations for TKR in a chronological way, starting with their pre-surgical expectations to the present day. Participants were prompted to consider how their anticipated experiences compared to their actual experiences and any unexpected experiences which occurred along the way (Table 1). The two interviewers met after each interview to discuss any new concepts arising from the interview that could be explored in subsequent interviews. Interviews lasted 30-45 minutes on average, were audio recorded, transcribed and de-identified prior to analysis.

Data analysis: Adopting inductive thematic analysis (Braun & Clarke, 2019), we identified concepts related to patient expectations in the interview data rather than fitting the data into an *a priori* framework. Two researchers identified codes on an ongoing basis throughout the data collection (SB; PO). The resulting list of codes were combined into a provisional codebook. This provisional codebook was then applied to all transcripts by one researcher (SB) and through this process codes were collapsed and expanded as necessary, yielding a refined codebook (SB). A second researcher (NK) applied the

refined codebook to a sample of six transcripts to check that it covered all relevant concepts. Coded data were organized into themes and presented to the authorship team where they were discussed, refined and challenged in the context of existing theory and clinical practice. The organisation of codes into themes and the abstraction of an overarching theme is presented in Table 2.

Results

In the final sample (n=20; 50% female; median age=72 years) 11 had previously undergone contralateral TKR (Table 3). None of the participants had experienced a major medical or surgical complication post-TKR.

Overarching theme: Therapeutic misconception

All participants described instances where their anticipated and actual experiences diverged. These discrepancies, captured in the overarching theme of 'therapeutic misconception', were grouped into four themes: i) pre-operative optimism, ii) peri-operative misunderstandings, iii) post-operative misestimations, iv) long-term misattributions. These themes are described below and supported by quotes indexed by the participants' study identification number, their gender (male (M) or female (F)), age, history of contralateral TKR (first or second TKR) and level of pre-operative expectation (lower or higher). For example: Participant 1, F, 70, first TKR, lower. Themes were consistent across the sample, regardless of HSS score or history of contralateral TKR; any exceptions to this are identified and discussed.

Theme 1. Pre-operative optimism

When recalling their pre-surgical expectations, most participants described high expectations that TKR would reduce their pain and improve their ability to walk normally. During the interview, eight participants said that they had expected to be pain-free. Participant 17 for example expected to be 'rid of the pain': “[I expected] two things mainly. One was, naturally, to be rid of the pain that I had. And the second was to be able to walk again” (Participant 17, F, 76, first TKR, higher). Only one participant found it difficult to articulate his pre-surgical expectations because he had never undergone surgery before and didn't know what to expect: ““I didn't know what I was going to go through because I had never had any major operation in my life, and I didn't know what to expect.” (Participant 9, M, 77, first

TKR, lower). Trait optimism appeared to play a role in high expectations, with many participants describing themselves as having an optimistic outlook on life. For example, Participant 5, who notably had lower expectations on the pre-operative HSS, declared: *"I'm generally optimistic in everything, rather than being pessimistic. I just thought everything would work out fine"* (Participant 5, M, 72, second TKR, lower). For most participants who had undergone TKR on the contralateral limb, their previous experience of surgery had a strong influence on their expectations pre-surgery. Those who had a positive outcome from their contralateral TKR described themselves as optimistic that they would achieve a good outcome: *"I was certainly optimistic because of having had one done and being virtually pain-free afterwards"* (Participant 18, M, 69, second TKR, higher). A few participants who had undergone a contralateral TKR over ten years ago and experienced suboptimal outcomes, remained optimistic that they would achieve a better outcome this time around because of 'medical advancements in TKR technology': *"It had been such a long time since the previous TKR and I thought technology whatever is so much better"* (Participant 3, F 60, second TKR, higher).

Theme 2. Peri-operative misunderstandings

Ten participants said they were surprised by the anaesthesia they received, only discovering that they would have a regional rather than general anaesthesia as they were being 'wheeled in' for surgery. For example, Participant 9 only realised he 'wouldn't be out to it' when he was receiving the 'needle in his spine': *"When I was having surgery, they took me into the anaesthetic room to put a needle in my spine to cut any pain, but it only affected the lower part of my body... I didn't have a clue. I just thought I will be out to it and wouldn't know a thing until I woke up... It was only when they gave me the injection to deaden the lower part of the body, I knew I wouldn't be out to it"* (Participant 9, M, 77, first TKR, lower). Not realising that they would receive a spinal block meant some participants were unprepared for what they would see, hear and feel during surgery. For some this was a positive experience; for example, Participant 9 said that the experience prompted him to reflect on what his knee had been through and how important the rehabilitation phase of recovery would be: *"I was very surprised, but I was quite happy about it. I could hear the surgeon saying 'will you please pass me the saw? The grinder?' They were cutting away, but I couldn't feel a thing, so to me that was interesting... It made*

me think, well I am going through a fair bit here. My knee is never going to get stronger unless I do all their work and rehabilitation!" (Participant 9, M, 77, first TKR, lower). Participant 5 described the experience as 'amusing' but suggested that others might find the experience distressing: "After I had the epidural they put up this curtain and I thought, I wonder what they're doing and the next minute I could hear the electric saw going! I was amused more than anything else, because I am a plumber I felt like saying 'what sort of blade are you using?' It didn't hurt at all, and it didn't worry me, but other people might panic over it" (Participant 5, M, 76, second TKR, lower). And indeed, Participant 20 described the experience of 'smelling burning bone and hearing the whine of saws' as 'scary': "I can understand, they get a better result, they get people on their feet. But it's a bit freaky finding out just as you're being wheeled into the operating theatre that they're going to give you a spinal not a general... I mean women are more used to it because they're predominantly with birth. I didn't understand it, I was thinking what the hell's an epidural? Am I going to be sitting there with a local and be aware of everything that is going on? No thank you. Especially after I smelt burning bone and heard the whine of those saws, I don't want to be awake for that!" (Participant 20, M, 64, second TKR, higher). Participant 12, who also reported being 'surprised' by the regional anaesthetic, said that he had had difficulty understanding the pre-operative information he was provided with: "I was given a brochure. The brochure doesn't really give you much of an understanding, not in layman's terms anyway... I wouldn't say a high educated person, but someone who is actually not well-educated, it would probably be a bit over the top for them, trying to understand what the protocols and procedures are" (Participant 12, M, 56, second TKR, lower).

Theme 3. Post-operative misestimations

Despite most being happy with their long-term outcomes, half of the participants felt that they had misestimated the length of the recovery period. For example, Participant 8 reported: "I think it was not knowing what I should feel or what stage it should be progressing at. I understand that everybody has a different sort of frame of what happens and how it takes place, but I just felt that I was not told enough as to what to expect from it. I thought a matter of six weeks and I'd be running around like a champion again. But basically, it has been nearly 12 months and I really feel that I'm only getting the relief and

benefit from it now” (Participant 8, M, 75, second TKR, lower). Ten participants said they had expected to recover quickly even though they had been advised by their surgeons that this might not be the case. For Participant 20, the experiences of others in his social circle appeared to have a stronger influence on his expectations for the recovery period than the 'warning' he received from his surgeon: *“The surgeon was completely open and honest about it, he said look, your expectations might not be what you think, what you can and can't do. But some things will be better. I guess the surgeon's warnings surprised me a bit, but I still had faith. I had spoken to a lot of other people who had it done, and I was sort of cautious but confident that it would be alright”* (Participant 20, M, 64, second TKR, higher). For others, previous positive experiences of surgery increased confidence in one's ability to recover from surgery: *“I went into it thinking well, I've been warned about this, but I didn't take it in. I think even a doctor told me that the knee isn't one to take lightly. But I have recovered well from surgeries in the past, so I had high expectations”* (Participant 10, F, 71, first TKR, higher). Social networks also appeared to play a role in high expectations about the recovery period. Participant 1 had been told that the recovery period could be difficult; however, expected to recover quickly because she was younger and in better health than her peers: *“I talked about it with my GP and over time I talked to other people about knee replacements and that was where I found out that, yes you go through hell for 12 months afterwards. And I said ‘Oh yeah you're pulling my leg, you're a lot older than me’, but it turns out it was exactly as they said”* (Participant 1, F, 70, first TKR, lower). For a few participants, feeling unprepared for the intensity and duration of pain they experienced during the recovery period had a significant psychological impact. For example, Participant 17 reported that during the recovery period, she found herself questioning whether she should have had surgery in the first place, describing feelings of fear, desperation and uncertainty about when the pain would resolve: *“I actually felt as if I'd had a sort of a breakdown. Because of the severity of the pain...all I could do was cry. It was frightening, and just so very unexpected”* (Participant 17, F, 76, first TKR, higher).

Theme 4. Long-term misattributions

While at the start of their journey, participants reported attributing functional limitations to their osteoarthritic knee, many continued to experience functional limitations despite improvements in their

knee symptoms (e.g. pain, stiffness) post-surgery. Some participants made sense of these functional limitations by adjusting their beliefs about their cause, attributing ongoing limitations to comorbidities or age. For example, Participant 5, who had high pre-surgical expectations that TKR would improve his ability to walk, now attributed his persistent difficulties walking to being overweight, not to his knee: *"The knees came up to what I hoped they would. I still have a bit of difficulty in walking, but that's not through the knees, it's because I'm a bit overweight. The old diet story"* (Participant 5, M, 72, second TKR, lower). Only one participant had experienced a relapse of knee pain but after consulting his surgeon, he believed his knee pain was referred from his 'bad hip': *"Well my expectations were met until probably six months ago when I started to get pain again in the knee. I said to the surgeon, 'Look. I still can't walk properly'. What showed up in the xray was how bad the hip is. I sort of blamed the knee not thinking it was the hip. I had been disappointed...until I realised how bad the hip was and that made sense to me"* (Participant 13, M, 71, second TKR, higher). For a couple of participants, concerns about the longevity of the prosthesis itself and the need to protect the prosthesis motivated activity restrictions in the absence of any ongoing knee symptoms or comorbidities. For example, Participant 2 believed 'the less I use it, the longer it will last': *"How long the knee is going to last is another thing, too. That is playing on my mind. They say anything from 10 to 20 years. I am thinking the less I use it, the longer it will last"* (Participant 2, M, 70, second TKR, lower).

Discussion

Reflecting on their expectations across the TKR journey, all participants described instances where their anticipated and actual experiences diverged including; anticipated versus actual functional outcomes, experiences of peri-operative procedures and the length of the recovery period. We captured these key knowledge gaps and misconceptions in a preliminary framework, adapted from an existing model of informed consent for research participants (Horng & Grady, 2003) (Figure 1). Underpinned by trait optimism, health literacy, previous experiences of surgery and social comparisons, this framework of 'therapeutic misconception' describes four dimensions of therapeutic misconception; therapeutic optimism, therapeutic misunderstanding, therapeutic misestimation and therapeutic misattribution. We

propose that these dimensions either alone or in combination run counter to the requirements for adequate informed consent for TKR.

[Insert Figure 1]

Therapeutic optimism has been described elsewhere in the medical literature as excessive hope or optimism in a positive treatment outcome (Chou & O'Rourke, 2012). In this study, participants described pre-operative optimism related to the treatment itself i.e. beliefs that TKR will have a positive effect on pain and function, as well as their ability to carry out the actions needed to cope with TKR. These two 'applied expectations', as they are referred to in the literature, are sufficient in and of themselves to promote a positive response to the treatment (Bowling et al., 2012) and therefore high applied expectations are usually encouraged to promote positive outcomes (Bowling et al., 2012). However in the context of informed consent, therapeutic optimism may be considered a form of self-deception (Horng & Grady, 2003) and it is the surgeons' duty to ensure patients accurately understand what their likely treatment outcomes will be, so they can make informed decisions about their own care.

Therapeutic misunderstanding can be considered as a patient's misunderstanding about any aspect of the procedure they are about to receive. In this study, half of the participants reported a lack of awareness or misunderstanding about the anaesthetic procedure. According to the Australian and New Zealand College of Anaesthetists Guidelines (Australian and New Zealand College of Anaesthetists (ANSCA), 2016), the pre-anaesthesia consultation should take place at an appropriate time prior to the planned procedure and that, in the case of elective procedures, it is not appropriate for this consultation to occur in the operating theatre or anaesthetic bay. Despite this, over half of the participants in our study reported being unaware that they would receive a spinal block, rather than general anaesthesia, in advance of the procedure. Many described their surprise at experiencing the sights, sounds and smells of surgery, although we note that the use of sedation during spinal anaesthesia is ubiquitous and this may have altered the patients' recollection of intra-operative experiences. Similar findings have been noted among patients undergoing elective joint replacement surgery in the UK (Strickland et al., 2017), suggesting that this experience may not be unique to our hospital setting. At our hospital, all patients

scheduled for TKR attend a pre-admission appointment 2-4 weeks prior to surgery, during which they discuss anaesthetic options with a nurse and receive an anaesthetic information leaflet to take home. On the day of surgery, all patients meet with their anaesthetist and have an opportunity to ask questions. Again, it is possible that patients who are in pain and anxious about their upcoming surgery are less likely to retain important information related to their anaesthesia (Richardson, 2013). It is also possible that anaesthetists are not fully informing patients about their options for anaesthesia because they believe that certain types of information will unnecessarily instill fear and apprehension in their patients, or they assume that patients are unable to comprehend this information (Burkle, Pasternak, Armstrong, & Keegan, 2013). Further qualitative research involving observation of pre-admission appointments combined with patient interviews is warranted to understand why patients are not more involved in their choice of anaesthesia.

Therapeutic misestimation can be considered as an unrealistic appraisal of the risks and benefits of an intervention. Half of the participants in our study reported being told by their surgeons that the recovery period could be difficult and that their expectations of pain relief and restoration of function might not all be met. Despite this, high expectations that a brief recovery period would lead to a resolution in pain persisted in this sample. While qualitative studies from Canada and Europe have also found that patients undergoing joint replacement are unprepared for the severity and length of the recovery period (Goldsmith et al., 2017; Kennedy et al., 2017; McHugh & Luker, 2012; Soever et al., 2010), this description of cognitive dissonance is novel to the TKR literature and has important clinical implications. Cognitive dissonance is an aversive state that occurs when an individual is provided with information inconsistent with their existing beliefs. If they are unable to change their beliefs, individuals may deny the conflicting information in order to restore a state of consistency (Festinger, 1962). Consistent with expectation theory, our study illustrates that patients present for TKR with expectations based on personal experiences, observation of others and information sources such as clinicians (Bandura, 2004). It is possible that confirmation bias, reinforced by trait optimism, makes it more likely that patients dismiss information which challenges their existing beliefs, and retain information which confirms their beliefs (Aspenberg, 2014). This may particularly be the case for patients with end-stage

knee osteoarthritis who perceive TKR to be their 'only hope' (Bunzli et al., 2019). It is also possible that during the pre-operative surgical encounter, patients may be in a state of heightened anxiety, making it less likely that they retain information presented to them. Low health literacy may mean that patients are unable to understand and/or mis-interpret information from their surgeons.

Therapeutic misattribution can be considered as a mistaken belief about the relationship between a symptom and an intervention. In this study, participants perceived that their knee symptoms were the cause of their functional limitations and that a TKR was needed to return to valued life activities. As they experienced improvements in knee symptoms, it became apparent to the participants that they had misattributed the cause of their functional limitations. Indeed, while TKR is an effective intervention for addressing pain associated with end-stage osteoarthritis, evidence suggests that levels of physical activity do not increase with the resolution of pain post-TKR (Arnold, Walters, & Ferrar, 2016). Knee osteoarthritis commonly co-exists with other chronic conditions such as heart disease, diabetes and low back pain, all of which can lead to functional limitations (Nuesch et al., 2011; Suri et al., 2010). Addressing knee symptoms in addition to comorbidities that act as barriers to physical activity is important to enable and encourage participation.

Design considerations

This study took place in a large Australian joint replacement service, which has a geographically, socioeconomically and culturally diverse referral base. Thematic saturation was reached after 20 interviews; however as is inherent in qualitative research, the findings from this small sample and single setting are not generalizable. While we used scores on the HSS to recruit a diverse sample, scores on the HSS in our sample population were high. This may reflect: a limitation of the HSS (previous studies have documented high baseline HSS scores among patients undergoing TKR (Mancuso et al., 2008)); aspects of the care that patients receive within this health service or; the type of patients within this health service. Low expectations have been linked to low health literacy in people undergoing joint replacement surgery (Hadden, Prince, Bushmiaer, Watson, & Lowry Barnes, 2018). It is possible that our sample had higher health literacy than the wider population as we excluded non-English speakers and sent written invitations to eligible candidates. Furthermore, people may have been more likely to

respond to our invitation if their expectations for TKR had been fulfilled, and therefore it is also possible that our sample held more realistic expectations for TKR than the wider population. Despite these limitations, we have pointed out instances where our findings concur with those from other samples in diverse settings. Recall bias is a key limitation of the retrospective study design; future prospective studies involving larger samples of patients presenting for TKR from diverse settings are needed to explore the generalisability of the proposed framework of therapeutic misconception.

Practice Implications

While future research is needed to challenge and refine this preliminary framework of therapeutic misconception in prospective samples, these findings can help guide surgeons to identify and address gaps in key areas of patients' knowledge and understanding when consenting for TKR. To address therapeutic optimism, surgeons can ask patients what they hope to achieve from surgery and how optimistic they are that they will achieve this. The use of decision aids which generate predictive probability of response to surgery based on personalised, evidence-based criteria may assist patients to understand their likely outcomes (Dowsey, Spelman, & Choong, 2016). To address therapeutic misunderstanding, surgeons can check patients' understanding of peri-operative procedures. Keeping in mind that understanding and retention of information can be influenced by health literacy and anxiety about an upcoming procedure, clinicians can use techniques such as 'teach back'; i.e. getting patients to repeat what they have read or been told about the surgical procedure and listening for any gaps/misunderstandings that need to be addressed. To address therapeutic misestimation, surgeons can ask what patients think the recovery period will be like. Providing patients with support materials containing information about the range of experiences that patients describe during the post-operative period may help instill realistic expectations about the intensity and duration of post-operative pain. It may also help patients to imagine the physical, emotional and social impacts of the recovery period. To address therapeutic misattribution, surgeons can encourage patients to reflect on the role that comorbidities may play in the functional limitations they experience pre-TKR. While helping patients to understand the relative contribution of knee symptoms and comorbidities can be challenging for surgeons (who may not be certain of this themselves), asking patients questions such as: "What tasks

do you currently have difficulty with? What stops you from doing them? When was the last time you were able to do them?" and including family members in the discussion may provide useful insights. Finally, addressing unhelpful beliefs that associate physical activity with prosthesis longevity should also be included in the informed consent process.

Conclusion

Our preliminary framework of therapeutic misconception captures discrepancies between anticipated and actual experiences reported by our sample of patients 12-months post-TKR. By assessing and addressing patients' expectations for the TKR journey, including peri-operative, post-operative and long-term outcomes, surgeons can help ensure that patients consent for surgery fully informed about about what surgery involves and what their likely outcomes will be.

Informed consent and patient details:

The authors confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

References:

- Arnold, J., Walters, J., & Ferrar, K. (2016). Does Physical Activity Increase After Total Hip or Knee Arthroplasty for Osteoarthritis? A Systematic Review *J Orthop Sports Phys Ther*, 46(6), 431-442.
- Aspenberg, P. (2014). Mythbusting in orthopaedics challenges our desire for meaning. *Acta Orthop*, 85, 547.
- Australian and New Zealand College of Anaesthetists (ANSCA). (2016). Guidelines on pre-anaesthesia consultation and patient preparation. In.
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Educ Behav*, 31, 143-164. doi:DOI: 10.1177/1090198104263660
- Bourne, R., Chesworth, B., Davis, A., Mahomed, N., & Charron, K. (2010). Patient satisfaction after total knee arthroplasty: Who is satisfied and who is not? *Clin Orthop Relat Res*, 468(1), 57-63.
- Bowling, A., Rowe, G., Lambert, N., Waddington, M., Mahtani, K., Kenten, C., . . . Francis, S. (2012). The measurement of patients' expectations for healthcare: a review and psychometric testing of a measure of patients' expectations. *Health Technol Assess*, 16(30).
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*, 11(4), 589-597. doi:10.1080/2159676x.2019.1628806

- Bunzli, S., Nelson, E., Scott, A., French, S., Choong, P., & Dowsey, M. (2017). Barriers and facilitators to Orthopaedic Surgeons' uptake of decision aids for total knee arthroplasty: A qualitative study. *BMJ Open*, 7(e018614). doi:10.1136/bmjopen-2017-018614
- Bunzli, S., O'Brien, P., Ayton, D., Dowsey, M., Gunn, J., Choong, P., & Manski-Nankervis, J. (2019). Misconceptions and the Acceptance of Evidence-based Nonsurgical Interventions for Knee Osteoarthritis. A Qualitative Study. *Clin Orthop Relat Res*, 477(9), 1975-1983.
- Burkle, C. M., Pasternak, J. J., Armstrong, M. H., & Keegan, M. T. (2013). Patient perspectives on informed consent for anaesthesia and surgery: American attitudes. *Acta Anaesthesiol Scand*, 57(3), 342-349. doi:10.1111/aas.12037
- Chou, P., & O'Rourke, N. (2012). Development and initial validation of the Therapeutic Misunderstanding Scale for use with clinical trials research participants. *Aging Ment Health*, 16(2), 145-153.
- Colloca, L., & Benedetti, F. (2005). Placebos and painkillers: is mind as real as matter? *Nat Rev Neurosci*, 6, 545-552.
- Dowsey, M., Spelman, T., & Choong, P. (2016). Development of a prognostic nomogram for predicting the probability of nonresponse to total knee arthroplasty 1 year after surgery. *J Arthroplasty*, 31(8), 1654-1660.
- Festinger, L. (1962). *A theory of cognitive dissonance*. Palo Alto, CA: Stanford University Press.
- Ghomrawi, H., Ferrando, N., Mandl, L., Huong, D., Noor, N., & Della Valle, A. (2011). How often are patient and surgeon recovery expectations for total joint arthroplasty aligned? Results of a pilot study. *HSS J*, 7, 229-234.
- Goldsmith, L., Suryaprakash, N., Randall, E., Shum, J., MacDonald, V., Sawatzky, R., . . . Bryan, S. (2017). The importance of informational, clinical and personal support in patient experience with total knee replacement: A qualitative investigation. *BMC Musculoskelet Disord*, 18(127).
- Hadden, K., Prince, L., Bushmiaer, M., Watson, J., & Lowry Barnes, C. (2018). Health literacy and surgery expectations in total hip and knee arthroplasty patients. *Patient Educ Couns*, 101, 1823-1827. doi:10.1016/j.pec.2018.05.021
- Horng, S., & Grady, C. (2003). Misunderstanding in clinical research: Distinguishing therapeutic misconception, therapeutic misestimation, and therapeutic optimism. *IRB Ethics Hum Res*, 25, 11-16.
- Jones, C., & Suarez-Almazor, M. (2017). Patient Expectations and Total Knee Arthroplasty. *Journal of Clinical Outcomes Management*, 24(8), 364-370.
- Jones, J. W., McCullough, L. B., & Richman, B. W. (2007). A comprehensive primer of surgical informed consent. *Surg Clin North Am*, 87(4), 903-918. doi:10.1016/j.suc.2007.07.012
- Kennedy, D., Wainwright, A., Pereira, L., Robarts, S., Dickson, P., Christian, J., & Webster, F. (2017). A qualitative study of patient education needs for hip and knee replacement. *BMC Musculoskelet Disord*, 18(1), 413. doi:10.1186/s12891-017-1769-9

- Leopold, S. S. (2019). Editor's Spotlight/Take 5: Misconceptions and the Acceptance of Evidence-based Nonsurgical Interventions for Knee Osteoarthritis. A Qualitative Study. *Clin Orthop Relat Res*, 477(9), 1970-1974. doi:10.1097/CORR.0000000000000910
- Levinger, P., Bartlett, J. R., Bergman, N. R., McMahon, S., Menz, H. B., & Hill, K. D. (2018). The discrepancy between patient expectations and actual outcome reduces at the first 6 months following total knee replacement surgery. *Knee Surg Sports Traumatol Arthrosc*, *Epub ahead of print*. doi:10.1007/s00167-018-5210-1
- Mancuso, C. A., Graziano, S., Briskie, L. M., Peterson, M. G., Pellicci, P. M., Salvati, E. A., & Sculco, T. P. (2008). Randomized trials to modify patients' preoperative expectations of hip and knee arthroplasties. *Clin Orthop Relat Res*, 466(2), 424-431. doi:10.1007/s11999-007-0052-z
- Mannion, A., Kampfen, S., Munqinger, U., & Kramers-de Quervain, I. (2009). The role of patient expectations in predicting outcome after total knee arthroplasty. *Arthritis Res Ther*, 11(5), R139.
- McHugh, G., & Luker, K. (2012). Individuals' expectations and challenges following total hip replacement: a qualitative study. *Disabil Rehabil*, 34(16), 1351-1357.
- Mulsow, J., Feeley, M., & Tierney, S. (2012). Beyond consent—improving understanding in surgical patients. *The American Journal of Surgery*, 203, 112-120.
- Nam, D., Berend, M., Nunley, R., Della Valle, A., Berend, K., Lombardi, A., & Barrack, R. (2016). Residual Symptoms and Function After Unicompartmental and Total Knee Arthroplasty: Comparable to Normative Controls? *J Arthroplasty*, 31(10), 2161-2166.
- Nuesch, E., Dieppe, P., Reichenbach, S., Williams, S., Iff, S., & Juni, P. (2011). All cause and disease specific mortality in patients with knee or hip osteoarthritis: population based cohort study. *BMJ*, 342, d1165. doi:10.1136/bmj.d1165
- Parvizi, J., Nunley, R., Berend, K., Lombardi, A., Ruh, E., Clohisy, J., . . . Barrack, R. (2014). High level of residual symptoms in young patients after total knee arthroplasty. *Clin Orthop Relat Res*, 472(1), 113-137.
- Richardson, V. (2013). Patient comprehension of informed consent. *J Perioper Pract*, 23(1), 26-30.
- Scott, C., Bugler, K., Clement, N., MacDonald, D., Howie, C., & Biant, L. (2012). Patient expectations of arthroplasty of the hip and knee. *J Bone Joint Surg Br*, 94(7), 974-981.
- Soever, L. J., Mackay, C., Saryeddine, T., Davis, A. M., Flannery, J. F., Jaglal, S. B., . . . Mahomed, N. (2010). Educational needs of patients undergoing total joint arthroplasty. *Physiother Can*, 62(3), 206-214. doi:10.3138/physio.62.3.206
- Strickland, L., Kelly, L., Hamilton, T., Murray, D., Pandit, H., & Jenkinson, O. (2017). Early recovery following lower limb arthroplasty: Qualitative interviews with patients undergoing elective hip and knee replacement surgery. Initial phase in the development of a patient- reported outcome measure. *J Clin Nurs*, 27(13-14), 2598-2608.
- Suri, P., Morgenroth, D. C., Kwoh, C. K., Bean, J. F., Kalichman, L., & Hunter, D. J. (2010). Low back pain and other musculoskeletal pain comorbidities in individuals with symptomatic osteoarthritis of

the knee: data from the osteoarthritis initiative. *Arthritis Care Res*, 62(12), 1715-1723.
doi:10.1002/acr.20324

Zywił, M. G., Mahomed, A., Gandhi, R., Perruccio, A. V., & Mahomed, N. N. (2013). Measuring expectations in orthopaedic surgery: a systematic review. *Clin Orthop Relat Res*, 471(11), 3446-3456. doi:10.1007/s11999-013-3013-8

Table 1. Example questions in semi-structured interviews

Thinking back to before your surgery, what did you expect from surgery?
What do you think about those expectations in hindsight?
How did you prepare going into surgery?
Can you describe what it was like going into surgery?
What did you expect your recovery from surgery would be like?
Can you describe what your recovery from surgery has been like?
Where did you expect to be now, 12 months down the track?
Can you describe to me how you are now?
Did you experience any unexpected events along your knee replacement journey?
In what way do you think you could have been better prepared for your knee replacement journey?
What advice would you give someone close to you who was considering a knee replacement?

Table 2. Process of data reduction

Code	Theme	Overarching theme
High expectations pain and function Previous experiences of surgery Hope in technological advancement Trait optimism	Pre-operative optimism	
Expecting general, receiving regional anaesthesia Peri-operative distress Lack of information about anaesthesia Difficulty understanding information about anaesthesia	Peri-operative misunderstandings	Therapeutic misconception
Recovery period longer than expected Recovery period harder than expected Self-efficacy Social comparisons Surgeon influence Cognitive dissonance	Post-operative misestimations	
Expectations fulfilled Functional limitations Causal attributions Adaptation Comorbidities Longevity of prosthesis	Long-term misattributions	

Table 3. Participant characteristics

Characteristics	Percentage participants (%) (n=20)
Sex	50 (female)
Age (years)	
50-59	5
60-69	20
70-79	70
80+	5
BMI (kg/m ²)	
<18.5	0
18.5-24.9	10
25.00-29.9	25
>30.0	65
Contralateral TKR	
YES	55
NO	45
Bilateral	0
Simultaneous	

BMI= Body Mass Index

kg/m² = Kilograms per metre squared

TKR = Total knee replacement

Figure 1. Framework of therapeutic misconception

Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:

Bunzli, S;O'Brien, P;Klem, N;Incoll, I;Singh, J;Davaris, M;Choong, P;Dowsey, M

Title:

Misconceived expectations: Patient reflections on the total knee replacement journey

Date:

2020-04-23

Citation:

Bunzli, S., O'Brien, P., Klem, N., Incoll, I., Singh, J., Davaris, M., Choong, P. & Dowsey, M. (2020). Misconceived expectations: Patient reflections on the total knee replacement journey. *MUSCULOSKELETAL CARE*, 18 (4), pp.415-424. <https://doi.org/10.1002/msc.1475>.

Persistent Link:

<http://hdl.handle.net/11343/275677>