The Unreported Patient Burden of Living with a Failed Total Knee Replacement

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Where this research was done?
Aim

To explore the experience of patients undergoing revision total knee replacement.
Methodology

• Phenomenological Study
• 10 Participants
• Qualitative semi-structured interviews
• Longitudinal Study – interviews at three timepoints
  1. Pre-operatively
  2. At time of discharge from hospital
  3. Six months post-operatively
## Participants

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
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<tbody>
<tr>
<td>Mean Age (years)</td>
<td>70.3 (SD, 11.1, Range 42 to 77)</td>
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<tr>
<td>Number of patients</td>
<td>10</td>
</tr>
<tr>
<td>Male</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Mean BMI</td>
<td>26.7 (SD, 3.5, Range 19.2 to 32.9)</td>
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<tr>
<td>Indication for revision</td>
<td></td>
</tr>
<tr>
<td>Aseptic Early</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Aseptic Late</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Infection</td>
<td>2 (20%)</td>
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Pre-op

**Pain**
Significant enough for a separate theme

**Physical Factors**
- Symptom burden
- Restriction

**Psychological Impact**
- Grief process
- Ignored
- Social isolation
- Change in personal identity
- Expectation of revision
Pain

“And it's the pain, I could cope with not being able to do stuff but the pain is horrendous at the moment … Pain is the main thing. I don't care what it looks like, if it's swollen? Pfft, I don't care. It's the pain I want to get rid of.” (PT004, Aseptic loosening)

I’m just desperate to get rid of the pain … the pain has been horrendous”

(PT002, Infection)

But it’s all very well if you’re not in pain but when you’re in pain you just want something to even dampen it a bit, take it away for a wee while, but I felt that, you know, there was always a fight about using tramadol” (PT002, Infection)
“Pain-free. Well, obviously not to begin with. I know it's very painful and I'm expecting that. But I’m hoping in six months I won't be lying in my bed thinking "Oh my god I can't move", you turn over on your leg and think oh shit I have to wake up again and I’m not having to take as many painkillers” (PT004, Aseptic loosening)

“I dunno if you can expect pain-free I dunno, I dunno if you could expect that, I would expect it to be better than it is anyway” (PT005, Instability)
Physical Factors

“It's quite restricting not having the full use of your knee, you don't appreciate it until it's happened because things that you would do automatically, you can't do it” (PT004, Aseptic loosening)

“I hate it. I hate it. I'm used to doing everything at one hundred miles an hour and simply going up and down stairs is a nightmare!” (PT004, Aseptic loosening)

“Oh I feel a bit useless at times because I can’t do what I used to do.” (PT001, Instability)
Psychological Factors

“It’s just sort of disappointing really, and I don’t know how many times I’ve said oh I wish I’d never started it … I would go back to that and not have what I’ve had, that’s how strongly I feel about it.” (PT010, Instability)

“I felt I wasn’t being taken seriously… I felt nobody was paying attention, weren’t listening you know … And the doctor said there was nothing wrong with the knee, but I was convinced there was.” (PT002, Infection)

“I did lose my job through this” (PT007, Infection)
The Surgical Episode

Hospital Experience
- Hospital environment
- Care experience

Treatment Burden
- Pain
- Psychological distress

Expectation of Recovery
- Previous recovery experience
- Attitude towards recovery
- Future expectations
Hospital Experience

“they just manage to keep you buoyant, kind of lifted and that’s what I was most impressed about cause” (PT007, Infection)

“the nursing staff were excellent, so understanding… all the care I’ve had is excellent.” (PT009, Instability)

“That was fine, the only thing I would have said was I found it a wee bit lonely because I had to be isolated because the infection but that was the only problem there was” (PT002, Infection)
Treatment Burden

“I went to sleep and I was sound asleep and I woke up with this excruciating pain” (PT010, Instability)

“Well possibly I didn’t want to bother anybody but you know I kind of thought here’s me making a fuss well I didn’t think it was nothing because you know that pain wasn’t nothing” (PT007, Infection)
Expectations of Recovery

“I don’t want to be intruding on their lives still you know, its two different homes and they operate in different ways you know and she’s got children and a husband and I’ve just got ...” (PT009, Instability)

“I hope that is going to be the outcome because if I couldn’t get that, it’s been a waste of time. It’s been a waste of my time, it’s been a waste of all hospital’s time, all the physicians, etc, all the staff, hopefully it will be ok” (PT003, Instability)
Six Months

**Recovery Burden**
- Support
- Mobility
- Pain

**Expectation vs. Reality**
- Outcome
- Change in expectation
- Previous experience

**Uncertainty**
Significant enough for a separate theme
Recovery Burden

“Just getting used to being by yourself. And then trying to get about just to, just didnae feel like getting up and going to make something to eat or... it was a real struggle to get something to eat” (PT008, Instability)

“Oh, it was agony, it was agony because it was a revision, eh, it was really, really sore, very very painful… I cannæ take co-codamol and I cannæ take another one, it makes me violently sick. (PT006, Aseptic Loosening)
Expectation vs. Reality

“I really want to not have to use something to walk with, I want to just walk, I’m not even bothered now if I’m limping or if I’ve got a funny walk I don’t even care anymore cause all I want is to be as pain free as possible” (PT007, Infection)

“it would be lovely to be independent again… I realise that I might not be able to get up and walk for miles but would be nice to be able to get up and walk about and do what you want to do” (PT002, Infection)
Uncertainty

“I don't know, to be quite honest with you, em, I'm quite happy with being able to walk, em, probably if it didn’t get worse just continue as I am just now, (PT006, Aseptic Loosening)

“Well you have to sort it out in your own head you have to get to the level that you, and you have to frank sometimes and think this could be the highest the bests its ever going to be but then if this is the best then that’s okay” (PT009, Instability)
Take home message.

- Patients experience evolved over the course of their treatment journey.

- There are consistent threads that run through the patients journey – pain, burden, restriction.

- Mode of failure is not the deciding factor in patient experience

- Burden felt by patients is not resolved by revision surgery, the focus just shifts.
Acknowledgements

Professor Colin Howie
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