Exploring factors that contribute to delay in seeking help with diabetes related foot problems: a preliminary qualitative study using Interpretative Phenomenological Analysis

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Background and aim: A significant number of patients with diabetes do not always seek help when they develop a foot problem such as an ulcer. This delay in patients presenting with foot problems has been attributed to poor outcomes such as lower limb amputation and premature mortality. The aim of this study was to explore patients' reasons for delay in seeking help with foot problems.

Methods: A qualitative study using Interpretative Phenomenological Analysis (IPA), which used semi-structured interviews. A purposeful sample of six patients with delayed help-seeking behaviour were recruited from a diabetic foot clinic, in the United Kingdom. Interviews were audio-recorded and transcribed verbatim, then analysed in a six-step model using the IPA method.

Results: The study identified nine superordinate themes associated with delay in seeking help with foot problems, these included: the level of prior foot care information; awareness of the foot problem; the ability to perform foot care behaviours; ulcer presentation and risk perception; competing priorities; the use of self-management strategies for the foot problem; the presence of specific help-seeking triggers; comorbid conditions and concurrent illness; and delayed secondary referral.

Conclusions: The findings of this preliminary study suggest that, to reduce patient delay, there is a need to increase awareness among patients as well as health professionals of the risks of foot problems. Ongoing foot care education needs to be given to patients in order to enhance knowledge on foot care, including the early warning signs of foot problems and what they should do to get help. It is also necessary to ensure that patients who have problems in being able to self-monitor their feet are subject to enhanced surveillance.

Key words: Care delivery, diabetes, diabetic foot, health behaviours, patient experience, qualitative study

Introduction

Foot ulcers occur in around 5% of patients with diabetes each year, and are associated with increased morbidity and mortality.¹ Diabetic foot problems require urgent attention as significant deterioration may occur if assessment and management are delayed.² In the UK, the National Institute for Clinical Excellence guidelines specify that patients with new ulceration, swelling or discolouration should be seen by the specialist diabetic foot team within 24 hours. Such foot problems may indicate infection or critical limb ischaemia, and delayed treatment can lead to deep infection and gangrene, increasing the risks of lower extremity amputation and mortality.^{1,3}

Unfortunately, there are still a number of patients who delay reporting foot symptoms to health professionals.⁴ Studies have estimated that 40–60% of amputations were related to patient delay.^{4,5} Survey studies have identified a number of factors associated with delay in seeking foot care among people with diabetes, these include:

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unawareness of presence of foot ulcer; underestimating the significance of the problem; and access to an appropriate health care professional.^{2,6} While there have been some qualitative studies on the views and beliefs of patients regarding foot ulceration, these studies have not directly examined factors contributing to delayed presentation. These studies show variations in patients' beliefs about the causes of ulceration with patients attributing the problem to internal damage such as reduced circulation or to external factors such as trauma.⁷⁻⁹ Most patients in these studies reported fear of foot problems and would seek help if they developed an ulcer, although some reported a belief that ulcers would heal if left alone. Some patients also do not understand health care advice and prefer to monitor the problem themselves or have it attended to by a family member. Therefore, there is a need to explore specifically with patients who have delayed seeking help for foot problems why they do not attend specialist foot care earlier. This study explores from the patients' perspective factors that lead to delay in reporting foot problems.

Methods

The aim of this study was to explore patient explanations for delay in seeking help with diabetes related foot problems.

Research design

A qualitative approach based on in-depth interviews was used for the study, following the method of Interpretative Phenomenological Analysis (IPA).¹⁰ IPA aims at understanding phenomena from the participants' point of view, through a process of interpretation.¹¹ It was adopted for this study, because it allows for an in-depth exploration of the personal experience and perception of a situation or event.¹⁰ IPA follows an idiographic approach where there is a detailed analysis of individual cases before examining commonalities between patients. The advantage of this approach in relation to the study question was that enable a detailed analysis of the story and events in each case to determine the contributing factors for delay in accessing the diabetic foot team. The integrated analysis then allowed the individual cases to contribute to the overall account of delaying factors, while retaining connection to the individual cases.

Sample

Following the IPA approach, participants were purposefully selected to participate in the study based on having a diagnosis of diabetes and delayed care seeking. Patients where defined as delayed care seekers based on the following criteria:

Patients requiring intravenous antibiotics on their first presentation to the diabetic foot clinic:

- patients presenting with gangrenous ulcers,
- patients who required either partial or full amputation of the lower limbs.

Patients with a recorded diagnosis of severe depression and psychotic disorders were excluded.

A sample size of 6–8 patients was identified as appropriate for this study to enable sufficient rigour of analysis within the study resources. Small samples are recommended in the IPA model as the level of analysis is very detailed.¹² It was felt that this sample would provide an adequate account of patient perspectives on delayed foot care behaviour to help provide an understanding of this behaviour and inform further inquiry.

Recruitment

Participants meeting the inclusion criteria were recruited through the diabetes foot clinic at King's College Hospital, London. The patients were recruited by the clinical team, and those who were interested and able to participate were subsequently consented by the researcher (TC).

Data collection

Data collection in IPA aims to elicit stories, thoughts and feelings about the phenomena from the participants.¹² One-to-one semi-structured interviews were used to do this,¹³ based on an interview guide with predetermined topics, which had been derived from existing literature on delayed presentation.^{14–16} The schedule was not prescriptive as questions were modified according to participants' responses, so that the researcher was able to probe responses. The researcher summarised what the patient had said at the end of each topic to enable confirmation and clarification of content. The researcher kept a reflective diary of the interviews. The interviews were audiorecorded and transcribed verbatim. The interviews lasted from 40 to 60 minutes.

Data analysis

The analysis was undertaken in a six-step model following the IPA approach.¹²

Step 1 Reading and re-reading data: The interview transcript for each case was read repeatedly, and the audio-recordings were listened to with the first reading. This enables familiarisation with the interview content.

Step 2 Initial noting: Each line of the transcript is analysed using the three discrete commentaries proposed by Smith *et al.*¹² descriptive, linguistic and conceptual. The descriptive commentary involves highlighting key elements relating to the participants' experiences. Linguistic commentary examined participants' use of language, including tone, repetition and hesitancy. During conceptual commentary, the focus is on understanding the meanings participants attach to their explanations. The researcher used interrogative means in order to ascertain what each line of the transcript meant to the participant and researcher through an explicit coding framework.

Step 3 Developing emergent themes: Emergent themes were developed from the exploratory notes derived from the initial noting. These themes reflected the participants' explanations of their behaviour, as well as the researcher's interpretation and again these were explicitly coded in the data.

Step 4 Searching for connections across emergent themes: In this step, themes were moved into clusters. Approaches suggested by Smith *et al.*¹² for identifying patterns and connections between emergent themes, which are: abstraction, subsumption, polarization, contextualization and function were used to guide this process. A table of superordinate themes with subthemes was then constructed for each case.

Step 5 Moving to the next case: The above steps were then repeated for subsequent transcripts. Within IPA, it is important to examine each case in its own right. This meant that the researcher has to bracket ideas (i.e. view each case with a fresh approach to the analysis without bringing the interpretation of the other cases to influence the analysis) from previous analysis in order to allow new themes to emerge case to case. Step 6 Looking for patterns across cases: Finally, similarities and differences across cases were searched. This pattern was identified by looking across each of the themes from the individual case analyses. A consolidated list of superordinate themes was then constructed from the collected cases. The analysis was undertaken by the lead author (TC) with the second author (AF) reviewing and checking thematic allocations with the data.

Study ethics

Ethical approval to undertake the study was obtained from London-Surrey Borders, NRES Committee and King's College Hospital R&D office.

Findings

A total of six patients matching the inclusion criteria were recruited and interviewed between September and November 2013. Participants were generally middleaged with Type 2 diabetes, their characteristics are summarised in Table 1.

In total, nine superordinate themes were identified from the collected cases, each theme is outlined below together with supportive data.

Level of foot care information

Participants reported variations in what they were told regarding their feet. In some cases, patients reported that they had received very limited information as to the risk to their feet and what they should do to check their feet.

Jane: 'When I first got diabetes, my GP said you've got to be careful with your feet, and I said why? He said because it can affect your feet. That was all really. He said the nerves might go but he didn't say very much more about it, except be careful with your feet'.

Other patients had been given more detailed information about foot risks and yet this did not promote prompt attending behaviour.

Linda: '[...] I think I was warned fairly early on that circulation will be bad and I really, I had to watch where I was treading and wear shoes and socks all the time because if I tread on a drawing pin, for example I wouldn't feel it, so I think I was warned about that, yes very early on'.

Ability to perform foot care behaviours

Patients related the importance of inspecting their feet or relaying on others to help check their feet. However, this protective behaviour was impeded if the third person was not available to do this or another complication such as loss of vision meant that the patient could not visualise the foot problem. Patients who live alone have particular problems in checking their feet.

Harry: 'My wife checks it out because she dresses the right foot for me. So she checks the left foot as well [...] underside your feet is not the most visible thing'

Arnold: 'It's difficult for me because at the moment am having treatment because my eyes have gone bad as well, since I have been in hospital. Am partially sighted so I can barely see so it's difficult to try and look to see if I have any marks, it's not easy, so you know it's difficult'.

Awareness of the foot problem

Most participants seemed to have been able to detect their foot problems themselves but still delayed seeking help, with the exception of two cases in which the patient had no awareness that an ulcer was present. Linda explains how her ulcer was discovered during a follow-up visits to the foot clinic.

Linda: 'I think probably Victoria (a podiatrist) discovered it'.

James describes how he was unable to detect his foot problem, because he was unable to weight bear on his foot when the ulcer developed. This may have masked any feelings of pain, which would have alerted James that he had a problem.

James: '[...] Because I never put my foot to the floor, I was on a wheelchair, you don't notice'.

James further describes how he only discovered he had a foot problem, when the 'foot burst open' and started producing exudate and odour, which prompted him to go to the hospital.

James: 'When I went home I was on for about a fortnight and I woke up one morning I could smell the smell and I know what that is. When I pulled the bed clothes back my foot had burst open and it was the same green slimmey sloppy again. I went back into hospital'.

Another problem associated with awareness was neuropathic anaesthesia. Patients reported that they understood that diabetes affects their sensation and that this

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Name*	Linda	Arnold	James	Jane	Harry	Adam
Age (years)	69	49	54	61	55	64
Type of diabetes	2	2	2	2	1	2
Duration of diabetes	15 (years)	4 (years)	25 (years)	25 (years)	49 (years)	8 (months)
Gangrene on first presentation	No	No	No	No	Yes	No
IV antibiotic on first presentation	Yes	Yes	Yes	Yes	Yes	Yes
Amputation	Yes	No	No	Yes	No	No
Lives alone	Yes	Yes	Yes	Yes	No	Yes

*Names changed to preserve patient anonymity.

reduced sensation, which may have concealed the presence of the foot problem to the patient.

Arnold: 'Feet seems to be one of the big things that diabetes affects, so sort of affects all your nerve endings as well so you don't feel nothing so you don't know. If you do yourself an injury or whatever something you discover later because you can't feel it'.

Ulcer presentation and risk perception

The manner in which the ulcer presented itself and the patients' perception of the risk associated with the ulcer seemed to impact on how they judged the need to get help with the problem. The most commonly reported ulcer presentation among the participants was a blister, which participants tended not to regard as significant.

Arnold: 'It just started with a blister, all I got was a blister'.

James: It's been raining, muddy and I put a pair of wellingtons (boots) on as you do [...]. It rubbed there and made a little mark that was it'.

Linda: '[...] it really began as a blister, what I thought was a blister really [...] but it wasn't clearing up'.

James: '[...] I dressed it thinking it was just a cut, never took notice of it, it wouldn't heal'.

One participant reported burns as the initial ulcer presentation, which she sustained from using hot water bottle and sitting in front of a fire.

Jane: '[...] and I sat in front of a fire and I boiled my foot basically and my sister put me to bed with very hot water bottle and I didn't move my feet and they got burned'[...]. I didn't know anything about diabetic foot ulcers, so I didn't think it was [...] I just thought it was just a nasty burn, you know, it will get better. It developed into an ulcer'.

Harry, who described having a red mark on his foot, had no feelings towards the mark. He explains how he thought the red mark was nothing serious and uses analogue of a mosquito bite to describe how he felt about the mark.

Harry: 'It never occurred to me sort of that it was diabetic related, really as far as I was concerned. As I said just got this hurt or this thing on my foot the same way you might have a mosquito bite that goes septic or whatever. You might bang into something and you got a bruise, something like that. So I really didn't think it was gonna be something serious'.

Competing priorities

For one patient, the reason for their delay was related to a personal decision not to seek help. Linda who was on holiday at the onset of the ulcer, opted to continue with her holiday rather than seek medical attention, even though she explains being aware of the ulcer for days.

Linda: 'when it first started I was on holiday and am afraid I was very stubborn and I thought am just, am gonna enjoy my holiday and am taking it'. [...] 'so I suppose I was aware of it for about 4–5 days'.

Self-management of the foot problem

Some patients delayed seeking help while instigating selfmanagement treatments to the problem. Linda, for example, performed self-management before seeking professional help.

Linda: 'I did some probably rather clumsy dressing myself and bathed it with water and soap and stuff but I came back, came in here (foot clinic) straight away and made an appointment'.

James also performed self-care measures at the occurrence of his first ulcer, but contrary to Linda, had no intentions of contacting the health care professionals at the time, as he expected the ulcer to heal.

James: 'so actually I dressed it washed it, had a shower every night and put plaster on it'.

Help-seeking triggers

This theme relates to factors that prompted participants who delayed seeking help to eventually seek help. It would seem a failure in self-management or a change/ deterioration in the ulcer facilitated the recognition of the seriousness of the situation and the eventual decision to seek help. James had tried self-management measures at first, but when the ulcer did not improve he eventually sorts help.

James: 'had a shower every night put plaster on it and the plaster was getting bigger each time because it was getting a little bit larger. Didn't realize what it was so I went to the doctor and said I've got a problem'.

It would also seem that some symptoms trigger patients to get help more promptly, specifically malodour or a purulent discharge. James, who was aware of his ulcer for 8 days, sought professional help when the ulcer started producing odour and purulent discharge as he describes below.

James: 'I could smell it, it had turned funny you know, I could smell the wound [...] so for 8 days it was just festering away on its own you know and eventually it was a bright green rotten. I rung the ambulance, went into hospital'.

Comorbid conditions and concurrent illness

In one patient, it would seem that a concurrent illness together with an underlying co-morbid condition impacted on their help-seeking behaviour. James developed a viral illness the day after he sustained the injury that precipitated his foot ulcer. He decided to treat his flu-like symptoms before he attended to the injury to his foot.

James: '[...] the next morning I went to work. I came back it was like I got a flu you know, the shakes and all this. Typical, went straight down the shop, bought Beechams powder [...] started going to bed, or on settee watching telly you know'.

James further describes how he later developed hip pain, which left him immobile and unable to tend to himself.

James: 'the next day I got a problem with my hips, I couldn't get up. So I lay basically there for 8 days'.

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Delayed secondary referral

This theme reflects the negative response of primary care professionals when being consulted for a foot problem. At the occurrence of their foot problems, two participants, Arnold and Harry, consulted their general practitioners (GPs). They both expected to be referred for secondary care but felt the GP was somewhat dismissive of their problem.

Arnold: 'I kept going to my GP and I kept asking them you know, do I need to go to the hospital? And they kept saying no, no it's fine, we just give you antibiotics, just come to the nurse. And it just got worse and worse and worse. It was probably 2 months from when it started as a blister till that I got to [...] (the diabetic foot clinic)'.

Harry: 'It was very brief, very brief. Here you are, have an antibiotic, go away. As if, I mean whether she didn't think it was much either I don't know but she certainly get impression of not concerned about it. Didn't want to refer it anywhere. I just went away, thank you for your prescription, goodbye'.

Both Arnold and Harry self-referred to the hospital diabetic foot clinic when their ulcers deteriorated.

Arnold: 'It was so bad that I took myself off to [...] hospital. They kept me there for about a week and then send me up here (foot clinic)'.

Harry: 'I went to the GP [...]. The next day it was all black. That quickly, it was horrendously quickly and I came into the foot clinic'.

The consequence of the GP's non-referral resulted in Harry and Arnold being hospitalised for 3 and 7 months, respectively. Arnold who underwent several wound debridement and had multiple hospital complications felt very aggrieved by the whole experience.

Arnold: '[...] Okay because I thought if it was worse, obviously I would have thought they would have sent me here (the foot clinic). And then I did ask, I said do you think I need to go to the hospital and they went no, so I felt reassured but really truthfully you know in hindsight I was let down really you know [...] they didn't send me to the hospital, I mean if they had send me here (foot clinic) quicker I wouldn't have ended up with a wound like that, I wouldn't ended up with being in hospital for 7 months you know, probably might have been a week or two something with a small operation but nothing like I had'.

Discussion

This preliminary study has highlighted a number of factors associated with delayed help-seeking behaviour in patients presenting with advanced foot complications. Early detection of initial ulcer presentation was found to be predictive of patient delay. Some participants were unable to detect the presence of a foot problem with information and capacity deficits (visual impairment, loss of sensation to the foot and immobility) both contributing to this lack of awareness. Such factors have been observed in previous studies.^{17,18} Decreased sensitivity to the feet among participants in a study by Hjelm *et al.*,⁸ contributed to the late discovery of foot lesions. This indicates that

patients need better information on foot monitoring and health professionals need to consider underlying deficits in the patient's capacity for self-monitoring.

While early detection of a foot problem appears to be important in treatment delay, even when patients are aware of the problem they still do not always seek help immediately. The perceived seriousness of their ulcer presentation seems to influence their help-seeking behaviour. Participants who perceived their ulcer presentation as trivial delayed seeking medical care particularly in the absence of triggers such as pain, odour or a purulent discharge. Studies of delay in help seeking for other medical conditions such as rectal bleeding, dyspepsia and myocardial infarction¹⁹⁻²¹ also identified perceived seriousness of a symptom as significant in the participants' decision to seek prompt medical care. Therefore, patients need to know that they should seek help prior to the development of more advanced signs of the problem. Previous studies with Swedish and African patients have reported similar observations in terms of delayed help-seeking behaviour with patient beliefs such as the ulcer was a natural occurrence or would heal it's self being important in explaining that behaviour.^{8,22} Therefore, it may be important in developing patient education on foot care to address such health beliefs in the curriculum.

The perception of the seriousness of ulcer presentation seemed to be related to their foot care knowledge. Participants who had received foot care information were more prompt in seeking medical care than those who did not receive any foot care information, in the abscess of any symptomatic triggers. Similar findings were revealed in Hjelm *et al.*'s⁸ study where Swedish men who received education about foot care showed more awareness of the seriousness of their ulcers compared to an immigrant population who received no foot care education. This latter group considered their ulcer to be more trivial and believed that it would heal by itself. This may suggest a direct relationship between patient delay, foot care knowledge and the perceived seriousness of ulcer.

The analysis also revealed that participants, who delayed in help seeking, did not prioritise their foot ulcer over other competing demands, such as a holiday. Similarly, women who delayed reporting symptom of breast cancer in Burgess *et al.*'s¹⁵ study cited family events, work or holidays as factors preventing them to arrange medical appointments. Attitudes to health have been shown to influence the decision to seek help, with patients weighing-up priorities based on what is important to them.²³ Perhaps this suggest an emphasis on helping patients understand more about the consequences of delay in help seeking in patient education.

A factor that may contribute to delay in help seeking is social support. It was clear that some patients in the study rely on informal carers to help them monitor their feet. If such support is absent particularly in patients with selfmanagement deficits, the risk of delay may be increased. Therefore, a lack of social support may be considered a risk factor for delayed presentation of ulcers and this needs further exploration.

Finally, the study showed that some of the delays were the result of delayed secondary referrals by the GPs. Despite national and international guidelines stressing the importance of early secondary referral in preventing lower extremity amputations,²⁴ participants who presented promptly to the GP with a foot problem, were not referred for secondary care. This finding is disappointing, but echoes the finding of a large prospective cohort, which found that over a quarter of delays were related to late referral from the initial health care professional.²⁵ Therefore, developing effective professional education on how to recognise and refer foot problems is still important.

This was a preliminary study, and it is intended that another larger study be undertaken to explore these factors further. It will also be important to develop interventions that can tackle some of the problems raised in the study. While such interventions should include patient education and information support, they also need to look at more systemic issues such as the development of more robust care-pathways to ensure foot problems are assessed in a timely manner. A larger study would also have scope to explore more the impact of other factors such as gender, ethnicity and social status, which may be important determinants of risk.^{8,22}

Study limitations

A limitation of the IPA methodology is that it uses a comparatively small sample size, which can raise questions about the transferability of findings. However, this study was designed as a preliminary study with very indepth analysis of patients with treatment delay. As such, it is unique in this focus and it provides the basis for larger studies to explore the identified themes further and in other care settings. It is also acknowledged that patients may not have been able to recall all the reasons for their delay and possibly withheld some details that were sensitive to them. Nevertheless, the interviews were conducted confidentially and by a researcher not associated with their current treatment, which hopefully minimised this potential bias.

Conclusions

This study has shown that patients' awareness (ability to detect) and perception (perceived serious) of a foot ulcer are key factors in their explanations for delay in seeking help. The findings highlight some areas for further exploration, including: the relationship between foot care knowledge, attitudes towards ulceration and patient delay; and the need to assess whether self-management deficits and social isolation should be incorporated into foot risk assessments. Overall, there is also clearly a need to enhance the provision of effective education for both patients and professionals to reduce delays in seeking help for foot problems in people with diabetes.

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