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To cite this article: Michael P. Dillon, Sarah P. Anderson, Emily J. Duke, Hannah E. Ozturk & Rwth Stuckey (2019): The lived experience of sequential partial foot and transtibial amputation, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2018.1555288](https://doi.org/10.1080/09638288.2018.1555288)

To link to this article: <https://doi.org/10.1080/09638288.2018.1555288>

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The lived experience of sequential partial foot and transtibial amputation

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ABSTRACT

Purpose: To describe the lived experience of people who have undergone sequential partial foot and transtibial amputation.

Methods: Using a narrative inquiry approach, adults with experience of sequential partial foot amputation and transtibial amputation on the same limb were sampled until data saturation. Semi-structured, face-to-face interviews were conducted and transcribed verbatim. Each interview was read, coded and a thematic summary with quotes was returned to each participant for verification. Data were triangulated through independent coding and analysis.

Results: The lived experiences of the 10 participants were characterized by three themes: enduring complications eventually resolved, health and wellbeing improved with knowledge, and advice from the lived experience. The foot complications that led to partial foot amputation often endured until after transtibial amputation, where participants reported being able to get on with their life. At the point of partial foot amputation, participants had little knowledge about the surgical procedure, likely outcomes or common risks. In the lead up to transtibial amputation, structured systems provided access to peer support and conversations with healthcare professionals. As participants' knowledge improved, many people were able to exercise control over their healthcare decisions.

Conclusions: The lived experience highlights the importance of high-quality information and meaningful conversations to inform decision making and prepare people for life with limb loss.

ARTICLE HISTORY

Received 8 May 2018
Revised 29 November 2018
Accepted 29 November 2018

KEYWORDS

Partial foot; transtibial; amputation; surgery; experience; shared decision making; health literacy

► IMPLICATIONS FOR REHABILITATION

1. Partial foot amputation is associated with high rates of complications and subsequent transtibial amputation
2. At the point of partial foot amputation, most people seem unaware of what the surgery involves or the likelihood of complications and reamputation
3. This research suggests that people facing the prospect of partial foot amputation may benefit from access to the structured systems already in place for most people facing transtibial amputation
4. Access to high-quality information, peer support, and meaningful conversations with healthcare providers can support informed decision making and help people prepare for the likelihood of complications and reamputation following partial foot amputation

Introduction

Research describing the lived experience following limb loss does not often include people with partial foot amputation (PFA) or considers people with lower limb amputation as a homogenous group [1–3]. As such, research has failed to recognize that the experience following PFA may differ to that of other levels of limb loss especially given the high rates of serious complications, and often protracted efforts to prevent further limb loss in the months and years that follow.

A recent systematic review [4] highlighted that 40% of people experience significant complications following PFA such as dehiscence, ulceration and wound failure. Three months after PFA only about 50% of wounds will have healed, and at one year about 25% of wounds will still not have healed [4]. As a result, a large proportion of people spend months in-and-out of hospital and wound clinics in

an effort to salvage the partial foot residuum. Looking forward, one year after PFA about 25% of all PFAs are revised [4] and about 12% of people will have undergone multiple revisions on the same limb [5]. Five years after PFA, approximately 50% of all PFAs will have been revised [4]; many to a transtibial amputation (TTA).

For people who experience these complications, delays in wound healing and multiple amputation surgeries, the experience is likely to be particularly traumatic. To some extent, this may explain why people living with PFA have described a persistent and pervasive fear about the prospect of reamputation that has not been reported by people living with other levels of lower limb loss such as TTA [6].

If we are to support people facing the prospect of PFA to make informed decisions about amputation surgery, and enable them to prepare for the likelihood of complications and reamputation in the months and years that follow, it is important that

research is conducted to understand the experience of people who have undergone sequential PFA and TTA.

In people living with cancer [7], kidney disease [8] and spinal compression [9], access to rich, condition-specific, information of this kind has been shown to improve health literacy, help inform decision making, establish realistic expectations about the path ahead, and thereby minimize negative experiences such as depression and anxiety.

Given the large proportion of people that will experience serious complications and reamputation following an *initial* PFA[4], it is important to illuminate the unique experiences of people who have undergone *sequential* PFA and TTA. What we learn about the lived experience could inform the content of condition-specific, pre-amputation education materials that can support meaningful conversations between health professionals, patients, and their loved ones. These conversations are important for informed decision-making and to establish realistic expectations that, in turn, can help minimize negative experiences such as anxiety and depression.

The purpose of this investigation was to describe the lived experience of people who have undergone sequential PFA and TTA.

Method

Ethics approval for the project was granted by a large metropolitan tertiary hospital (HREC 2013.252) and endorsed by La Trobe University Human Ethics Committee. Participants provided informed written consent acknowledging that their data would be presented anonymously.

Design

A narrative inquiry approach was adopted to enable participants to describe their experience in the form of a story about their life with a focus on four common time periods: before PFA, after PFA, before TTA and after TTA.

Recruitment

Participants were purposively sampled from the prosthetic and orthotic department of a large metropolitan tertiary hospital (Melbourne, Australia) and from volunteers with limb loss that attend the prosthetic and orthotic training courses at La Trobe University (Melbourne, Australia) as model patients. Following an initial face-to-face or phone discussion, a letter formally inviting their participation was sent. Participants were also convenience sampled through email and magazine advertisements circulated to members of an amputee peer support group, *Limbs4Life*. Irrespective of the recruitment method, those wishing to participate needed to contact the researchers to confirm their willingness to participate.

To be eligible for inclusion, participants had to be adults over 18 years of age who had experienced a PFA followed by a TTA on the same limb with the last amputation surgery at least 6 months prior. Participants had to be willing to share their experience in an interview conducted in the English language. Participants were recruited until data saturation; that is, until no new themes emerged from the interviews.

Procedure

Data collection

When participants contacted the researchers to confirm their willingness to participate, arrangements were made for the first interview.

Each interview was conducted at the hospital by one of two researchers (HO and ED). At the beginning of this first interview, a summary of the study was provided and the purpose and procedure explained. Participants were able to ask questions prior to providing informed consent. Following informed consent, a face-to-face, semi-structured interview was conducted with each participant following an interview guide ([Supplementary Material](#)). Interviews were audio recorded. At the completion of the interview, participants also documented the major events of their health journey in a separate timeline.

Following each participant's first interview, the audio recording was transcribed verbatim by a professional transcription service. Transcriptions were read and analyzed by the researcher who conducted the interview. Elements of the transcription were reordered to mirror the chronological order of major events documented in the timeline of each participant's health journey. Transcriptions were then coded line-by-line. Concepts that emerged from the line-by-line coding were schematically presented in each of the four time periods common to all participants (i.e., before PFA, after PFA, before TTA and after TTA) and included the participant's own quotes ([Figure 1](#)). Where there was uncertainty in the interpretation, concepts were flagged for specific discussion with each participant as part of their second interview.

Prior to the second interview, each participant was mailed their schematic summarizing the concepts and the supporting quotes that described their individual experience ([Figure 1](#)). Participants were asked to review this document prior to their second interview.

The second face-to-face interview was conducted with each participant as part of the member checking process. During the second interview, the individual's schematics were reviewed, and participants could clarify the researchers' interpretation to ensure the concepts and supporting quotes accurately reflected their lived experience. These second interviews were also audio recorded for later reference if required.

Interview data were collected and processed in this manner until data saturation had been reached and the ideal sample size, therefore, obtained [10].

Thematic analysis

Having confirmed that the interpretation of each participant's narrative accurately described their experience, an independent analysis of the interviews and the schematic data was undertaken by an investigator who was not involved in the original interviews or the process of member checking. This independent analysis was used to triangulate the data, by determining if the themes which emerged were consistent with the previous analysis and if any had been previously missed. This independent analysis, along with the member checking by the participants, assisted data triangulation and engendered confidence in the trustworthiness of the findings.

The original transcripts were imported into NVivo 10 (QSR International Pty. Ltd). The narratives were analyzed to identify concepts common across participants within each of the four chronological time points (e.g., before PFA). These concepts were coded within NVivo 10 (QSR International Pty. Ltd) in a node structure. Using a process adapted from Liamputtong [11], these

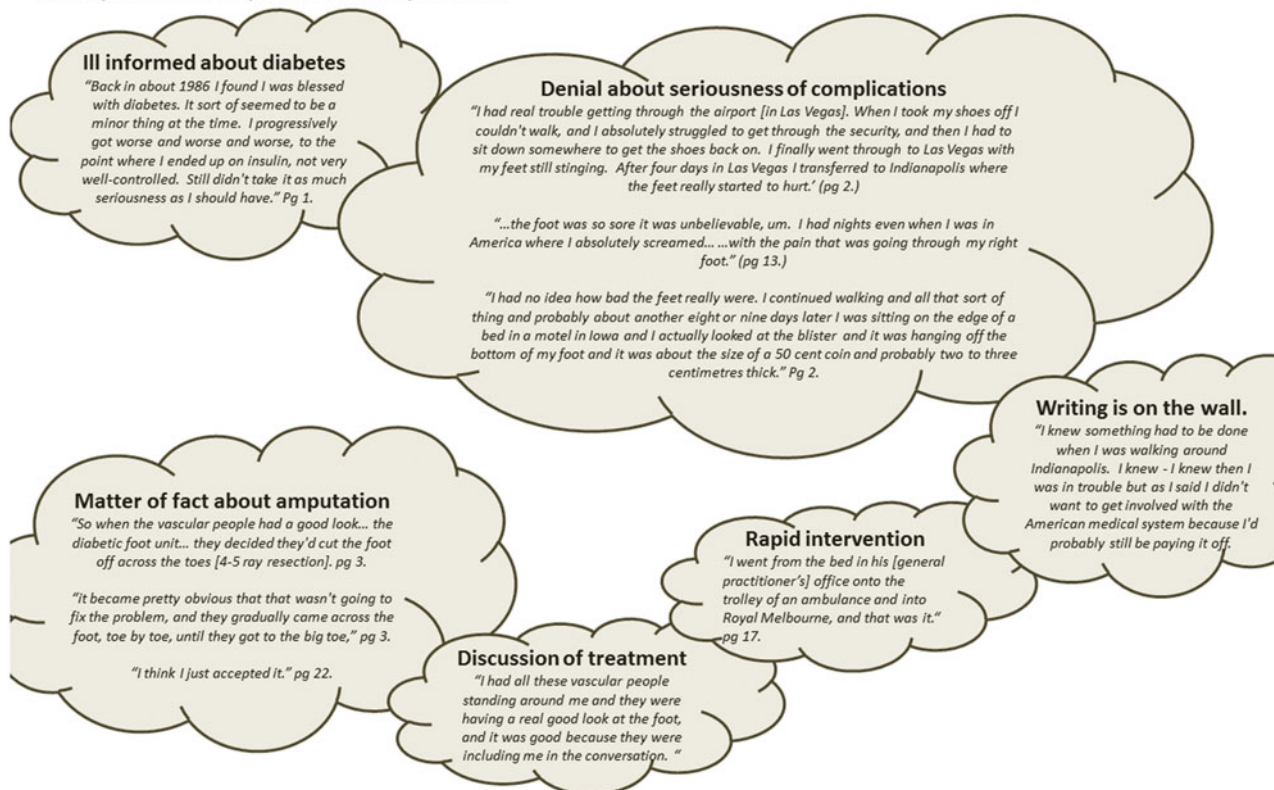
Participant: No 4
Time point: Before partial foot amputation.


Figure 1. Schematic summarizing the concepts that emerged from the analysis of each participant's transcript. The concepts were grouped into the four common time periods (i.e., before partial foot amputation, after partial foot amputation, before transtibial amputation, after transtibial amputation) and included the participant's own quotes for illustration and evidence. The relative size of the bubbles highlights the significance or importance of the concept for the participant and in this way, concepts that dominated the interview were presented in larger bubbles. Each participant was provided with a set of these schematics in anticipation of the second interview as part of the process of member checking.

concepts were used to analyze each participants health journey from before PFA to after TTA. Themes were then developed that characterized the collective experience over time and linked together the concepts coded in the node structure. These themes were presented schematically and included illustrative quotes to support and evidence the concepts (Figure 2). Researchers then met to discuss the themes, concepts and supporting quotes. Where disagreement existed between these researchers, discussion continued until consensus. The original interview transcripts and the participant timelines were referred to as needed to evidence and inform these deliberations.

Results

Participants

The 10 participants had a mean age of 52.5 ± 15.9 years (range 21–73 years) at the point of the first interview. Eighty percent of participants were male. PFA was due to: diabetic complications (non-healing ulceration or infection, 50%), bacterial infection (Meningococcal or Pneumococcal, 30%), crush injury (10%) or gangrene secondary to a burn (10%). The time between PFA and TTA was 3.7 ± 3.5 years (range 0.1–10 years). The time since the last amputation was 6.6 ± 9.7 years (range 0.5–24 years). All participants who commenced the study completed and as such, there were no participant drop outs. Individual participant details have been reported in Table 1. The mean interview time was 49 min (range 35–77 min).

Thematic analysis

Three themes were identified from the participants' narratives: *enduring complications eventually resolved*, *health and wellbeing improved with knowledge*, and *advice from the lived experience*.

Each of these three themes are presented, in turn, in the following subsections. The first two themes describe the participants' experience across the four common time points spanning life before PFA to life after TTA. The last theme is reflective and describes how participants believe the lived experience could be informed and improved for others.

Theme 1. Enduring complications eventually resolved

As a prolog to this first theme, all participants described active lives before the complications that lead to their PFA. For many participants, these complications endured for months or even years before their PFA, as well as afterward. These complications had a significant and negative impact on many aspects of their life. It was not until after their TTA that these long-standing complications resolved and participants felt they got their life back.

Prior to PFA, most participants reported having full active lives with little mention of health complications.

"I was... at uni [university] ... studying full-time and working as well ... a very regular 18 year old's life. (Participant 5)

"well I suppose I was very active. I used to walk all the time and just go and do whatever I wanted to do at any time" (Participant 9)

-- ENDURING COMPLICATIONS EVENTUALLY RESOLVED --

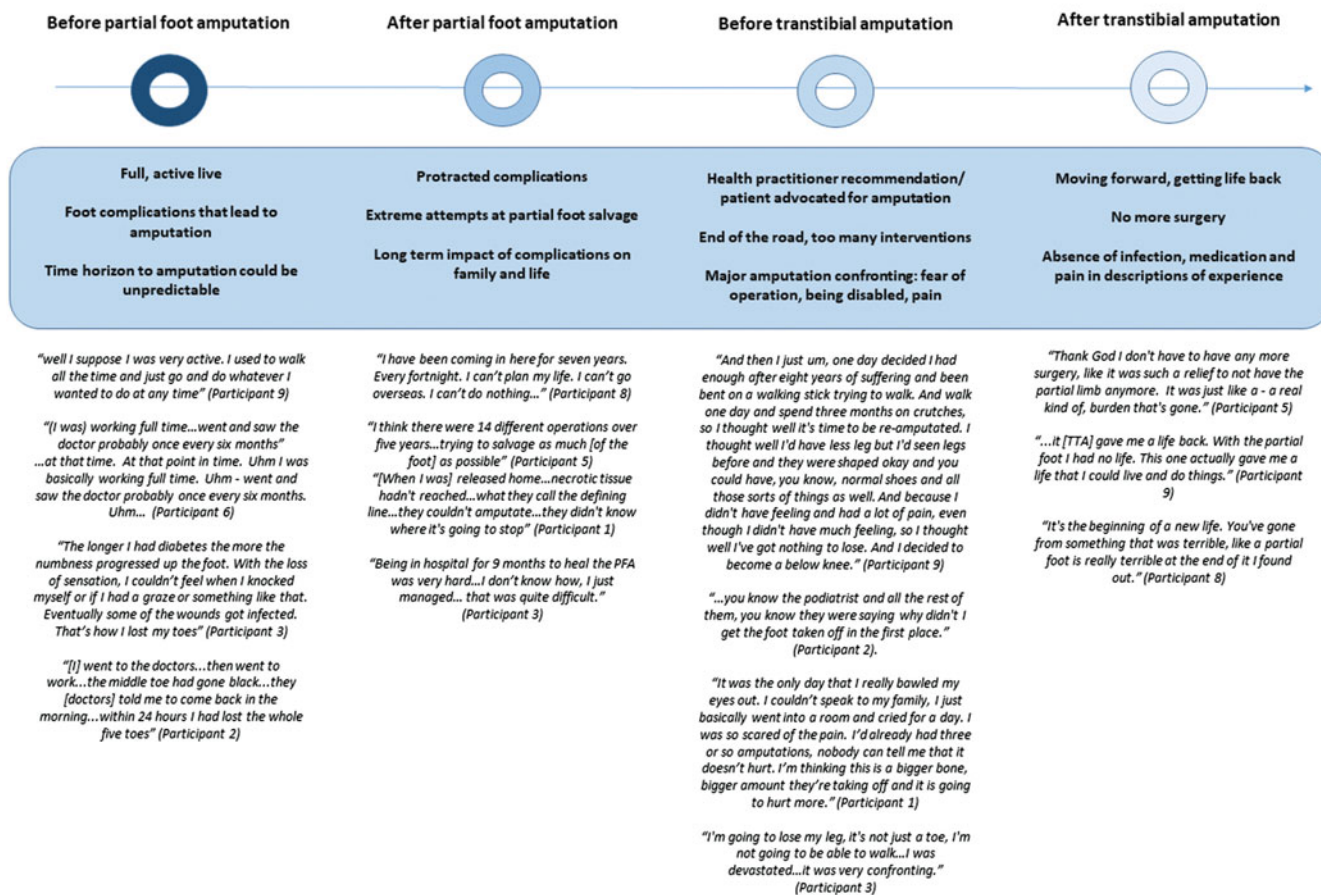


Figure 2. Schematic showing one of three themes – enduring complications eventually resolved – codes (shaded box) and an illustrative sample of the participant quotes within each of the four chronological time periods (i.e., before partial foot amputation, after partial foot amputation, before transtibial amputation, after transtibial amputation).

Table 1. Individual participant demographic data.

Participant	Sex	Age at interview (years)	Cause of initial PFA	Time between PFA and TTA (years)	Sequence of surgical procedures	Time since TTA and data collection (years)
1	Male	44	Pneumococcal infection	0.8	PFA, debridement, skin graft, TTA	2.1
2	Male	66	Burn induced diabetic gangrene	3.0	PFA, revised PFA, 3 debridements, TTA	2
3	Female	47	Diabetic ulceration	1.0	PFA, 2 debridements, TTA, revised TTA	6.9
4	Male	68	Diabetic related infection	0.1	PFA, revised PFA, multiple debridements, TTA	7
5	Female	38	Meningococcal septicemia	4.0	PFA, multiple surgeries for infections, skin grafts, muscle flaps etc, TTA	17
6	Male	52	Diabetic ulceration	10.0	PFA multiple debridements, revised PFA, TTA	5
7	Male	21	Meningococcal septicemia	0.3	PFA, TTA	1.3
8	Male	73	Diabetic related infection	7.0	PFA, revised PFA, 4–5 surgical debridements of PFA, TTA	0.5
9	Male	52	Trauma – crush injury at work	8.0	PFA, several debridement and skin graft, TTA	24
10	Male	64	Diabetic related infection	3.0	PFA, bilateral PFA, debridements, TTA	0.5

Details as reported by individual participants. PFA: partial foot amputation; TTA: transtibial amputation.

"(I was) working full time... went and saw the doctor probably once every six months" (Participant 6)

All participants experienced some foot complication that ultimately led to the need for a PFA. Complications included ulcers, infection and/or gangrene.

"The longer I had diabetes the more the numbness progressed up the foot. With the loss of sensation, I couldn't feel when I knocked myself or if I had a graze or something like that. Eventually some of the wounds got infected. That's how I lost my toes" (Participant 3)

"I had severe burns on the foot and the consequence was the second toe went gangrenous." (Participant 2)

While the complications often occurred over an extended period, the time horizon to amputation was often unpredictable.

"[I] went to the doctors... then went to work... the middle toe had gone black... they [doctors] told me to come back in the morning... within 24 hours I had lost the whole five toes" (Participant 2)

"[When I was] released home... necrotic tissue hadn't reached... what they call the defining line... they couldn't amputate... they didn't know where it's going to stop" (Participant 1)

Following PFA, many of the complications that lead to the initial amputation endured. There were often intensive and protracted efforts to salvage the partial foot and prevent further limb loss which had a significant impact on life.

"I think there were 14 different operations over five years... trying to salvage as much [of the foot] as possible" (Participant 5)

"I have been coming in here for seven years. Every fortnight. I can't plan my life. I can't go overseas. I can't do nothing..." (Participant 8)

"Nine months later it happened again... they scraped the bone and took more off... in total that was done three times... [over 18 months]." (Participant 2)

Such long-standing complications after PFA had predictable, but often unforeseen consequences that had a significant impact on work and family life.

"After nine months I literally fell into having to find a job... because I was self-employed working as a contractor when this [PFA] happened. They [Centrelink – a Federal Government service that provides social security services] forced me to look for a job because they considered only losing five toes you're still capable of work... even with an open wound." (Participant 2)

"I was housebound with a two-year-old son and a partner that can't work and we were just – it was basically all about my health." (Participant 1)

"Being in hospital for 9 months to heal the PFA was very hard... I don't know how, I just managed... family visited... Daughter was staying with her dad quite a bit... at the time... going through teenage problems and that was quite difficult." (Participant 3)

For many participants, the need for TTA was inevitable to resolve the long-standing complications following PFA. Often the need for TTA had been suggested by either medical or allied health staff as a treatment option, or as a last resort, to resolve long-standing complications.

"I had an operation to - to debride it and while I'm on the operating table they said if it doesn't heal we'll have to take the leg off." (Participant 6)

"... probably for the last - at least for the last three years before, the podiatrist had been recommending it." (Participant 8)

"... you know the podiatrist and all the rest of them, you know they were saying why didn't I get the foot taken off in the first place." (Participant 2).

For some participants, the experience of long-standing complications following PFA leads to a tipping point where they advocated to undergo a TTA.

"One day I decided I had enough after eight years of suffering and being bent on a walking stick trying to walk... so I thought well, I've got nothing to lose. And I decided to become a below knee." (Participant 9)

"I can't do anything much with a half toe, like it was like I can't run or anything, because like you don't have your toes to control your balance or anything. So I thought about it... it's going to be easier just having a prosthetic leg than having a half leg... I want to do the below-the-knee." (Participant 7)

For others, the decision to undergo a TTA was confronting given their prior experience of PFA.

"It was the only day that I really bawled my eyes out. I couldn't speak to my family, I just basically went into a room and cried for a day. I was so scared of the pain. I'd already had three or so amputations, nobody can tell me that it doesn't hurt. I'm thinking this is a bigger bone, bigger amount they're taking off and it is going to hurt more." (Participant 1)

"I'm going to lose my leg, it's not just a toe, I'm not going to be able to walk... I was devastated... it was very confronting." (Participant 3)

Following TTA, discussion about complications was notably absent from peoples' description of the experience; instead, participants described being able to move forward and get their life back.

"Thank God I don't have to have any more surgery, like it was such a relief to not have the partial limb anymore. It was just like a - a real kind of, burden that's gone." (Participant 5)

"... it [TTA] gave me a life back. With the partial foot I had no life. This one actually gave me a life that I could live and do things." (Participant 9)

"It's the beginning of a new life. You've gone from something that was terrible, like a partial foot is really terrible at the end of it I found out." (Participant 8)

Theme 2. Health and wellbeing improved with knowledge

The second theme highlights that, over time, a marked shift was observed in participants' understanding, education and knowledge, which in turn impacted their health and wellbeing.

In the period before their PFA, participants described being poorly informed with little knowledge of what they were about to experience. Many participants reported they were unaware that if efforts to salvage the foot failed, amputation would be the end result. As such, it was interesting to consider that the need for a PFA was often presented as a *fait accompli*, without discussion about the treatment options.

"Basically got told... my toes were very necrotic... they were just like charcoal. So I was basically just told, you're not allowed to live with dead tissue on your body, it's not good for you. They didn't mention below-knee amputation to me at that point, which I don't know whether that's a good thing or a bad thing." (Participant 1)

"... then probably three or four days later it had been decided without my knowledge that they're going to do it [PFA] and that was just mentioned in passing that it's going to happen." (Participant 6)

At the point of PFA, participants seemed poorly informed about the procedure, the expected outcomes and the likelihood of complications. As such, the outcomes of their PFA often turned out to be different from their expectations. Typically, people weren't expecting as much of their foot to be removed and were not prepared for the likelihood of further interventions such as debridement. Participants were often confronted by the outcome they experienced.

"The overriding emotion was like, oh, wow, look how much they took off already... it was horrific, really confronting. I felt violated afterwards." (Participant 1)

"... yeah, so over every 24 hours, for four days, they cut a bit more off." (Participant 4)

"... they kept cleaning it and they say cleaning debriding, to me I thought it was cleaning it but it was actually getting shorter every time." (Participant 9)

When these complications did occur, people did not seem well prepared for the difficulties ahead.

"It would heal, then breakdown. There wasn't a period where I didn't have to see a medical person or come into hospital. I was here a lot... This was not the kind of life I wanted to live." (Participant 5)

"I never even imagined it [debridement] could be so bad. It was the worst pain I've ever experienced. I was screaming my head off... I've never suffered so much." (Participant 1)

Participants identified that it was very difficult to learn about options and make decisions given the influence of pain, illness, medication and the psychological impact of amputation; particularly given the way many of the interactions were conducted.

"You're on massive amounts of pain killers... Your decision making isn't as clear as it would normally be. Your emotions are all over the shop... It's very foggy you know. You'd take pain killers and two hours later you realise you're still looking at the fish tank. It made communication so hard." (Participant 1)

"... doctors' rounds where they - they'd come with 100 different people [laughs] into the room and you don't know who half of them are. Um they were talking amongst themselves and talking about me... I didn't really know a great deal about what medications I was - um what the name of the antibiotic was or... I don't understand a lot of doctors' terms." (Participant 3)

In the lead up to TTA, people often had better access to information and meaningful conversations. Access to education seemed better structured with formal mechanisms in place to access professional peer support programs provided by external organizations. There were also opportunities for chance encounters with other patients as well as clinicians. These forms of education seemed to be powerful ways that patients could have their questions answered and see what might lie ahead. Participants seemed reassured by these experiences, even if the information may have sometimes been difficult.

"... the OT [occupational therapist] came in and talked to me about, um, rehabilitation and prostheses and things like that. So that lifted my spirits, that... you know there was a light at the end of the tunnel. It wasn't going to be all doom and gloom." (Participant 3)

"Before my below-the-knee amputation. I was in the room with a guy who'd had the below-knee amputation done five days beforehand. And I could talk to him, and all these things that I didn't know about, that I wanted to ask, he could just tell me. And it was really reassuring. It really made me feel more at ease." (Participant 1)

As people became better informed about their health condition, they were able to more effectively contribute to decisions about their healthcare, leading many people to advocate for themselves and make the decision to undergo a TTA.

"After being in hospital and having a couple of toes amputated, I learnt how to speak up a little bit and ask questions. I asked the doctors what do you actually do, how do you take the leg off? They were open and honest with me which made me feel comfortable that they weren't beating around the bush." (Participant 3)

"They [the surgeons] said they were just going to take it off below the ankle... I said, bugger that, you may as well do it properly, take the lot, and the surgeons agreed." (Participant 2)

"I was making decisions and asking questions and everything was so well orchestrated - before [the TTA] that it was the best possible process afterwards. It was - you know, I had the whole care team and you know, it was all very - it was done extremely well." (Participant 5)

Following TTA, participants commented on the fact that they underwent rehabilitation, through which they gained knowledge about life with limb loss.

"I realised I'd get a lot of physio [physiotherapy], um and rehabilitation and then the physios [physiotherapists] and - and the OTs [occupational therapists] came in and talked to me about um rehabilitation and... prosthesis and things like that. So that kind of lifted my spirits, that... you know there was a - a light at the end of the tunnel." (Participant 3)

"Once I became a below knee, and I went out to hospital, everybody's got to see the psychologist at least once. So I seen him and I decided to keep seeing him. So I did that for three and a half months and um, yeah by the time I'd finished with him and had a decent leg and seen what I was able to do, I was sort of ready to go out there and take on the world again really." (Participant 1)

Theme 3. Advice from the lived experience

Many participants expressed a desire to help illuminate the path for others facing the prospect of amputation and reflected on advice they believe would have helped their journey. There were two main reflections: *knowing what to ask*, and *the benefits of peer support*.

When amputation was suggested as a form of wound treatment, participants recommended asking specific details about all the PFA and TTA options before proceeding with surgery. These details included: what will happen during surgery, expected physical changes or outcomes, duration and nature of recovery or rehabilitation, the predicted likelihood of improved wound healing for an individual with similar co-morbidities, and particularly the impact that the recovery and amputation level would have on their function in daily life.

"Rather than ask how you would cut the toe or leg off, I'd ask how is it going to affect me?" (Participant 3)

"I would ask what the mobility comparisons would be between the two amputations... I probably should have asked more questions about being confined to the house, everything that was involved around the VAC [Vacuum Assisted Closure] machine... having to be on pain killers. The quality of the time. If there were statistics on success rates, I'd point those out too." (Participant 1)

The benefits of peer support and education were espoused by a number of participants as having the greatest impact on their understanding.

"The only person that really understands at the end of the day, is another amputee that's been through it. You could be told by a physio [physiotherapist] but... to be told by somebody that's been through it, that's another story." (Participant 9)

"Limbs4Life, they have a peer support program. I spoke to somebody from Limbs4Life, he was great... he'd had a very similar experience to me, so to be able to talk to him was really, really reassuring. So like Limbs4Life, they were an invaluable sort of service that they do. I'm sort of surprised that the hospital system doesn't do it. Or the rehab system doesn't do it." (Participant 1)

"So the prosthetist here... guided me to meet other patients, which was a good thing." (Participant 5)

Several participants provided advice about how decisions about amputation could be better informed; including ways to provide information and support decision making.

"You get information from doctors and nurses, but I find it easier to read something off paper... and let it really sink in [brochures] you

can take with you and read them in your room and read them when ever you feel like it in your own time.” (Participant 3)

“[If] I was to ask the doctors to come and talk to me ... would they be able to say it in simple terms?” (Participant 4)

“Sit down, have a cup of tea with them to get to know, get the feeling of them. Just let the conversation flow.” (Participant 8)

“For the clinician staff guiding the patient as to what surgical outcomes they can expect: give them the full options. Be prepared to provide a whole host of options and choice. You need to listen. Give the fact base and, um, give them time to contemplate. If that is at all feasible. Do not expect them to choose the one that you would choose as well. Be prepared that whatever that decision is for that person ... needs to be made for that - the person needs to make their decision.” (Participant 5)

Discussion

The purpose of the study was to describe the lived experience of people who have undergone sequential PFA and TTA.

Three themes characterized the lived experience: *enduring complications eventually resolved*, *health and wellbeing improved with knowledge*, and *advice from the lived experience*. Woven through the detail of these themes are a number of noteworthy insights that warrant discussion.

The experiences of PFA reported in this study were very similar to those reported in the only other study that included a discrete cohort with PFA [6]. Common to both these studies were the experiences of repeated wound failure, reduced mobility, fear of further amputation, as well as the lack of information about, and involvement in, decision making prior to PFA. Many of these experiences are common across the broader body of literature describing the lived experience of amputation [6, 12, 13].

It was notable that participants in this study tended to reflect positively on their TTA experience, which was not the case in previous studies [6, 12, 13]. We hypothesize that the experience of TTA in our participants was informed by their prior, and often negative, experiences of life with PFA: the burden of ongoing medical appointments, pain and disability associated with an unhealed wound, the uncertainty and anxiety about whether wounds would heal and the prospect of further amputation surgery [6]. During the time that participants lived with PFA, many had the opportunity for chance encounters with others who had shared the same experience and witnessed first-hand what life might be like with a TTA. As their understanding of the different treatment options improved, some participants advocated for TTA and in these cases, the self-determination is likely to have also influenced how participants felt about life with TTA.

Given that many participants had lengthy exposures to the healthcare system in the lead up to their PFA, it was surprising that people seemed poorly informed about the amputation surgery and the likelihood of complications. In part, this may be explained by the notable absence of structured systems for pre-amputation education and counseling in peoples’ description of the PFA experience. By contrast, much better systems seemed to be in place to support people prior to TTA where access to psychologists or counselors, visits by a member of the rehabilitation team, and professional peer support were integral to the treatment pathway and therefore, routine.

Given good evidence that pre-amputation education greatly improves the lived experience [6, 14, 15], it begs the question why the same systems of support that were in place for people facing the prospect of TTA were not in place for those facing the prospect of PFA? While many types of PFA are regarded as ‘minor’ amputations given the surgical procedure is relatively straight

forward and results in the removal of a small amount of tissue, there is good evidence to suggest PFA is not a straight forward intervention. As described in the introduction to this article, a recent systematic review [4] highlighted that 40% of people will experience serious complications in the months following PFA; a rate comparable to that observed in people with TTA [4].

The participants’ own advice helps paint a very clear picture of how we can improve the experience for others facing difficult decisions about PFA and help prepare people for the likelihood of challenges down-the-road. Participants in this study highlighted the need to have access to good information about the different treatment options and facts describing the likely outcomes, risk of complications and functional impacts. Ideally, there would be opportunities to access this information in different and timely ways, such as orally and in writing, to help reflect on and consolidate the information provided. The participants’ experience also highlighted the importance of meaningful conversations with others to help inform their decisions and deliberations including health professionals, family, and others with a lived experience of limb loss.

It is striking how much of the participants’ advice is consistent with a shared decision-making approach. Shared decision making is an approach to clinical consultations and decision making that emphasizes the need for meaningful conversations that can help inform patients about all the treatment options – what is involved, the likely outcomes and risks of each – as well as support their deliberation [16]. Resources used to support shared decision making, such as decision aids, often provide much of the factual information in a form accessible to patients and can be helpful to supplement conversations, facilitate reflection and share information with family [16].

Studies describing the lived experience of people with similarly serious medical conditions such as cancer [7, 17], spinal cord injury [8] and renal disease [9] highlight that good health literacy improves psychological well-being, reduces depression and anxiety, facilitates self-efficacy and involvement in decision making, and thereby increases satisfaction with the treatment received and reduces decision regret.

There are many reasons why clinicians and hospital organizations should reflect on the lived experience of sequential PFA and TTA described in this study to inform better practice. Many of the experiences reported in this investigation are confronting. There is clearly a compelling need to adapt practices in keeping with the participants’ advice to improve the lived experience of those facing difficult decisions about PFA, and the prospect of sequential PFA and TTA.

Limitations

The experiences described in this study reflect those of people who have undergone an initial PFA and experienced complications that ultimately lead to TTA. The experiences are, in part, a reflection of one large tertiary health services in metropolitan Melbourne. As such, we caution that the experiences characterized in this study may not be generalizable to vastly different healthcare systems. We do not claim that all people undergoing PFA will experience the sort of complications described in this study, but it would be remiss not to highlight that complications and reamputation are common. As such, we argue the importance of candid conversations that provide accurate information about all the treatment options including the likely clinical and functional outcomes and potential for complications and reamputation.

Participants in this study were heterogeneous in terms of their cause of amputation and other demographic characteristics. Care should be taken to generalize these experiences; particularly to subsets of the population not included in this research (e.g., children).

A number of steps were taken to ensure the integrity of the data including member checking. While we have taken care to confirm that our interpretation of each participant's experience was truthful, one of the participants was unable to review their summary schematic and participate in the second interview that formed part of the process of member checking. However, all other participants' did undertake this process to support data integrity.

Given the aim of the study, recall bias was an inherent challenge in having participants accurately reflect on their experience in an interview conducted, in some cases, many years after their amputation. Given that all participants had undergone sequential PFA and then TTA, and currently live with TTA, it is likely that accurately describing the lived experience of PFA is more difficult than that of TTA. It is difficult to hypothesize how this may have influenced the results and we hope that by explicitly highlighting this bias, readers can make their own determination about the potential impact on the results and conclusions.

Given the small number of participants and that most participants were recruited from a single healthcare service, individual details about the sex, age or cause of amputation of each participant would make them easily identifiable; particularly given the detail of the experiences reported in the manuscript. Hence, to be able to report detailed demographic data to help contextualize the participants' quotes, we have been deliberate in concealing the name of the hospital and ethics committee that approved the study so as to maintain anonymity of the participants.

Conclusion

This is the first study that has described the lived experience of people who have undergone sequential PFA and TTA.

Findings from this study highlight that the foot complications that led to PFA endured and it was not until TTA that these complications resolved and participants reported being able to get on with their life. At the point of PFA, participants had little knowledge about the surgical procedure or the likely outcomes or common risks of amputation. Over time, the understanding of participants improved given formal systems that provided access to peer support visits or counseling, as well as chance encounters with others who had already lived the experience. Based on their own lived experience, participants provided advice consistent with the need for good-quality information and meaningful conversations that can help inform decision making and prepare for the journey ahead.

We encourage clinicians and hospitals to reflect on the lived experience of sequential PFA and TTA as described in this study. The first-person experiences reported in this investigation are confronting. Given these experiences, there is a compelling need to adapt our practices in keeping with participants' advice to improve the lived experience of those facing difficult decisions about PFA, and the prospect of sequential PFA and TTA.

Acknowledgements

We are grateful for the many participants who shared their experience of sequential partial foot and transtibial amputation to help

improve the experience for others facing difficult decisions about amputation surgery.

Disclosure statement

No potential conflict of interest was reported by the authors.

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