Amputation, early death and surviving diabetes-related foot disease — is it time to talk more openly with patients?

Martin Fox and Lisa Smith-Burgess

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Article points

1. Diabetes related foot disease is associated with modifiable risks of amputation and premature death.
2. Most current patient information resources avoid informing people with diabetes clearly about these risks and effective interventions that can help reduce them.
3. Most podiatrists working with diabetes who responded to a survey, would like access to printed resources, to support them to raise awareness and focus on effective risk-reducing interventions.
4. A poster and leaflet resource has been developed and piloted with interested clinicians, to help them inform patients of their DFU-associated risks and effective ways to tackle them.

Key words

- Communicating prognosis
- Diabetes-related foot disease
- Discussing outcomes
- Patient education

Authors

Martin Fox is Vascular Specialist Podiatrist, Lisa Smith-Burgess is Vascular Nurse Specialist; both at Manchester Leg Circulation Service, Pennine Acute Hospitals NHS Trust

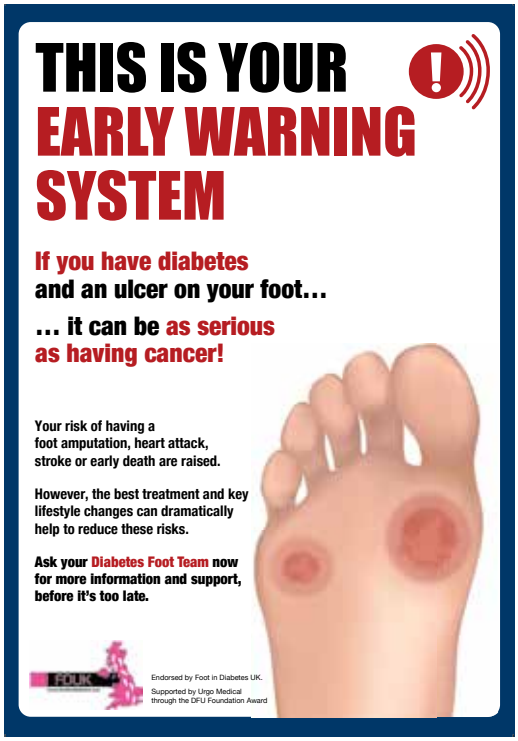
Diabetes-related foot disease is commonly perceived by the public and clinicians to be associated with foot ulcers, gangrene and amputation. Current NHS resources and clinical services involved with foot disease are directed at identifying and tackling foot risks, to help prevent potentially avoidable amputations. However, most of the significant complications of lower-limb diabetes are also associated with a dramatically increased risk of modifiable cardiovascular events and early death. Although people with diabetes-related foot disease have a higher risk of dying early from associated complications than they have of losing a leg, public awareness of this is low. This is a difficult and sensitive area of patient education to tackle and most current patient information resources tend to avoid it. There are no specific support or guidance materials available currently, to help clinicians tackle this key issue with foot disease. Consequently, there are no patient awareness and information resources readily available, to help inform people with foot disease about their specific associated risks of amputation, cardiovascular events and early death, or target specific cardiovascular risk-reducing opportunities and effective interventions, to help improve the survival of both limbs and lives.

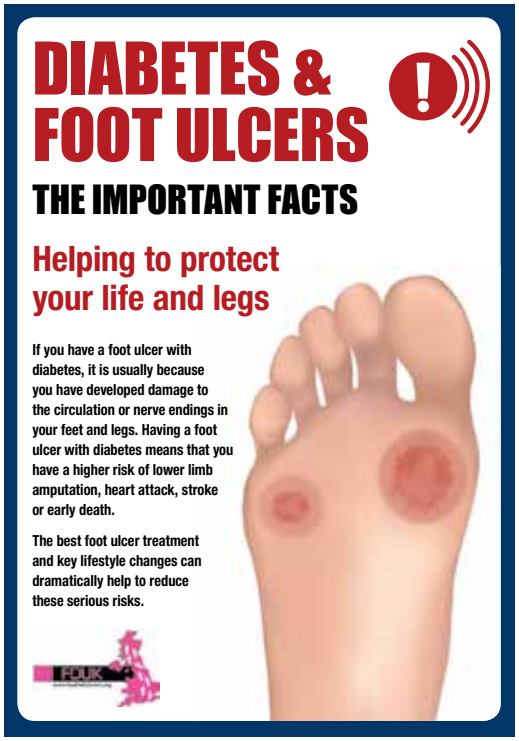
In 2014, a national Diabetic Foot Ulcer (DFU) Foundation Award was sponsored by Urgo Medical to support clinicians to develop innovative projects aimed at improving the care of people with diabetes-related foot problems. The DFU Foundation Award panel was composed of leading diabetes foot experts from around the UK.

One of the winning projects from the Manchester Leg Circulation Service aimed to raise awareness of people with DFU about their high associated mortality risks and support clinicians to help them discuss and focus on effective risk-reducing interventions. The project was to be centred around a visually striking poster campaign to raise mortality risk awareness in people with DFU, supported by a clinician and patient information resource pack, to help provide clear, consistent and balanced information, on associated modifiable cardiovascular risks and how to effectively reduce them. This article describes the DFU risk awareness-raising project and outcomes from the pilot use of the poster and leaflets developed to inform patients and support clinicians.

Method

A survey of diabetes foot clinicians was initially undertaken to identify if clinicians felt there was a need for DFU risk awareness-raising materials and whether early drafts of the DFU risk awareness-raising posters and leaflets might be of use. There were 67 respondents from an online survey of UK podiatrists contacted via regional and national networks using SurveyMonkey. Sixty-three (93%) said they did not have health awareness posters or leaflets available in their clinics to help inform people with DFU clearly about their modifiable mortality and amputation risks. fifty-three (79%) of the respondents said they would consider using the draft posters and leaflets initially drafted by the Manchester Leg Circulation Service. Of those that responded with 'not sure' (12) or 'no' (2), the main reasons given were themed





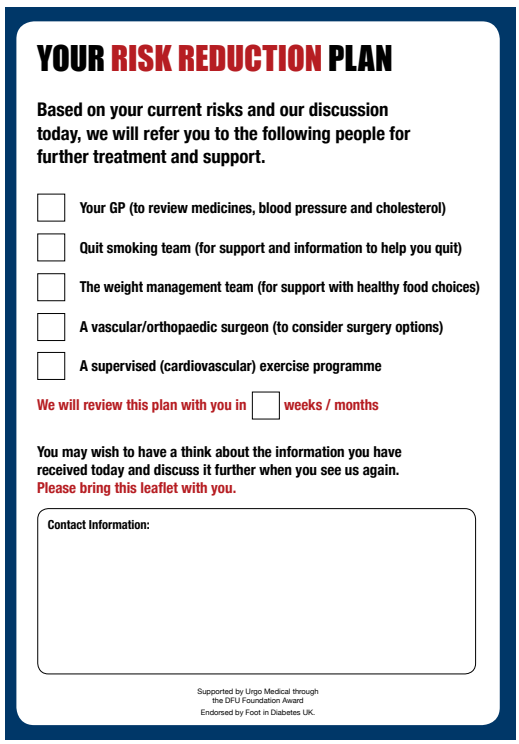


Figure 1. Diabetic foot ulceration risk awareness-raising project poster and leaflet.

around infection control, organisational policy concerns regarding posters on walls and concerns from clinicians about informing patients about the amputation and early death risks and using comparisons with cancer mortality rates. Sixty-four (96%) of the respondents said they felt that clinician support materials, to help discuss modifiable mortality and amputation risks, would be of use to them.

This survey and the case for the development of a DFU risk awareness raising campaign was submitted

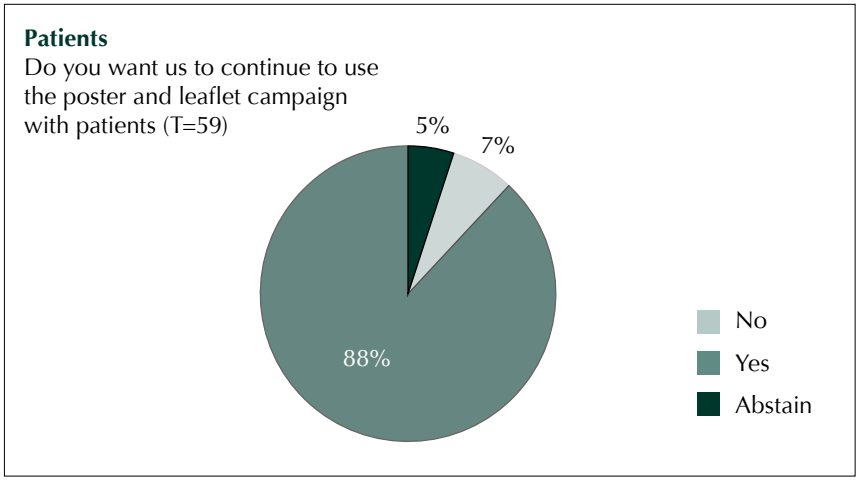


Figure 2a. Overall responses of patients and clinicians involved in the pilot.

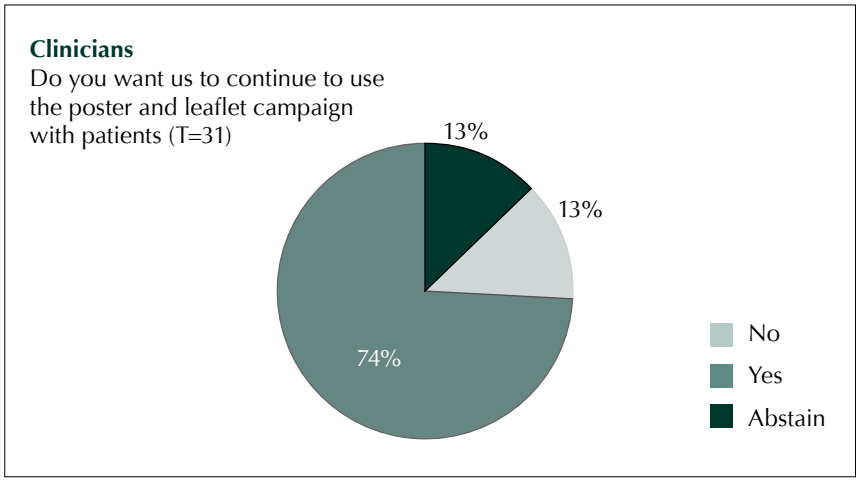


Figure 2b. Overall responses of patients and clinicians involved in the pilot.

to the Urgo DFU Foundation Award panel in 2014, short-listed by the expert panel and subsequently chosen as a winning project, following a 'Dragons Den' type interview. This meant the project would be supported with £10,000, to finance protected time, materials development and awareness raising initiatives and activity, during the project. During the initial development phase, input and advice was sought from an expert multidisciplinary clinician group (the FDUK executive committee), an expert patient group (The Oldham Amputee Support Group) and a clinical psychologist working with diabetes-related foot disease. Creative design support and input was secured from a communications agency, specialising in health and wellbeing (Page and Page). This all helped to work up the key messages, wording, visual concepts and design of the DFU risk awareness-raising project poster and leaflets (*Figure 1*). A request was then made to UK diabetes foot teams, via FDUK and a regional Podiatry NHS Clinical Effectiveness Group, for the UK-wide involvement of interested teams to pilot the posters and leaflets. NHS podiatry and multidisciplinary diabetes foot teams were targeted. Twenty-four diabetes foot teams replied to say they would be interested in the pilot. They were subsequently supplied with the pilot posters, clinician support leaflets, patient information leaflets and evaluation forms, for both patients and clinicians to complete, during a 3–6 month pilot phase.

The main aims of the pilot campaign summarised to the teams involved were:

- To raise awareness of people with DFUs, about the associated modifiable morbidity, mortality and amputation risks
- To encourage patients with DFUs to ask clinicians about these risks and about how they can best reduce them
- To provide patients and clinicians with written support information to help clarify risks and negotiate planned risk reduction interventions, using a cardiovascular approach. The 24 interested teams were asked to post the anonymous evaluation forms from their patients and clinicians back to our service, to enable collation and analysis of the results of the pilot.

Results

Of the 24 teams that were sent the posters and leaflets, 10 of the teams (42%) returned evaluation forms over 3–6 months. This resulted in 59 patient evaluations and 31 clinician evaluations of the pilot in total. The overall responses of both patients and clinicians on whether they felt the materials should continue to be used after the pilot, are displayed in *Figure 2(a&b)*. Responding patients found the poster and leaflets to be highly effective and highly useful in raising awareness, prompting discussions and setting personal DFU risk reduction plans. Overall, 52 patients (88%) who responded stated they wanted clinicians to continue to use the poster and leaflets with patients.

Responding clinicians found the poster and leaflets effective and useful in raising awareness and setting personal DFU risk reduction plans. Nine of the responding clinicians (29%) stated they did not

find the poster effective at prompting questions and discussion about risks and support available, but the majority of responding clinicians did find the clinician support leaflet and patient leaflet to be useful. Overall, 23 (74%) of responding clinicians stated they wanted to continue to use the poster and leaflets with patients.

Discussion

It has been shown that the 10-year outcomes for people with DFUs indicate that 15% of them go on the have an amputation and mortality is around 70% (Morbach et al, 2012). The DFU-associated mortality rates are comparable and often worse than those of some of the common cancers (Armstrong et al, 2007). Outcomes of DFU-associated amputation and mortality are potentially modifiable. Rapid access to multidisciplinary teams has long been shown to reduce amputations (Edmonds et al, 1986; Krishnan et al, 2008). More recently, it has also been shown that focusing on cardiovascular risk management in people with DFU can demonstrate dramatic reductions in 5-year mortality rates, or conversely, improvements in 5-year survival (Young et al 2008).

Despite these positive findings, most patient information materials currently produced on diabetes and foot disease risk do not highlight or clarify the links between foot screening results and the association of DFU with potentially avoidable amputation, cardiovascular events and early death.

Reviewing some of the comments that came in during the project, this may be due in part to clinicians and patients not feeling comfortable with discussing such difficult issues as amputation and death. Some comments highlighted that unless the clinicians pointed out the posters and asked patients their thoughts on the key messages, discussion on this difficult theme did not occur simply by the posters being visable. Some responding clinicians also suggested they think that discussing amputation, early death and comparisons with cancer mortality outcomes may scare or worry patients, rather than help inform and empower them.

This concern could also be indicated in the lower percentage of the clinicians involved in the pilot (74%) who wanted to continue using the posters and leaflets, compared to the percentage of patients who wanted to continue use (88%). Of relevance perhaps to clinicians who are considering discussing DFU in relation to mortality risks and survival opportunities, a recent study has shown that the beliefs and expectations of people with DFU about their illness can have a significant independent effect on their survival (Vedhara et al, 2016).

A literature review on the theme of discussing prognosis or breaking difficult news about diabetes-related foot disease revealed very little published research or guidance on how to approach this issue in clinical practice. NICE Guidance on patient experience in adult NHS services, however, recommends that clinicians should give patients the opportunity to discuss their diagnosis, prognosis and treatment options (NICE, 2012). Also, Naik et al (2012) suggested that 'effective risk communication in modern health care is indispensable. Anyone and everyone involved in healthcare services will increasingly find themselves providing risk information to patients'. They go on to state that 'by adopting simple and practical strategies and with the best available evidence base, the prospects now would seem more promising'.

Although clinicians responding in this pilot overwhelmingly stated that clinician support materials to help discuss modifiable amputation and mortality risks would be of use in their clinics (94%), less of these respondents (79%) said they would use the draft posters and leaflets provided. Looking at the results (*Figure 2*) and comments that were returned, discussing associated amputation and mortality risks, as well as using the cancer comparison with DFU, seemed more difficult for clinicians than for patients.

With an absence of specific guidance on if, how and when to best discuss risks/prognosis with DFU, patient consultation tools, such as 'SPIKES' (Setting, Perception, Invitation or Information, Knowledge, Empathy and Summarise or Strategise), as advocated by Kaplan (2010), can provide guidance on how to broach breaking difficult or bad news, using a structured consultation plan. Although developed in cancer care, the principles may well be suited to discussing amputation and mortality risks associated with DFU and have been considered to a degree in designing the project leaflets for supporting clinicians to consider initiating such discussions. Another study exploring how best to discuss prognosis in cancer found that when asked, people with cancer prefer detailed prognostic information about their illness (Hagerty et al, 2004). The results of this pilot also suggest that people with DFU when asked, prefer

open, honest information on prognosis, risks of amputation, vascular events and early death, along with information on how to reduce these risks and support event-free survival.

There has been some recent consideration given to the 'hard, but necessary' need to discuss prognosis in primary care with patients who have a lower life expectancy, relating to a variety of presenting life-shortening diseases. It is proposed that although prognosis is a sensitive topic, practitioners who master the art will likely have more satisfied and trusting patients, which may help them avoid harm, receive higher quality care and experience a better quality of life (Schonberg and Smith, 2016). Cardiovascular risk-reducing interventions such as DFU-related medicines concordance (Young et al, 2008), and harm-reducing lifestyle changes, e.g., quitting tobacco or switching to e-cigarettes (McNeill et al, 2015), may have more context for patients within the 'hard, but necessary' discussions about the DFU-associated risks and modifiable outcomes, of amputation, heart attack, stroke and early death.

Conclusion

There is a current lack of readily available patient information resources that raise awareness about DFU-associated amputation and mortality risks and provide specific information and support to patients on effective risk reduction interventions. There is no specific guidance for clinicians treating DFU on how to discuss prognosis and effective risk reduction strategies. The lack of posters and leaflets to support clinicians with this activity has been acknowledged and a demand expressed for support in this area.

This pilot DFU Award project has developed poster and leaflet resources to support clinicians to raise patient awareness and discuss modifiable risks of amputation, cardiovascular events and early death. Most patients and most clinicians who used the DFU risk awareness campaign posters and leaflets found them to be effective and useful at raising awareness, understanding of risks to life and limbs, and setting personal DFU risk-reducing cardiovascular plans. Most responding patients and clinicians found the comparison of DFU with cancer to be effective at highlighting the risks associated with DFU. Although the majority of patients indicated the poster prompted them to ask questions about DFU risks and treatment, a significant proportion of clinicians seeing these patients indicated it did not. Overall, the vast majority of patients involved in the pilot and a lesser majority of clinicians involved indicated they wanted to continue the use of these poster and leaflets, to help support awareness around the DFU-associated risks of amputation and early death and the interventions that can improve survival.

The authors would like to thank Urgo Medical, Page and Page, the FDUK executive committee, the Oldham Amputee Support Group and Professor Mike Edmonds, for support and advice during this project. The DFU Risk Awareness Campaign resources — poster, patient leaflet and clinician support leaflet — are now available as PDFs. Hard copies may also be available in future. Email Martin Fox at *martin.fox@pat.nhs.uk* for further details. ■

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