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**A path of perpetual resilience: exploring the experience of a diabetes-related amputation through grounded theory**

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Diabetes is a common chronic condition that incurs enormous personal and public health burdens. Diabetic complications can lead to further functional problems such as amputations

of the lower extremities. Diabetic foot problems result in significant social, medical and economic consequences and constitute the most common reason for hospital admissions for people with diabetes (Colagiuri *et al* 2003).

Several studies have examined the area of psychosocial coping following diabetes-related amputation. Thompson and Haran (1984) surveyed 134 amputees and their helpers at a prosthesis centre. They found that participants experienced a high degree of social isolation, and had unmet needs in relation to finances, employment and social activity. Livneh, Antonak and Gerhardt (1999) surveyed 61 amputees attending an amputation outreach centre on sociodemographic variables, disability-related factors and coping strategies as predictors of psychosocial adaptation to amputation. Younger age and shorter duration since amputation were linked to higher levels of depression. An active problem-solving approach, and less reliance on emotion-focused coping was linked to a lower level of reported depression and better adjustment to, and acceptance of disability. In a follow-up paper Livneh, Antonak and Gerhardt (2000) reported that respondents' perceptions of coping with amputation-related stress were best explained by three dimensions: active/confrontive versus passive/avoidance coping, pessimistic/fatalistic versus optimistic/positivistic coping, and social/emotional versus cognitive coping. The authors suggested that participants' responses may have been limited by the use of scales and survey tools.

Bodenheimer *et al* (2000) surveyed 30 male amputees (53% with diabetes) on sexual functioning, depression, anxiety and health status following amputation. Sexual problems were common in the subjects. Participants reported no significant anxiety or depression when compared with other outpatients, however, sexual functioning pre-amputation was not reviewed to determine if the amputation itself was linked to sexual dysfunction, and many

participants had pre-existing conditions that cause erectile dysfunction. Rybarkzyk, Szymanski and Nicholas (2000) conducted a review of research and clinical practice in lower limb amputation. The amputation cause, degree of impairment and disability, age, body image and coping skills all impacted on adjustment to amputation. The authors concluded that further studies were needed on psychological and coping interventions.

Behel *et al* (2002) surveyed 42 amputees from five prosthetic clinics on their feelings of vulnerability, symptoms of depression, quality of life, and psychological adjustment to amputation. They reported that increased feelings of vulnerability were associated with depression, lower quality of life and poorer adjustment. De Godoy *et al* (2002) interviewed and examined 30 carers (controls) and 30 amputees who had undergone amputation in the previous 1-6 months, on their quality of life, physical capacity, social and emotional issues, mental health, pain and general state of health. The quality of life was generally lower for amputees compared with the control group, however, mental health and vitality were not different from the control group. Use of an unrelated control group may have yielded different results.

While these results are interesting, these studies are subject to a number of limitations that impact on the value of the findings. Firstly, the participants were all drawn from rehabilitation or prosthesis clinics involving mostly lower limb amputees and are not reflective of the wider amputee population including digit, and partial foot amputees who may not receive rehabilitation or specialised prosthesis care. These populations may also have had better outcomes post-amputation due to the fact that they attended specialised clinics. Secondly, limited research has been done on positive adjustment to disability. After many years of suffering with chronic debilitating diabetic foot ulcers, an amputation may result in improved quality of life for the patient, therefore individuals who undergo a lower limb amputation may not view it as a negative event (Rybarczyk *et al* 2000). Thirdly, the research methodologies used in these studies are based on tools and numeric values as interpretive concepts rather than a descriptive reality of everyday experiences for the amputee. Much of the richness and complexity of the human experience can be lost in the use of tools with close-ended items (Polit & Beck 2004), and instruments used to measure patient outcomes in disability studies are generalised, not focusing on an individual's rehabilitation goals (Geerstzen, Martina & Rietman, 2001). The coping strategies described are often specific to the time and situation in which the data collection tool is applied, and the tools have limited response options.

The literature review demonstrates that there is little information on the lived experience of the diabetes-related amputee. Offering amputees the opportunity to provide reflective and individual experiences of amputation through qualitative research processes allows the researcher to discover what is most meaningful for participants without depersonalising or limiting the data. The research aim was to allow diabetic amputees to describe their experiences of amputation and to use this information to generate grounded theory that will lead health professionals and relevant others towards a more comprehensive understanding of the realities of post-amputation

life (Behel *et al* 2002). The research question was: ‘What is the diabetic person experiencing in their day-to-day life, post-amputation?’

### Research design and methods

Ethics approval was granted by the relevant Human Research Ethics Committees. A Health Service employee compiled a list of 30 potential participants from operating theatre lists and patient medical records where amputation and diabetes were identified on the admission data, and sent an information sheet and consent form to them. A reminder letter was sent six weeks later. Five persons with a diabetes-related amputation consented to be interviewed along with their partners or carers. Interviews were conducted in the amputees’ home, with either a partner or carer present. Participants were issued with a de-identifying code and could cease the interview at any time. Participants were encouraged through open-ended questions to describe how their amputation(s) had affected their life. Interviews took 30-45 minutes, and were recorded on audiotape and transcribed later.

Data analysis began following the transcription of the first interview, and continued during data collection from consequent interviews. The transcribed interviews were examined line by line (open coding), and comments and interpreted key messages from within the data were written in the margins of the transcripts. The interviews were re-read, using a constant comparative method, and codes were identified in each individual interview and across all five interviews. All the phenomena contained within the content perceived as important or interesting were named, building up a list of recurring codes from within the data. The data were then divided into discrete and meaningful segments that formed units of analysis to be compared one by one in order to create categories (Glaser 1992).

The individual lists were combined into similar groups and examined for their main codes; some codes emerged early on in the data analysis where each interview was read word for word (open coding), and many related to the core concepts and categories that were emerging, a process Glaser (1992) described as selective coding. Using theoretical coding, examination of the developing phenomena began, in a process of advanced coding, discovering properties and building concepts that would provide insight into the emerging categories. The theory emerged within the informants' socially constructed realities.

Categories were developed by cross-referencing the codes and concepts, viewing their interrelated properties and developing an emerging theory. This was assisted by memoing, which involved brainstorming potential descriptive labels to name the codes, concepts and categories. In the final phase of data analysis the categories were integrated into a developing coherent theory. A core category to which all other subcategories related was named and a conceptual framework was built that developed into a grounded theory.

Throughout the analysis of the data a 'cyclical' approach was used; there was frequent return to the raw data for comparison and a gradual focusing of the theory. Once the central category had been conceptualised, the raw data and the resulting analytical memos, codes and categories were re-examined seeking verification and exploring contradictions to the theory. To evaluate the accuracy of the developing theory, external validation and a computerised qualitative data analysis program (NUDIST) were used.

## Results

All participants were Caucasian, one was female, four were male, and their ages ranged from 41-77 years (mean 1.6 years). Participants had been diagnosed with diabetes for 17-50 years (mean 28.4 years). All participants had additional diabetic complications. The analysis of the codes led to the development of three core categories and the basis psychosocial process of ‘a path to perpetual resilience’ (Table 1).

Insert Table 1 here

The three core categories that described the participants’ experiences of their amputation, ‘Imposed Powerlessness’, ‘Imposed Adaptive Functionality’ and ‘Imposed Endurance’, are consequences of the impacts of lower limb amputations and are associated with issues of physical, social and psychological functioning.

### *Imposed Powerlessness*

The participants’ experiences of progressive diabetic foot disease, in the presence of other complex complications combined with the adverse impacts experienced by participants during interactions with the healthcare system and their lack of knowledge of their risk for diabetes-related amputation formed one of the core categories, ‘Imposed Powerlessness’, described by the concepts ‘Persistence of Afflictions’ and ‘Unsolicited Adversity’ (Table 1).

All participants continued to cope with persistent afflictions such as ongoing and new foot lesions, intermittent phantom pain, and stump problems. All participants had one or more multi-organ complications such as renal failure, autonomic bowel problems, stroke and blindness, which complicated their adaptation to their amputation:



*I don't think people understand the complications with diabetes. Some nights I have gone to the toilet and taken a pillow with me because you know, you're not game enough to get off it, it's difficult rushing to the toilet in the dark when you haven't got all the toes on your feet.*

'Unsolicited Adversity' is the explanatory label descriptive of the codes 'Damaged Trust' and 'Uninformed Position', which represents the participants' sense of powerlessness due to adverse medical care and lack of education on the risks of diabetic amputation. Poor consultation on decisions regarding their care, incorrect care, and the lack of expertise of some health care professionals led to a lack of trust in the healthcare system. Some of the adverse events experienced by the participants included being dropped on their stump following the amputation, and inappropriate access of an AV fistula leading to a large bleed requiring blood transfusion which then made the participant non compatible with their kidney donor. One participant stated:

*I had my toe amputated on a Saturday afternoon and the Doctor said he was going to take me back to theatre again on Monday because it was all open, then another doctor came around Monday morning and said "You can go home" and I come home with a toe that you looked down and seen the bone in it and I had no earthly idea what to do with it or anything. There were also so many conflicting ideas how the PIC line was supposed to be looked after.*

*Carer: They did it a different way each time, it shouldn't happen that way with anything that's supposed to be so risky I don't think. That puts doubt in your mind, just the way it happened. It gives me no confidence at all.*

Some health professionals exhibited a total lack of empathy:

*This doctor just said "We'll fix your toes, I'll just cut your leg off there below the knee."*

One participant talked about the period after his below-knee amputation:

*I felt terrible, I didn't remember talking about it and signing the form beforehand, I had to stop them from cutting this second one off too.*

Carer: *My experience was that with the last amputation that occurred, they wanted to do it like a day surgery, do it in the morning and send him home in the afternoon. We just said "No we're not equipped. We can't cope with that." I don't think people realise how serious diabetic foot problems are.*

All of the participants claimed no prior knowledge of the potential risk for diabetic amputation.

When talking about the information he received prior to his amputation, one participant stated:

*No, no one told me about how I might feel or what was going to be involved. You're just more or less left on your Pat Malone (alone).*

Another stated:

*no one told me that people with diabetes could have amputations. They told me after I'd had the first toe amputated. I would have liked to know why they went black in the first place. In the beginning no one was telling me why I was losing a toe.*

### *Imposed Adaptive Functionality*

The category 'Imposed Adaptive Functionality' represents the physical aspects of an amputation. Recurring themes in the data were issues of mobility, changes to roles and responsibilities, environmental changes, and social impacts, such as restricted social contact.

All participants experienced impaired mobility. Participants recognised the limitations of their mobility and adapted their movements and habits to maximize their physical abilities. Some modified their walking styles and most consciously planned walking tasks:

*Even though there's only three stairs I've got to be in the right step or else I've got to stop, ... if I go to go up a step I've got to turn around front on and stand a minute....*

and

*When you only had one foot with the toes amputated off you'd find it easier if you always walked down on the right side of the street because you're better balanced.*

The effort required when walking with a prosthesis restricted the distance this participant was able to walk, and those participants with toes amputated described difficulty walking on rough terrain (due to balance) and walking up or down slopes due to the inability to use the toes for leverage or tension:

*Oh, I can't walk up, no way can I walk up a hill, I just can't do it. Or down an incline or anything.*

All participants described changes to their roles post-amputation, including changes in relationships with their spouses, socialisation opportunities, the ability to earn an income, and to their roles at home. Social participation was impaired due to reduced mobility, inability or reluctance to drive, and embarrassment in social situations due to poor balance. Extended trips required extensive planning to manage wound care, wheelchair access and dialysis.

Participants who had worked prior to their amputation, lost income post-amputation due to difficulty standing for long periods or performing manual tasks:

*You get people in to do the mustering and all that sort of thing. You don't do as much as you used to and therefore your cattle are deteriorating and things just falling down and I just sit there and watch it.'*

All participants experienced significant financial costs linked to their amputation, for dressings, special shoes or prostheses, structural changes to their home and the need to travel to access specialist services. Participants' partners' often performed the daily tasks done by the participant

prior to the amputation. This resulted in the loss of independence for the participants. Tasks assumed by partners included those associated with mobility or balance such as shopping, hanging out washing, carrying heavy loads, and gardening. For participants who had other complications, the spouses became part-time carers, assisting with personal hygiene, and wound care:

*what makes me upset is the fact that I can't do the jobs I used to, I've lost a lot of my independence. I was surprised by the amount of work my wife has to do. I'm a cripple and got to rely on her.*

### *Imposed Endurance*

The category 'Imposed Endurance' reflects the participants' descriptions of the psychological and emotional impact of their amputation and their coping through adaptation and acceptance (Table 1). The emotional impact immediately post amputation was one of shock, anger, and disbelief, reflected in the code 'Feeling Shocked'. These feelings mostly occurred immediately after the amputation even though participants believed they had mentally prepared themselves. Participants described feeling 'fear' and 'turmoil' upon awakening from the surgery, and described periods of acute emotional distress:

*That's your darkest moment you know, the first week you're not real good...you're pretty down ...*

Participants who had below-knee amputations described their amputations with greater suffering than those who had partial amputations, and a blind participant who could not see his foot seemed to experience less distress than the others post-operatively. Other emotions described were lack of confidence in mobility, embarrassment and fear, particularly in social situations:

*If we go to the cattle sales and I've got to take one step at a time going up and down the stairs round the saleyards, that embarrasses me'*

The three participants who had toe and forefoot amputations described greater fear of further amputations than the two who had below-knee amputations. This appeared to be a recurring rather than a 'self-limiting' emotion.

*In six months with my feet ... if it gets worse, I could be looking at losing quite a lot of my foot. I try not to think about it but it does worry me. If I sit and think about it I'll think, "No, get your mind off it", you know, because it does worry you, well, you know, you lose that bit and then it'll be another bit and then it will go on.*

A recurring theme coded under 'Developing Hope', was one of deciding to stay positive and not letting the amputation cause significantly limiting impacts. This appeared to be the mechanism by which the participants tolerated their physical predicament through 'enduring' without 'yielding'. Three participants consciously decided to 'accept' their amputation and described a type of 'self speak' they used to remain positive:

*I made up my mind that I was going to accept it ... I was prepared for it. Well I tried to Prepare myself for it. No, I just sort of took things as they came...*  
and

*I don't think it's affected me, it's made me more determined if it's done anything. I'm determined not to let it make me sit at home and not do anything; I'm more inclined to think "All right I'm going to have a go.*

Another participant looked forward to getting his new prosthesis as a way of keeping positive:

*In another few weeks I'll be able to walk again anyway, so I'm looking forward to that more than what I am at the present time, see, because I've got a future to look forward to, and not the present. I'm trying to keep the present at the present and look ahead, simple as that.*

These attitudes expressed by the participants throughout their dialogue, represent positive adjustment, acceptance and adaptation.

### *A Path of Perpetual Resilience*

Integrating the codes and categories into a coherent theory resulted in the core category being conceptualised as 'A Path of Perpetual Resilience'. Perpetual resilience represents the life of the participants as one of ongoing impacts and corresponding adaptations necessitated by their amputation and diabetes complications, and portrays the chronic nature of the diabetes disease process and participants' fortitude in adapting and adjusting to life with an amputation whilst attempting to remain positive in the face of ongoing adversity. The phrase 'A Path of Perpetual Resilience' unifies the concepts contained within the core categories. 'Imposed Powerlessness' describes the chronic nature of the participants' diabetic complications and the impact these have on their lives, 'Imposed Adaptive Functionality' depicts the immediate and ongoing (perpetual) adaptations the participants' make following an amputation, and 'Imposed Endurance' is coping with grief and loss, while remaining resilient enough to perpetuate hope. These 'imposed' situations have forced the participants onto a path that they will travel repeatedly, requiring them to be resilient to maintain their journey in life.

### Discussion

The participants in this study demonstrate that diabetes-related amputation is a diverse disability co-existing with other medical problems. Participants presented with similar emotional, physical and psychological responses and adaptations. There were few comments regarding more negative aspects of amputation, which may indicate that this group of participants were more passive towards their adversity, or had dealt with their experiences.

The codes and categories revealed a chronological pathway. At the beginning of the path there was a type of powerlessness related to the relentless disease process and associated complex medical care including the amputation. The participants then adapted to the physical and social impacts of their amputation, allowing them to gain some control. At the end of the path the participants emerged from their grief and loss, to arrive at a psychological healing and acceptance. Due to the nature of chronic illness this process of adaptation is ongoing. Similar adaptive response pathways by participants to the physical and social impacts of their amputations were found in studies by Dunn (1996), Forbes (1999), Rybarczyk, Nicholas and Nyenhuis (1997), and Treat-Jacobsen *et al* (2002), who described a progression from the immediate impacts of chronic illness (and amputation), to a sense of loss, experiencing limitations, modification and adaptation (among fear and uncertainty), to acceptance and positive adjustment. This is a cyclic process repeated when there is further crisis, for example, following another amputation. Forbes (1999), found that learning to live with a chronic illness is tied to losing, maintaining and regaining hope in a never-ending process.

The participants in this study actively worked towards a positive view and acceptance of their condition. In another study conducted by Wann-Hansson *et al* (2005), a number of participants affected by peripheral vascular disease also used a deliberately active process to reach acceptance of their limitations. Participants encouraged themselves to avoid giving up, and contrasted their own situation with others who were worse off.

The acceptance and positive adjustment seen in this group of participants is what Dunn (1996) describes as finding a silver lining amidst adversity, and is a beneficial process allowing the person to make sense of their experience and gain some control in their world. Dunn (1996) and Rybarczyk *et al* (1997) found that positive illusions were linked to psychological well-being,

and Dunn (1996) suggests that the act of finding something favourable was important, rather than the particular favourable attribute itself. Thus the process of psychological healing relevant to enhancement of physical wellbeing should be discussed with clients who are about to undergo an amputation.

Social influences may have contributed to the resilience of this group of amputees. All except one had supportive partners, and the exception lived in supportive accommodation with a carer. Livneh *et al* (1999), investigating the role of sociodemographic variables in psychosocial adaptation to amputation, found strong and positive social support was the only variable to be consistently linked across many studies, to successful adaptation. The partners also underwent adaptation to their roles and were involved in what Fisher *et al* (2002) call joint patient–partner disease management behaviours. The impact of an amputation on partners should be considered when planning care for the amputee as our results demonstrated the partners shoulder a substantially increased burden following the amputation. Clinical evaluation and treatment should be expanded to address the health status of the partner as well as the patient, and assessing couple relationships should become part of diabetes pre-amputation care (Fisher *et al* 2002).

The participants all experienced multiple complications from their diabetes that may have contributed to their acceptance of their amputations. Dunn (1996) found that older participants adapted better to amputation compared to younger participants as the older group had prior experience with illness and disability, and lower expectations concerning their functional status. Similarly, Williamson *et al* (1994) found that chronically ill individuals gradually habituated to decreases in functional status and adjusted better to amputation. Interestingly, some studies on functioning post-amputation (Greive & Lankhorst 1996; Nissen & Newman 1992), found the



presence of co-morbidities in amputees impaired return to normal life, except for those with diabetes (despite worse functional outcomes).

Literature reviewed to link the emerging theory with existing theory revealed studies with similar codes and categories. The codes 'Ongoing Disease Processes' and 'Consuming Influences' building the concept 'Persistence of Afflictions' were similar to themes found by Gibson and Kenrick (1998) in their study on living with peripheral vascular disease. Subjects experienced anxiety related to the outcome of surgery and disease progression, and their concurrent health problems placed additional demands on their self-care abilities due to their complex physical, psychological and social needs.

In this study all participants had experienced adverse interactions with the healthcare system and described a lack of adequate communication with healthcare staff identified by the codes 'Damaged Trust' and 'Uniformed Position.' Communication gaps were also reported by Treat-Jacobsen *et al* (2002), and Sjö Dahl *et al* (2008). Participants frequently reported receiving incomplete information, however this may be partly due to gaps in memory due to shock, denial and repression of memory associated with a traumatic event. Sjö Dahl *et al* (2008) suggest that adequate support/preparation and empathetic individually tailored communication can improve the patients' uptake of information, adaptation to the amputation and quality of life.

Persons with diabetes should be educated on the risks at the time of diagnosis. Nurses, who have ongoing contact delivering wound care to patients with diabetic foot ulcers, are uniquely positioned to ensure that patients are aware of their potential risks for amputation, and to advocate for their patients, encouraging the health team to adopt interventions providing the best outcomes for their patients.

Participants complained about the lack of communication and preparation by surgeons prior to the amputation. Van Ross (1997) considers communication is an important factor in rehabilitation, suggesting that the preoperative period should involve a meeting between the patient and the rehabilitation team and an experienced amputee, to facilitate discussion and counselling about the proposed surgery. Assessment of physical, psychological, social and general health should be done preoperatively to ensure that other diabetes-related complications are factored into the post-amputation rehabilitation care (van Ross 1997).

At times, participants' also experienced poor standards of clinical healthcare provision, which resulted in a lack of confidence in the healthcare system. Future planning of care may need to consider that the amputation is a consequence of a chronic disease that is not cured following surgery. Gibson and Kenrick (1998) suggest the goals of acute care fail to address the needs of chronically ill patients and that the 'cure' orientation of surgery has to be modified to reconcile it with the processual, 'care' orientation required in the treatment of chronic illness. Gonder-Frederick, Cox and Ritterband (2002) believe we need to integrate the model of chronic disease management into our healthcare system.

Exploring what enabled the participants of this study to remain positive may help future amputees, and provide health professionals with insights into the coping mechanisms used to adapt to adversity. As no specific theories of coping with a lower limb amputation are reported in the literature, this is a valuable area for future research that can serve to inform health professionals and therapeutic interventions (Oaksford, Cuddihy & Frude 2005).

There were some study limitations. Participants were all from the same geographical area, and were treated in the same health setting and the study sample was small. A larger sample may have yielded maximum variation in patterns from across a wider field of physical and social

settings, cultural backgrounds and ages. Even so, qualitative research values the richness of the human experiences and does not emphasise large numbers to ensure significant findings (Taylor, Kermode & Roberts 2007). Additionally, the participants who volunteered may represent a group who possessed optimistic and adaptive natures, and they may have chosen to participate because they were not experiencing psychological difficulties post-amputation (Oaksford *et al* 2005). Consequently, it cannot be assumed that the findings from this study should be generalised to all amputees with diabetes, however, given other studies on participants with chronic diseases and conditions of the lower limbs have reported similar themes these results do provide a basis upon which to build further research.

## Conclusion

As diabetes emerges as a growing epidemic, diabetes-related amputations will also become more prevalent. Despite improvements in early detection and prevention of complications, there will be a substantial load on the healthcare system to manage diabetes and its complications. Studies such as this may provide a richer understanding for health professionals on how to assist these people to adjust.

## Disclosure

The authors have no conflict of interest.

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Table 1. Outline of the codes, concepts, core categories and basic psychosocial process.

Participant Data	Codes	Concepts	Category	Basic Psychosocial Process
'There's hardly a time when I haven't got a foot ulcer' ...	Ongoing disease processes	Persistence of afflictions →	Imposed Powerlessness	A Path of Perpetual Resilience
'It's not just one thing it's many.' .....	Consuming influences			
'We'll fix your toes, I'll just cut your leg off' .....	Damaged trust	Unsolicited adversity →		
'No one told me.' .....	Uninformed position			
'Unable to walk like you used to' .....	Impaired mobility	Movement impacts and adaptations →	Imposed Adaptive Functionality	
'Thinking before you do anything' .....	Considered movement			
'Missing cooking' .....	Diminished activities	Role restrictions and adaptations →		
'Decreased ability to care for the farm' .....	Diminished capacity			
'I couldn't believe it when I looked down and saw half a leg' .....	Feeling shocked	Grief and loss →	Imposed Endurance	
'You don't go and mix with people, you're stumbling and the like' .....	Feeling affected			
'I made up my mind that I was going to accept it' .....	Realising the amputation	Adaptive convictions →		
'If you don't remain positive you get more and more upset'	Developing hope			

