

What's it really like? The lived experience of patients and their families following partial foot amputation secondary to diabetes mellitus

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Citation: Wilson P, Kerr D, Mahon L (2021) What's it really like? The lived experience of patients and their families following partial foot amputation secondary to diabetes mellitus. *The Diabetic Foot Journal* 24(4): 1–7

Key words

- Diabetic foot
- Interprofessional education
- Multidisciplinary teams
- Podiatry education
- Teamwork

Article points

1. Partial foot amputation has a significant effect on patients with diabetes.
2. Effective communication between family members, healthcare workers and patients is important in enabling positive coping strategies.
3. Patients perceive a partial foot amputation as a fresh opportunity to self-care.

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Partial foot amputation (PFA) or minor amputation is performed to prevent major amputation, manage uncontrolled infection or treat peripheral arterial disease where revascularisation is unsuccessful. The experience of patients and their family members following PFA has not been well described. This study investigated patient and family experiences following PFA using a qualitative approach. Seven participants were interviewed following a semi-structured approach and analysed using an interpretive phenomenology. Three themes were gleaned from the data. These were “journeying together” — effective communication and relationships, “another stab at it” — a perceived second chance and “sure, it’ll be grand”, utilising positive coping strategies. PFA has an effect on the health and wellbeing of patients and families who require support from healthcare professionals before and following PFA. Whether additional support could contribute to better outcomes is unknown and warrants further investigation.

Diabetes Mellitus (DM) is a lifelong, life-limiting condition, which requires significant change to an individual's lifestyle in order to effectively manage the disease and prevent complications (Weinger et al, 2018). Complications, once developed, can include damage to eyes (retinopathy), kidneys (nephropathy) and nerve endings (neuropathy). One of the most feared consequences of these complications is lower-extremity amputation, which may occur following a period of diabetic foot ulceration (DFU) (Frykberg et al, 2018; Wukich et al, 2018).

How people deal with assaults on their physical health and wellbeing is unique and based on individual factors. The management of DFU is often complex and multifaceted, placing restrictions on their daily lives (Delea et al, 2015; Coffey et al, 2019). Patients may be asked to attend for multiple appointments with different specialists, restrict their movement, change their diet or take different

medications (Bishop, 2007; Schaper et al, 2020). Even when treatment plans are followed, not all of these wounds heal and have a high rate of recurrence (Kee et al, 2019; Schaper et al, 2020).

The longer a person has a DFU, the greater the chance of treatment failure, partly due to the ongoing complications of DM (Caruso et al, 2020). Up to 80% of amputations are preceded by DFU (Hurst et al, 2020). Amputation is usually performed to comprehensively manage either infection or peripheral arterial disease. Partial foot amputation (PFA) or minor amputations (amputation distal to the ankle joint) may be considered as limb-salvage procedures preventing more proximal amputations, although not without complications (Jupiter et al, 2020; Littman et al, 2020). While a PFA may be successful in dealing with the immediate physical problem, it may not necessarily consider the patient's perspective and this can lead to a perceived loss of control on the part of the patient (Hamill et al, 2010; Coffey et

al, 2018). Some authors feel that patients may be better served by an initial aggressive amputation rather than multiple procedures (Nehler et al, 2003; Boffeli and Thompson, 2014). The impact of amputation on health and wellbeing has been investigated and, while the level of distress for those undergoing PFA is less than for major amputation, feelings of fear and anxiety have been reported (Livneh et al, 2000; Hamill et al, 2010; Livingstone et al, 2011; Williams et al, 2011; Murray and Forshaw, 2013).

A significant event such as amputation is likely to have an impact on a person's wellbeing and cause psychological stress. This is to be expected and is a normal phenomenon (Frankl, 1985). Those patients with a strong social support network following major amputation have better outcomes than those without (Sansam et al, 2009; Czerniecki et al, 2012). Families of patients are not immune to such stressors, with high rates of anxiety reported (Vileikeyte, 2001; Duggleby et al, 2010; Hoban et al, 2015; Weinger et al, 2018).

The psychological impact and experience of both patients and their families following PFA secondary to diabetes has not been well described in the literature (Hamill et al, 2010; Livingstone et al, 2011). Where experiences have been reported, these experiences have been in the formal rehabilitation setting as part of larger studies (Hamill et al, 2010; Livingstone et al, 2011).

Methodology

The aim of this study was to investigate the lived experience of patients and their families who had a PFA secondary to diabetes using a semi-structured interview methodology. Purposive sampling was used from hospital inpatient records, which were cross referenced with theatre notes for accuracy (O'Callaghan et al, 2012; Kuhnke et al, 2014). Patients and their family members were selected who underwent PFA during 2016 or 2017 in a large academic teaching hospital. Ethical approval was granted (2019–10; 39[08]). Ninety patients underwent PFA in the centre in the 2-year period. Of these, 83 were excluded as per the exclusion criteria and seven were invited to take part. Four patients were

recruited and three family members. A total of seven interviews were conducted following a semi-structured model.

Of the four patients, three were male and one female; age range was 48–84 years old. Two patients had digital and two forefoot amputations. Of the three family members, all were female: two partners and a daughter were interviewed.

Interviews were described verbatim and data analysed in two groups. Data were coded using NVivo and cross referenced with members of the research team for accuracy. Using an interpretive phenomenological analysis, themes from the interviews were collated (Rosca et al, 2021).

Results

Based on the reflections of the patients and family members' experiences and using the constant comparative method, the researchers gleaned three overarching themes from the data (Offredy and Vickers, 2010). These themes were "Journeying together" — relationships and communication at home and with HCPs; "Another stab at it" — perceived opportunity for a fresh start; "Sure – it'll be grand" — utilising humour and other positive coping strategies.

"Journeying Together" — relationships and communication at home and with HCPs

The relationship and communication with HCPs were important to all of the study participants. The opportunity for discussion and the manner in which the proposed treatment was presented was missed by some HCPs, thus leaving participants with the feeling of loss of control over what was happening.

"The surgeon explained they were really trying to prepare me for the worst, but I didn't want to believe it, didn't want to know, fighting you, you fighting with him" (Sarah — patient [Pt])

"I think in the way they are told – think it could be more tactful — so if you are there and you think your toe is going to be amputated — you need someone to come along and say 'look, you have a big problem, it looks like we are going to have to take the toe away but leave it with us,

we'll get few X-rays and then we will come back and talk to you.' You don't just say that it has to go." (Patrick — Pt)

Family members expressed the need to be included in the decision-making process and for their opinions to be valued as much as the patients'.

"He just dismissed — he dismissed anything I ever asked" (Mary — Family [FM])

"I just think it was very worrying in the beginning that the infection wouldn't stop — and the surgeon was saying 'once we start chopping, we don't stop'. That was frightening" (Kate — FM)

Most participants stated that the PFA had an effect on their relationships at home. Some participants were anxious about the way things had changed and the degree of uncertainty. Family members feared the potential consequences of surgery. Some responses showed surprise at the physical changes and the speed of deterioration.

"You know, it made me more aware of everything you know, whatever." (Chloe — FM)

"Well, a little bit wobbly here and there but we got through it" (Kate — FM)

"I didn't really talk about that. I didn't think I could burden them. My daughter had three young children, my mother was 68 at the time. I didn't want her to worry, like she's 68, she doesn't need to worry, she's at the age where she shouldn't be worrying about me, I should be worrying about her" (Sarah — Pt)

"They have to put up with me for so long" (John — Pt)

"Another stab at it" — perceived opportunity for a fresh start

Some participants expressed regret about the DFU and the need for surgery, to blame either of themselves or someone else — this was then echoed in the family responses.

"If I had been a better diabetic, would this have happened? Yeah maybe, but it might not have been as severe" (Sarah — Pt)

"He said he got a blister, said it was my fault he was doing my garden using the lawnmower" (Joan — FM)

"This foot — the shoe's skinned, and the toes were bent up skinned the top of it and I didn't look after it" (Conor — Pt)

All participants, whether they expressed this, viewed the amputation as a 'fix to the problem', allowing them to 'get on with it.' This was in the context of the DFU, which had been present prior to surgery.

"I was just thinking the pain and the mess of it would be gone" (Conor — Pt)

"I could see the state of the toe, I saw the X-rays and I could see multiple fractures. Sure, I wasn't surprised; it was in the back of my mind" (Patrick — Pt)

"Take it off — there no need for it" (Joan — FM)

"I didn't mind — once it didn't affect his balance or anything and it wasn't the big toe or whatever. No, I was honestly glad" (Chloe — FM)

Anxiety for the future is seen in the responses from the patient perspective in the context of how their families would cope having to go through this process again.

"Having the threat of losing the other toe" (Patrick — Pt)

"I worry is it coming back — it's sore" (Sarah — Pt)

"How would my partner be able to manage if I lost a leg? If we were still together, what impact would that have?" (Sarah — Pt)

Patients reported seeing this process as a fresh start, or having the ability to make changes, which would enable them to prevent the process from recurring.

"I am attending the dietitian. I'm back here



tomorrow and we've gone through the food pyramid and that." (Patrick — Pt)

"If you only listen to the voice of people when you get diabetes at the start" (Sarah — Pt)

"Sure, it'll be grand" — utilising humour and other positive coping strategies

When the participants were asked how they coped with the experience of amputation, all responses included humour as part of their coping strategies.

"You know me, I cope with everything, try to give him confidence — but you worry and we did make jokes about it, but he enjoyed it. He is grand now and we are all grand — and we don't think about it — unless he annoys me and then I would say: sure, you have no toes!" (Kate — FM)

"When he gets drunk, he falls down and you have to pick him up. That's when it affects him and he's saying — ah, my balance, my balance. It's not the six pints that he's had!" (Kate — FM)

"I don't worry about it so much. People say what would happen if it kicked up again and I say 'it will be a Long John Silver job'" (Conor — Pt)

"Off with his head — off with his toes" (John — Pt)

Most respondents exhibited the adoption of positive coping strategies. The patients reported that this was facilitated by the strong network of support both at home and from the hospital.

"We got through it once. He got it into his mind. He coped once he got it into his head like he couldn't put them back on but once he got it into his mind, he was OK" (Kate — FM)

"Things like this do happen, you just have to try turn negative into positive — what can I do, you just have to keep going forward" (Sarah — Pt)

"All I had to do was look around the hospital and see all the people who were worse than I was" (Patrick — Pt)

Discussion

Patients and their families describe a variety of experiences when dealing with the need for amputation. The first theme of 'journeying together' highlights the importance of communication and relationships between the patient and their family, the patient and the HCP, as well as the HCP and the family. The second theme of 'another stab at it' highlights the perceived second chance to manage things differently in the future. The final theme gleaned — 'sure, it'll be grand' — highlights the use of positive coping strategies including humour and spirituality.

The application of a positive or negative coping strategy after amputation is dependent on a variety of internal and external factors (Duggleby et al, 2010). The contribution of these factors may influence long-term outcomes. Internal factors, which include having a positive outlook on life, have been associated with a positive strategy (Duggleby et al, 2010). External factors which include information about the illness or the level of support offered, may also influence the experience — these factors may be more readily adaptable to intervention by HCPs (Livneh et al, 2000). Whether individual experiences will lead to a positive coping strategy or otherwise is not always something that can be identified within a normal consultation.

Paton et al (2014) found that participants in their study had preconceived ideas about what the HCP would say. This, in turn, had an impact on their level of trust in the HCP and their subsequent actions. Even when a person is in agreement with the need for amputation, there are emotional and psychological processes to consider, which may be impacted by the communication of the HCP (Chini and Boemer, 2007). The process of acceptance begins before the surgery and maybe as early as initial DFU diagnosis. Patrick (Pt) stated that, while he could see the need for the amputation from the X-rays, he was unhappy with the way in which he was told that an amputation was needed. This highlights the need for effective and appropriate communication from all members of the healthcare team (Hamill et al, 2010). Kate and Sarah in this cohort expressed a loss of control in the decision-making process based on the communication they received from the HCP, while Joan expressed frustration about not being included in the decision-making process. HCPs may overestimate their

effectiveness in communication (Price, 2008). HCPs also need to be cognisant of their own beliefs, culture and traditions, which may be different to the patient's (Alden et al, 2017). This is seen here when John (Pt) expressed disbelief at early discharge from hospital, as well as the manner in which news was communicated to him by a HCP whom he had not met before and felt was not involved in his direct care.

Patients who are suffering with the complications of DFU may not be in a position to understand fully what is being advised to them, especially if they suffer no pain. This is why the communication delivered by HCPs must allow them to make the right decision for them (Hamill et al, 2010). The inclusion of the family member in this process may allow more realistic goals and expectations following surgery. Family members may provide an array of support to patients both during and after the consultation and throughout the decision-making process (Laidsaar-Powell et al, 2017). The frustration expressed by Joan and the lack of control expressed by Kate and Sarah in these situations is in contrast to the self-management strategy that is advocated for in the management of diabetes (Watt and Ponto, 2008). The provision of patient-centred care needs to reflect a collaborative approach between HCP and patient, which may include family members in the decision-making process (Bauman et al, 2003; Garriss and Weber 2018).

The support provided by family members in the data presented suggests that a strong support network at home is important in enabling the patient to adapt to the new normal that they will face. The effect of such social support has been shown to be associated with positive outcomes and greater satisfaction following amputation in major amputees (Jacobi and Machleod, 2011; Pereira et al, 2018). The data here suggest that this is the same for those undergoing PFA. Respondents compared themselves to others in similar situations, which has been shown as giving people the impetus to continue following surgery (Hamill et al, 2010). This is shown in the example of Patrick (Pt) who stated that looking at other people who were worse off than him encouraged him to continue. This is important in the human capacity to turn negative experiences into positive achievements (Frankl, 1985).

There is a complex relationship between receipt of knowledge and behaviour change in individuals with diabetes (Paton et al, 2014; Natovich et al, 2016). It is likely that this extends to family members, who may be in receipt of information which is 'third hand' from the patient if they are not present in the consultation. Given the speed of the deterioration of the DFU to surgery, decisions may occur quickly, which can cause fear for both the patient and their family. This was seen in the dataset here when Kate (FM) reported that it was "very very frightening". Patients who are dealing with difficulties both physical or psychological before amputation may keep the details from their family members in order to prevent showing distress to their families (Chini and Boemer, 2009).

Sarah (Pt) reported that she did not want to burden her family with her problems. A disconnect between the information given and the information received during the consultation can be seen in the data here when Sarah (Pt) reported "fighting" with the HCP who told her amputation was needed. Such level of disconnect can be compounded by the presence of cognitive decline, which is sometimes seen in this cohort of patients as a consequence of DM (Natovich et al, 2016; Schumann et al, 2010). Conor (Pt) reported that "having to keep going up and down for appointments" had an impact on the whole family during treatment for DFU.

Patients and family members in this cohort expressed the understanding of the need for the procedure to solve the problem of the DFU. Both Conor (Pt) and Chloe (FM) reported that "the mess of it would be gone" following amputation, while John (Pt) reported that "if it had to be done — it had to be done". PFA may give relief and solve the problem in the short term for those suffering with chronic disease (Horgan and MacLachan, 2004). Sarah (Pt) reported that she was more paranoid about her feet and diabetes than she was before and Patrick (Pt) expressed concern about the future chances of losing another toe. In reality, the likelihood of further ulceration and amputation in this cohort is high (Jupiter et al, 2020).

Following an amputation due to systemic disease, patients may show signs of anger following amputation (Horgan and MacLachan, 2004). Sarah (Pt) reported "fighting with HCPs" and Kate (FM) reported disbelief that the HCPs "could not fix the problem".

In this cohort, individual responsibility, guilt and blame were noted. Joan (FM) reported feeling responsibility as Patrick (Pt) got the DFU when he was mowing her lawn, while Patrick (Pt), in turn, blamed the dirty water at the beach. Couture et al (2012) found that personal acceptance for the need for amputation was associated with greater levels of independence. This is echoed in the response of Conor (Pt) who reported not looking after the DFU on his toe prior to amputation. Sarah (Pt) stated that she “could have been a better diabetic”.

The fear expressed in the response by Sarah (Pt) that “it was coming back” is consistent with other studies, which have identified that such fear is seen following PFA with the ever-present threat of further amputation (Livingstone et al, 2011). The continued threat of this amputation adds weight to the argument of initial aggressive amputation for this cohort of individuals (Nehler et al, 2003).

Humour appears to be an important component in the positive experience in the current data, with most respondents stating this was part of the coping strategy both for the individuals and for those at home. John (Pt) reported “off with his head — off with his toes” when discussing his attitude to the need for surgery, while Conor (Pt) said “it’ll be a Long John Silver job next!” It may be that the PFA gives some respite from the DFU, which has been shown to have as much significance to quality of life as amputation (Weinger et al, 2018). Chloe (FM) reported being glad to get rid of her family member for a while, referring to the ongoing treatment of DFU. Kate (FM) reported making jokes about the situation in order to deflect the ongoing challenges at home. This has been shown to help deal with pessimistic emotions after amputation (Couture et al, 2012).

Resilient individuals are those who are able to deal with traumatic experiences and creatively construct life afterwards (Frankl, 1985; Southwick and Charney, 2018). Participants in this cohort show resilience in finding positive meaning following amputation despite anxiety about the risk of further amputation. Sarah (Pt) reported that “I just got it in my head that it was not going to happen”. Patrick (Pt) found that comparing himself with others who were much worse off than him made it easier to cope. The individual reflection on the experience facilitated an acceptance of the

amputation and allowed them to move on with their lives as seen in other cohorts following major amputation. Some of them reported the use of a spiritual approach (Kralik et al, 2006). Patrick (Pt) reported asking — “Why me, Lord — Why not me Lord?”, while Sarah (Pt) reported going to church more often.

Participants in this cohort showed that their experience following PFA is similar to those undergoing major amputation (Livingstone et al, 2011). Through reflecting on their past experiences, this group of individuals show hope for the future and resilience in the experience of both DFU and PFA. While the coping strategies employed in each case were different, overall they were positive in nature, supported by flexible relationships with family members.

Limitations

This is a small study; those who were willing to take part may preferentially represent those with a positive outlook on the experience, irrespective of whether they are patients or family members. This may account for the lack of maladaptive or negative coping strategies noted in this cohort.

Conclusion

The impact of PFA on quality of life can be likened to both DFU and major amputation and should be considered as such by HCPs. Participants in this cohort show the application of positive coping strategies in response to the experience of DFU and PFA. This utilisation of positive coping was independent of the indication for PFA. ■

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