‘What ever I do it’s a lost cause.’ The emotional and behavioural experiences of individuals who are ulcer free living with the threat of developing further diabetic foot ulcers: a qualitative interview study

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Abstract

Objective Individuals who have had one diabetic foot ulcer (DFU) are at high risk for developing further DFUs. This study was designed to examine the emotional and behavioural consequences of living with this heightened risk of re-ulceration.

Participants and setting Fifteen women and men living in south-west England were interviewed at home or at the university by an academic psychologist.

Design Interviews were audiotaped and transcribed verbatim. Thematic analysis using the constant comparative method was employed for data analysis.

Results Participants reported having little perceived control in preventing further DFUs. This lack of control was associated with a range of negative emotions including fears and worries about developing further foot ulcers, amputation and guilt for the past neglect. Tensions were present between participants’ beliefs and reported behaviours, that is, what they felt they ought to be doing and what they were actually doing to care for their feet; most engaged in ‘strategic adherence’, that is, conducting a trade-off between living a normal life and following foot-care advice.

Conclusion A lack of perceived control appears central to the emotional and behavioural responses of individuals living with the threat of re-ulceration. We propose that these responses may serve to increase individuals’ risk of re-ulceration and that these ‘risk factors’ should be considered part of the management of this patient group.

Diabetic foot ulcers (DFUs) are a common complication of diabetes.¹ They are often slow to heal, are associated with increased risk of

amputation and death and are costly to treat, with costs to the UK health service estimated at £220 million per annum.^{2–4} The risk of developing

a DFU has been reported as being 15% over a lifetime, and individuals who develop a DFU have a risk of recurrence of 25–80% within a year.^{1,5} Thus, whilst the likelihood of developing another DFU is high, surprisingly little is known about how individuals contend with this health threat, both emotionally and behaviourally or how this impacts on their lives.

The limited evidence that does exist has focussed on individuals with active foot ulceration or those without a history of DFUs. These data suggest that the experience of a foot ulcer is associated with a range of negative emotions, for example, feelings of anger, fear, depression and loss of self-esteem which impact negatively on patients' lifestyles.^{6–8} Other research suggests that these negative emotions may influence the risk of re-ulceration⁹ as they are believed to be associated with a range of parameters that could affect re-ulceration, for example, glycaemic control, physical activity, help-seeking behaviour, adherence and self-care behaviours.^{10–13}

There remain, however, very limited data on the emotional status of patients without foot ulcers, but with a history of ulceration; or indeed how these individuals cope with these negative emotions. In view of the significant behavioural/self-care demands placed on this patient group to minimize the risk of re-ulceration,² we might expect evidence of significant distress in many. Furthermore, in keeping with existing theories regarding the factors determining emotional responses to challenging situations, including illness, we might further expect a range of social and psychological factors to affect these emotional responses.^{14,15} For example, in diabetes, it has been shown that if an individual perceives they have little control over their illness, they are more likely to experience higher levels of emotional distress and are less likely to self-manage their condition than individuals who perceive they have greater control.^{16,17}

In view of the fact that so little is known about the experiences of individuals who are ulcer free but live with the high risk of recurrence, the aim of this qualitative study was to explore the emotional and behavioural consequences of living with the heightened risk of re-ulceration.

Research design and methods

Fifteen in-depth semi-structured interviews were conducted between February and September 2009 with individuals living in the south west of England with a history of foot ulcers but who were ulcer free at the time of the study. Specifically, we set out to explore participants' emotional experiences and what they were doing to care for their feet whilst in this ulcer-free phase. Potentially eligible participants were identified through hospital podiatry clinics and approached initially by a Podiatrist. Participants who gave permission for their contact details to be passed on were contacted by telephone to assess eligibility. Participants were eligible if they had Type 1 or 2 diabetes; their ulcer had healed and they were not actively seeking treatment. Participants were excluded if they were suffering from severe mental illness (e.g. psychosis and alcohol dependency), had severe communication difficulties or those for whom English was not their first language. Eligible participants were invited to be interviewed at a location of their choice. Twelve participants choose to be interviewed at home and three at the university. Interviews conducted at the university took place in a quite private room. The details of the study (Participant Information Sheet, Consent Form and a Covering Letter) were sent prior to interview. Informed written consent was obtained prior to conducting the interview. Participants were asked a series of open-ended questions developed by the research team which were informed by the extant literature (see Table 1). These questions were refined during early interviews and served as a topic guide to encourage participants to express their thoughts and feelings and to allow issues that were salient for them to emerge. All participants were provided with a summary report of the interviews and invited to comment on the qualitative findings, and none exercised this option. Ethical approval was obtained from the National Research Ethics Service, Frenchay Research Ethics Committee (07/H0107/62), Bristol, UK. An external Trial Steering Group, which included a patient representative, oversaw the safety and conduct of the study.

Table 1 REDUCE study topic guide for qualitative interviews

Participant's background	
Prompts: marital status, health history; diabetic history; when diagnosed; what does the participant do to look after their diabetes e.g., diet, exercise, monitoring blood sugar, medication?	
Terms/language: participant perception	
Prompts: What do you think of when you think of a foot ulcer? Can you tell me what words you use to describe a foot ulcer (e.g. blister, cut)? What is a foot ulcer?	
(i) Factors that gave rise to foot ulcer	
Prompts: Thinking back to the last time you had a foot ulcer what do you think caused your foot ulcer? How did this make you feel? How did it affect your daily life?	
(ii) Behaviours that affect risk of reulceration	
Prompts: Now that you are ulcer free, what are you doing to look after your feet?	
(iii) Factors which influence ability to engage with foot health behaviours	
Prompt: When you had your foot ulcer how did it make you feel? What did you do to deal with these feelings?	
(iv) What is participant doing to prevent another foot ulcer?	
Prompt: Have you thought about how you would prevent another foot ulcer? Anyone suggested ways to prevent? Have you been doing any of these things? Why not?	
Visit podiatrist	
Prompt: When you went to the podiatrist did h/she ask you to do certain things (specific advice/treatment); can you give me an example; did you understand this; did you follow this advice; what was helpful; what was less helpful?	
Social support: significant others	
Prompt: what support do you have? Does your partner/significant other help you manage your foot ulcer? What does he/she do? Is it helpful? Is it less helpful?	
<i>Intervention</i>	
We intend to develop an intervention to help people reduce their risk of developing further foot ulcers.	
Could you talk about your foot problems in a small group setting to people with similar problems?	
How would you feel about this? (Comfortable/uncomfortable)	
What would help to make you feel comfortable?	
What would make you feel uncomfortable?	
What would be helpful?	
What would be less helpful?	
Would you be willing to go along and take part?	
Would you go alone and or with a partner?	

A purposeful maximum variation sample was sought to include both genders and types of diabetes, a range of DFU experiences (e.g. first time and those who had several DFUs) and those from a variety of socioeconomic backgrounds. All transcripts were anonymized and transcribed verbatim. Detailed field notes and a reflexive journal were written to inform later data analysis.¹⁸ Preliminary analysis commenced alongside early interviews and then progressed iteratively. A thematic approach was used drawing on the constant comparison method.^{18,19} Open coding of individual transcripts generated an initial coding framework, which was added to and refined, with coded material regrouped as new data were gathered. New codes were incorporated into the framework and similar codes were merged. The

codes were gradually grouped into broader categories, and through comparison across transcripts, overarching themes were identified. Interviews continued until saturation was reached with no new information emerging. Data within themes were scrutinized for disconfirming and confirming views across the range of participants. AB led the analysis, using the software 'ATLAS.ti' to aid data organization and coding. RC and KV coded a subsample of transcripts, the two sets of coding were discussed, and the broad coding framework to be applied across all transcripts was agreed. The coding framework was discussed at regular intervals, and all authors agreed the final themes. To humanize and protect participants' anonymity, pseudonyms have been given.

Results

A total of 22 potential participants were referred, but four were ineligible as they had active ulceration and three declined (two were unable or too busy to agree to interview and one participant changed their mind following receipt of study documentation). Fifteen participants (eight women and seven men) participated in the qualitative interviews. Interviews lasted on average 100 min (range 58–150 min). All interviews were digitally recorded and transcribed verbatim.

The average age of women was 45 years (range 26–60), whilst men were older (mean age = 58 years; range 49–73). Seven participants were married, three divorced, four unmarried and one living with a partner. Fourteen participants were White British and one of Black African ethnicity. Ten participants reported leaving school at 16 years, with 9/13 obtaining GCSE, 3/13 A Level and 1/13 a first degree (two participants declined to provide this information). Self-reported annual income indicated that 7/13 earned <£14 999, 2/13 < £19 999, 2/13 < £29 999 and 2/13 > £40 000. Seven participants were diagnosed with Type 1, and, 8 with Type 2 diabetes. Four participants experienced a DFU for the first time, 11 had at least two or more recurrences and three reported having Charcot foot. Prior to interview, 14 participants with this information available had been ulcer free for a mean of 5.85 months (range 2–11). Information from medical records indicates that because the interviews were conducted, 5/15 participants have re-ulcerated.

Key themes

A lack of perceived control in preventing further DFUs

The first key theme concerned a lack of perceived control whilst living with the threat of developing further DFUs. Most participants, despite being ulcer free, felt they had little or no control in preventing further DFUs. One participant reported making efforts to engage in positive foot care, for example, being more vigilant in checking

and moisturizing her feet. However, despite these endeavours, there was a sense of hopelessness in preventing further foot ulcers as this was perceived as a 'defeating and lost cause.'

... I've been more vigilant, looking at them [feet] creaming them. I think well, I've got them [DFUs] again. It's not fair, I'm taking better care of my feet than I've ever done, and I'm still getting ulcers. ... sometimes your best isn't good enough, it'll happen anyway. I feel that the ulcers are defeating me and whatever I do, I feel like it's a lost cause. (Michelle)

Others seemed more resigned when asked whether they could do anything to prevent further DFUs. One participant referring to his diabetes and DFUs felt he had little control over these aspects.

Participant: I can't do anything about it anyway.

Interviewer: When you say you can't do anything about it, what do you mean?

Participant: Well I can't do anything about the diabetes or the foot ulcer. If I get a foot ulcer, I get a foot ulcer. (Frank)

Whilst not all participants exhibited such hopelessness, this overall lack of perceived control was present in other accounts. Some described how, in their efforts to regain control, they had become 'obsessive' about trying to prevent further DFUs recurring. Examples ranged from always wearing shoes around the house to vacuuming constantly to prevent debris on the carpet damaging their feet.

... I'm obsessive I always put shoes on, I Hoover a lot so there's no bits on the floor... But sometimes, when things happen to my feet, I think: "Where did that come from? Why can't I do anything about it?" Because there are things that happen that you really don't have any control over at all. (Polly)

These feelings were further reflected in other accounts. One participant described his obsessiveness in attempting to prevent further DFUs. The fear being that should this get out of control other areas of life would also become out of control.

I've become a bit obsessive about it [DFU] now... If they take a grip and they get out of control, you're out of control then. (Tom)

In contrast, one participant, not unduly worried about developing further DFUs, also reflected upon the difficulties in trying to control and prevent further DFUs. This meant he was, nevertheless, constantly aware that this was a possibility.

I suppose because with the ulcer it's harder to control I do think about it. Not to the extent that it worries me, but I'm aware of it all the time. (Dan)

Negative emotions: fears and worries

This lack of perceived control in this ulcer-free phase gave rise to a range of negative emotions such as fears and worries in developing further DFUs. One participant described feeling overwhelmed and anxious at the thought of developing another DFU as experiencing a recurrence restricted life particularly the ability to live independently. Examples cited included walking to the kitchen to put the kettle on. For this participant, having a below knee amputation further compounded these difficulties.

I get anxious, worried, it [DFU] really does take over my life. Because I immediately start to think of things I can't do... Just walking out to the kitchen, it's simple things like standing [to put the kettle on]. (Heather)

Throughout participants' accounts, these negative emotions prevailed. One described being 'petrified' when she had new orthotic shoes, the fear being that these would rub and result in another DFU.

... I'm petrified that when I start wearing them out [new orthotic shoes] it's going to start rubbing my feet... (Michelle)

Interlinked with this fear was uncertainty about the future, particularly being relatively immobile should a DFU recur.

You never know if you're going to get another DFU and be laid up again. (Polly)

Furthermore, having reduced or little sensation appeared to add to these fears and worries.

It does worry me because I've got sort of no sensation in my toes. (Jane)

Fear of amputation

The most pressing fear was the threat of losing a limb. Many participants described having developed a DFU made them fear that ultimately they might have to face the possibility of amputation.

I'd say the one thing I fear, [is] that an ulcer could lead to an amputation. (Dan)

It occasionally crossed my mind when I'm generally low. I think: "Oh my God supposing I do end up losing my leg eventually". (Polly)

One participant described this experience as an 'emotional rollercoaster' in never being sure if he would lose his toes but having periods of relief when the immediate threat of amputation receded.

... its been like an emotional rollercoaster. You've been at the bottom, 1 min you're not, then you might lose your toes, then you don't know, and then suddenly you've got away with just taking a bone out. (Leo)

Blame and guilt

Interwoven with these fears and worries were issues concerning blame and guilt. Many participants expressed regret they had not paid attention to their feet in the past. Some reflected that they were 'paying' for it now having recently experienced another DFU, whilst others suggested that it was their 'fault' for this neglect.

It's my fault that that's [DFU] happened, because I haven't been taking care of myself. (Jane)

For some, the focus of their guilt was upon poor diabetes control in the past. Many commented on their lack of vigilance and the past neglect with some likening this as a 'punishment' in denying one was living with diabetes.

If I'd been more vigilant doing my blood testing, checking my feet prior to amputation. (Michelle)

... that's my punishment, I was trying to do my life and pretend I wasn't diabetic. (Polly)

First experiences of a DFU

Participants who experienced only one previous DFU also reported a lack of perceived control and uncertainty as to whether they

could prevent further DFUs recurring. This was influenced by a lack of knowledge as to what a DFU constituted or looked like. One individual reflected that despite engaging in positive foot care (getting up 20 min early to check her feet and moisturize) and having reasonable blood glucose control, she felt she had little control and did not know what to look for in a DFU.

I now get up 20 min before I normally would do... I'm doing all this seeing to my feet, moisturising them, look at my feet, cream my feet. You just think: "I'm doing all of this and yet I still run into problems anyway... I don't know enough about what I'm looking for..." (Jane)

Others also described a lack of knowledge. For one participant, this culminated in a delay in seeking help; the perception being her DFU was not serious enough to consult the doctor.

I never knew I had an ulcer, because I didn't know what they looked like. I thought: "It's a bit of numbness." It [foot] was a tiny bit red, I thought it wasn't nothing much to really go to the doctor about, So I just hung on. (Mia)

Whilst another participant indicated that as little pain was experienced there was no urgency in seeking help for his blisters, the perception being these were not serious. However, this initial response to self-treat resulted in a DFU.

I had these enormous blood blisters on the bottom [of] each foot ... [I thought]: "I'll just keep an eye on these for now," because I wasn't getting any pain. I treated them [with] antiseptic wiping ... and left it for so long. I didn't feel it was bad enough for me to be panicking over it. (Max)

Participants experiencing their first DFU also displayed negative emotions. Some described feeling 'low and tearful', and a sense that life had changed considerably as a result of developing a DFU.

Interviewer: When you had your ulcer you said you were worried and frightened, how did you deal with those emotions?

Participant: Crying, nobody knew I'd cried but I felt quite tearful. I got very low. I thought I was getting on ok, then this comes along. It really knocks you. (Mia)

Discussing experiences with others

Most participants found few opportunities to talk with family or friends about their emotions or experiences. Some suggested that, as foot ulcers were malodorous, there was a certain stigma attached, hence a reluctance to discuss these issues.

I think it's just one of those things that you don't particularly want to discuss with friends...I think some people associate ulcers with being a nasty, smelly old wound... (Dan)

Others felt they could not talk about their experiences of a DFU with friends, feeling they would be a 'burden' if they discussed such issues.

It's not a fun subject. I wouldn't really burden my friends with it [DFU]...when I was most worried about it I didn't talk to anyone too much... (Sarah)

There was also a sense that if one expressed feelings to family, friends or work colleagues, one would not be believed. This disbelief was attributed to a lack of understanding as to the seriousness of a DFU and why a DFU required long periods off work.

The family and friends, no they didn't understand at all. "He might be having it on." My sister she was like: "Oh, he's just sitting around...sat around with his foot up in the air."... My boss said: "You've only got a sore foot, that's all it is." You just can't explain, they don't know, it's ignorance again. (Leo)

Not all participants experienced unhelpful reactions from family and friends. Some described the ease with which they could talk with others and the practical support offered, for example, lifts from work or to the hospital.

If anything is worrying me I know I can ask my wife or my daughters to have a look at my feet. Most friends are very good. If [names wife] got a problem picking me up from work, they [will] pick me up. (Tom)

Behavioural experiences: living with the threat of developing further DFUs

The aforementioned lack of perceived control also appeared to be associated with what participants were 'doing' behaviourally to care for

their feet now that they were ulcer free, yet living with the threat of developing further DFUs. For some, it seemed that despite feeling they had little control, the experience of a DFU prompted some positive behavioural change. For example, getting up earlier in the morning to check and moisturize one's feet.

I now actually get up 20 min before I normally would do because I wouldn't be able to fit it in... (Jane)

Other examples featured wearing protective padding to protect newly healed skin, not walking around barefoot, keeping in regular communication with the podiatrist and seeking help if problems arose.

I wear a dressing even though it's healed, so it's protected inside my shoe, because it is fragile skin. I don't go barefoot at all [and] keep in constant touch with the podiatrist. (Polly)

Whilst other accounts featured increased vigilance and being more aware of one's feet generally.

I take so much notice of my feet now. It's no longer that you're looking at your foot and thinking, "Where's that come from?" I'd know if there was a problem with my foot in a matter of a couple of hours really. (Tom)

Past experiences of amputation further influenced some of this change; particularly the desire to keep remaining limbs.

I've lost this leg... I protect my foot because I don't want to lose another one. (Heather)

For some, this experience served as a "wake-up call"; the realization being that a DFU was a serious event.

I was 23, when it started and had massive holes in my feet that wouldn't heal, I think that is a massive 'wake-up call'. (Sarah)

Other aspects influencing behavioural change although not necessarily in a positive sense featured the length of time it took for a DFU to heal, the treatment regimen and having to attend the clinic for long periods. One participant reflected on how life was generally restricted when a DFU was active, particularly having to ask for time off work to attend appointments.

It means a disrupted lifestyle for however long it takes for that to mend. You have to start altering your life to that then. I'd have to go in and inform work that I'd need every Monday [to] finish at 3 o'clock, or every Wednesday I wouldn't be in until 11 o'clock so I could get to the clinic. ... (Tom)

Within most accounts, there were discrepancies between what participants reported they were doing to care for their feet and what they thought they ought to be doing now that they were ulcer free. Most reported taking strategic risks to balance and live life as normally as possible. For example, some reported walking barefoot at home knowing this was contrary to health-care advice, whilst others ensured the carpet was clean prior to walking barefoot at home.

I am told that I shouldn't walk barefoot. Walking, even from the bedroom to the bathroom without shoes on is bending the rules. But I do it very, very carefully... It's the only little risk I take (Dan)

I still run up and down and I do it barefoot. But I make sure the carpet is well clean. I'm cautious. (Oscar)

Further, the desire to live life normally made some participants impatient to resume activities (e.g. gardening). For one participant, despite attempts to gradually increase activity levels, the temptation to 'go all out' proved too strong and resulted in a further DFU.

I'd scalded the foot that took all of that year out of it really, because it wouldn't heal. And then it healed, and in the summer I started cutting the grass. I built up from sort of 10 min a day, and I did the whole lot after about three weeks. And I got the little blister, which obviously burst and then went into an ulcer. (John)

For one younger participant, the desire to resume a normal life was related to the feeling that she was missing out socially.

... I'm 24, I want to be doing things... I don't want to keep missing out on things. (Sarah)

Maintaining femininity and taking risks

Some female participants reported taking risks, for example, wearing fashionable shoes, (i.e. high heeled shoes as opposed to specialist footwear) in a desire to maintain their femininity.

For one individual, this decision was taken assuming that the risk to her feet was minimal because she was sitting down.

... I like to wear skirts and earrings and be terribly girly. If I'm going out for a sit down meal, I like to wear them [fashion shoes]. She'd [podiatrist] probably say never to do that. So there's a bit of me trying to live my life. So I'm going to wear these shoes tonight because I'm going to sit down. (Polly)

Others raised concerns about not being able to dress in a feminine manner. Some described actively changing the clothes they wore as the orthotic shoes were unattractive and drew attention to one's foot problems.

I used to wear floaty dresses. How can you put a floaty dress on and wear that? The other shoe I've got looks like a policeman's shoe. (Michelle)

More worrying was the suggestion that the risk of a 'little ulcer' was preferable to wearing orthotic shoes. For one participant, the loss of femininity and not being able to wear skirts appeared to be a key factor in engaging in this risky behaviour.

I think I'd rather continue with a small open wound that just doesn't close, than having to wear some God forsaken shoe. I could wear trousers, but I like to wear skirts more... I'd rather live with my little ulcer and keep having dressings weekly than wear that shoe. (Jane)

Maintaining positive foot-care behaviours

Related to these behavioural manifestations were issues concerning how long would or could participants maintain the positive behaviour reported in some accounts. Most were recently healed, that is, <6 months. One participant described her relief in finally healing. However, this was tempered by the knowledge that continuing with this positive behaviour was going to be a challenge. Hence, there was uncertainty as to how long this engagement would endure; the sense being that as time progressed this may well decrease.

Having healed for me is the main thing... It's also keeping it up. At the moment it's still quite new and exciting. But I suppose you can get used to it and not take as much care. (Sarah)

Other participants reflected similar views, particularly whether they would continue to engage in positive behaviour in the longer term.

It's only just healed, so I am not 6 months down the pipe [line], I might give you a different answer...so it's only about the last 2 weeks it has been healed. (Leo)

Conclusions

To the best of our knowledge, this is the first study to explore the emotional and behavioural experiences of individuals who are ulcer free, but living with the heightened threat of re-ulceration. The interviews revealed that most participants experienced a lack of perceived control in preventing further DFUs, and this seemed to underpin individuals' emotional and behavioural experiences. This was evident in both participants with a history of only one previous ulcer, as well as those with multiple experiences of ulceration. The central role of perceived control in influencing patients' emotional and behavioural responses is supported by both existing theory (e.g. stress and coping and self-regulation theory:^{20,21}) and previous empirical findings, such as work highlighting the importance of perceived control to achieving dietary self-management in diabetes.¹⁶

Most participants, particularly those experiencing their first DFU, lacked adequate knowledge regarding DFUs. These findings are also consistent with other research. For example, a recent study found that individuals attending clinic for the treatment of a DFU did not know what a DFU was and were unaware they had been diagnosed with this condition.²²

The preponderance and range of negative mood was an unexpected finding given that individuals were ulcer free at the time of interview. However, other research has shown that uncertainty about DFU recurrence and fear of possible amputation are major stressors for individuals coping with active foot ulceration.⁶ This observation combined with the fact that many of our participants reported such uncertainty and fears may help to explain why

participants in our study continued to experience negative emotions despite being ulcer free.

It was also clear from the interviews that, despite reports of individuals making some behavioural changes as a result of experiencing a DFU, there were tensions between participants' beliefs and their reported behaviours, that is, what they felt they ought to be doing and what they were actually doing to care for their feet. Many appeared to engage in risk taking, going against expert advice, with some willing to risk 'a little ulcer' rather than wear orthotic shoes. This tension between expressed beliefs and actual behaviours appears to be akin to 'strategic adherence' (i.e. taking risks contrary to health-care advice, to balance and live life as normally as possible) and was common amongst our participants. This behavioural response has been observed previously in other patient groups (e.g. renal kidney transplant and non-adherence to immunosuppressants) and also in patients with diabetes.^{17,23}

A key behavioural concern raised by participants was related to how long they would and could maintain the reported positive behaviours. This was perhaps most clearly illustrated in patients' reports of failing to pace activities sufficiently once their DFU had healed. This resonates with other research, in particular the suggestion that long periods of inactivity followed by sudden bursts of activity over a short time span may place individuals at greater risk of developing further DFUs.²⁴ The difficulties associated with making long-term behavioural changes were also evident in the accounts of women who reported that having to wear orthotic shoes made them feel less feminine and challenged their identity. These findings suggest that the negative aspects of such footwear extend beyond issues of comfort and style that have been reported in previous work.²⁵

The observations regarding difficulties in maintaining behavioural changes in the long term also serve to highlight the intimate interconnection between our participants' behavioural and emotional responses. Although we elected in our results to present the findings from

these areas separately, the interplay between these phenomena was evident throughout participants' interviews. For example, the heightened fear experienced by some individuals led to reports of hyper-vigilance regarding foot-care behaviours. Conversely, many of the examples of 'strategic non-adherence' left patients feeling guilty and fearful.

We should, however, acknowledge a number of methodological caveats that should be considered when interpreting the results from this study. First, our participants were self-selected, and so we may not have fully represented the views of this patient group (e.g. the views of individuals who are house bound, those who did not attend podiatry appointments or those who visit community podiatrists). Second, we acknowledge that individuals from minority ethnic groups were underrepresented. Third, the researcher (AB) was also the study co-ordinator as well as a health professional (chartered psychologist and nurse), these aspects may have influenced her relationship with participants and the views expressed. However, close consultation and discussion with RC helped minimize these factors. These aspects may affect the transferability of our results, although we believe that as a clinical population was sought this is unlikely to influence the overall findings.

In sum, our findings suggest that the emotional and behavioural responses of individuals living with the threat of re-ulceration may serve to increase their risk of further ulcers; and that their lack of perceived control appears to be central to these responses. However, these psychosocial risk factors are rarely considered once the physical wound has healed, the perception being these individuals no longer have health-care needs (e-mail communication from GP). There is, therefore, a need for health-care professionals to consider the psychosocial needs of this patient group and for appropriate interventions to be developed to address these needs. We propose that such an intervention would ideally challenge individuals' beliefs regarding their control over the condition, and in so doing, enable them to develop more adaptive emotional and behavioural responses to the management of their feet, for example, seek

help early. Furthermore, the interconnection evident between participants' emotional and behavioural responses would advocate a cognitive-behavioural approach. Ultimately, this will improve patient care for individuals who are ulcer free but living with the heightened risk of re-ulceration.

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Declaration of conflict of interest

No conflicts of interest have been declared.

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