

Communicating the risks to life and limb: what do we say and how do we say it?



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“The biggest problem with communication is the illusion that it has taken place.” George Bernard Shaw.

An expert colleague in the field of diabetic foot disease recently suggested to us that there are around seven key themes covering the majority of related research, education and clinical evidence. Offloading, infection, ischaemia, wound care etc ... you get the idea. But another theme that is perhaps most important to our patients is one with virtually no evidence base or best practice model to refer to currently. What on earth do we tell patients about this devastating disease and how do we best discuss it with them, to positively influence health behaviour change? Communicating diabetic foot disease prognosis, severity and choices of treatment is a difficult and challenging skill, which is still a relatively dark art!

The national and international multidisciplinary team ‘giants’ of the diabetic foot world are generally fairly quiet on this theme. While they feed, nurture, stimulate, inspire and drive the growth of increasing quantities of mainly biomedical research, the communication and psychosocial approaches to tackling the deadly outcomes we oversee seem to be withering on the self-fulfilling branch of ‘not enough evidence, not enough research’. What hope do we have of tackling health-related apathy, misplaced beliefs, fear, chronic wounds, amputations, associated depression, destroyed lives and early deaths, if we do not know how best to communicate about key modifiable outcomes and the effective risk-reducing interventions that we do have available?

Following the diabetic foot education interventions mooted by Mallone et al (1989), which were not found to give clinical benefit in the stronger randomised controlled trial (RCT) by Lincoln et al (2008), the focus of our diabetic foot health promotion efforts have primarily been about trying to give well-meaning (but largely un-evidenced)

information on preventing ulcers and amputation, while also acknowledging a lack of consensus on what information is best to give and how best to deliver it (McInnes, 2010).

Behavioural change interventions, such as motivation interviewing, which have shown some promise in other chronic illnesses, have not been robustly tested by the diabetic foot community, perhaps due to a lack of highest quality evidence in this field and a lack of investment in specific skills training. A relatively lone voice in the diabetic foot community, asking for us to communicate known mortality risks and try out communication methods, such as motivational interviewing to help facilitate health behaviour change, seems to have largely been ignored (Robbins et al, 2008).

So, in this ‘evidence-void’, we are seemingly happy to give out patient information leaflets, full of largely non-evidence-based ‘information’ and ‘advice’, with not a single clear reference to modifiable amputation or vascular-related death risks, or information in plain English on how to reduce these risks. Are we really informing or misinforming our patients? Are we protecting them from a hard truth, or hiding it from them? Are we helping them to live longer and healthier lives with their diabetes-related disease, or are we allowing them to die early, without having communicated key life and limb survival options clearly? Did we decide there was little point in exploring how best we can communicate with patients and their families about these big issues? Or have we just not opened up the conversation? It’s easy isn’t it, particularly in our continually busy clinics, to carry on giving out unwanted and largely ineffective advice.

So in the absence of a strong direct evidence base on what information to give people and how best to deliver it, would it make sense to consider the strategies emerging around other long-term conditions with highly modifiable mortality rates – e.g. cancer and cardiac disease? People

with cancer (when they are asked) prefer detailed prognostic information about their illness (Hagerty et al, 2004). Can we apply the same principles of giving clear prognostic information to our diabetic foot patients on modifiable vascular risks associated with amputation and early death? This information could naturally then lead to a discussion of the positive angle of optimising survival rates! Two sides of the same coin perhaps, but once we start to discuss death more openly, we create a great opportunity to discuss survival.

People with cardiac disease have been shown to significantly reduce their risks of vascular events and mortality if they engage in cardiac rehabilitation programmes (Witt et al, 2004). Could our (cardiovascular-risk) diabetic foot disease patients benefit from those same interventions, perhaps even sharing access to the existing commissioned cardiac rehabilitation services available in many NHS organisations? If we can make it happen for people with peripheral arterial disease (Matthews et al, 2015), can we make it happen for people with diabetic foot ulcers? By engaging actively with cardiac rehabilitation interventions, might we stimulate a new era of key research and audit into a broad range of cardiovascular-based diabetic foot interventions?

We could, of course, wait for more evidence on communicating vascular risks and negotiating health behaviour change in people with diabetes and foot disease, before changing what specific information we provide and how we deliver it. But while we are waiting, could we start by telling patients with diabetic foot disease the balanced truth about amputation, death and survival rates? Can we raise their awareness and offer verbal and printed information on the key reasonable evidence-based interventions to date: that multidisciplinary foot teams can help save their limbs (Edmonds et al, 1986) and that better cardiovascular risk management can help save their lives (Young et al, 2008).

In Manchester, we run a cardiovascular-focused peripheral arterial disease service, which also sees many people with diabetes and foot disease. Virtually none of the patients when they initially attend have a reasonable understanding of their life and limb risks, or know what they can do to reduce them, despite having spent many hours previously with a range

of clinicians in GP practices, podiatry and diabetic foot clinics.

In our experience, opening up communication on these difficult themes with patients and their families involves a bit of courage, but it expands upon existing patient information resources and creates timely opportunities in patient consultations from which to start the conversation. Diabetic foot clinicians tell us, wherever we ask, that they want further support to help them gain confidence to communicate more effectively about risks and survival. There is a recognised need by many for more training and education in this vital area of practice. For now, we hope that the Urgo DFU 2014 Award project materials, due to be launched soon and described elsewhere in this journal, will go some way towards providing simple support to clinicians ready to have a go. We would like to ask you, the readers of this journal: "What opportunities can you create to communicate foot disease-related risks and survival strategies to your patients? And if you are already doing it, can you help us learn how to do it far better?"

"... one opportunity leads directly to another, just as risk leads to more risk, life to more life, and death to more death." *The Book Thief* by Markus Zusak. ■

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