Patient Engagement with Diabetic Foot Care: A Psychological Perspective.

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Article points:

- To date, there has been little psychological research conducted in the diabetic foot population and there is a strong need for this.
- Increasing patient adherence to foot treatments and engagement with self-care regimens are central to improving clinical outcomes.
- I draw on insights from a psychological pilot study conducted by myself and colleagues from NHS Lothian and the University of Stirling (McBride et al., 2016).
- Psychological aspects relevant to the diabetic foot population are broadly discussed in the context of directions for future focus.
- Increased health psychology input could help support healthcare professionals and patients in managing the behavioural elements of foot care.

Key words: Engagement, adherence, health psychology, psychology, foot self-care, self-management.

Patients with a diabetic foot ulcer represent an extremely vulnerable group of individuals, with multiple morbidities and higher mortality rates than most common cancers (Robbins et al., 2008). To date, despite their poor health outcomes, there has been little research to explore psychological characteristics of these patients or to test the use of psychological interventions in this population. In this article, I argue that there is a strong need for increased psychological focus, and draw on insights from a pilot study (McBride et al., 2016), conducted by myself and colleagues at the Edinburgh Royal Infirmary (NHS Lothian and University of Stirling), which tested an intervention aimed at increasing patient involvement in foot treatment decisions.

Most diabetic foot healthcare professionals want patients to take a more active role in their foot care. This is because foot ulcer prevention and faster wound healing are largely dependent on patients properly adhering to foot treatments (e.g. wearing a specialist foot device at home) and engaging with foot self-care regimens (e.g. self-examination for early warning signs). Some studies have indicated that foot treatment adherence is low (Armstrong et al., 2003, Wu and Armstrong, 2006), and repeat ulceration and poor wound healing statistics also support this (Jeffcoate and Harding, 2003). It has therefore been nationally recognised that promoting patient engagement with foot care is central to improving health and clinical outcomes in this population (McInnes et al., 2011). The National Institute for Health and Care Excellence (NICE, 2015) has also released guidelines which emphasise the importance of increasing patient involvement in the diabetic foot care pathway.

Insights from our psychological pilot study

In line with the national recommendations, myself and colleagues at the Edinburgh Royal Infirmary (NHS Lothian and University of Stirling) conducted a pilot randomised controlled trial to test an intervention aimed at increasing patient involvement in treatment-related decisions and to facilitate shared decision making (McBride et al., 2016). We were primarily interested in whether this would increase patients' confidence in their own ability to make treatment-related decisions, and whether this would have any impact on their adherence to foot treatments. To our knowledge, this was the first study to test shared decision making in the diabetic foot population.

The results of our study indicated no impact of increased patient involvement on decisional confidence or adherence to foot treatment. This did not provide support for the idea that shared decision making can improve these outcomes at this progressed stage in the diabetes disease trajectory. However, despite null findings from our primary outcomes, we observed interesting psychological characteristics which had not previously been noted in this population. In particular, patients with a diabetic foot ulcer reported that they were extremely confident in their ability to make decisions and take an active role in their care from the outset (e.g. asking the doctor questions, getting facts about treatments, exploring risks and benefits) - they reported a mean score of 83.5% decisional confidence at baseline. This was surprising as, although we cannot be sure of a direct link, it is generally expected that high decisional confidence is reflective of a group of individuals who take an active and engaged role in their care. Based on the poor health outcomes and poor adherence to foot treatment observed in this population, we had therefore anticipated lower decisional confidence at baseline.

Further, with reference to one of our secondary outcomes, patients on average reported that they did not experience much decision uncertainty after discussing their treatment plan with a foot healthcare professional (reported a mean score of 19.5% decision conflict). In general, this is usually a positive indicator as it suggests that the patient felt involved in their treatment plan and therefore had little to feel uncertain about when making treatment-related decisions. However, in this particular case, what may counteract this is that patients in our intervention group showed a significant increase in decision conflict over 12 weeks; i.e. increased patient involvement seemed to make patients more uncertain about their foot treatment decisions. This could suggest that at first these patients did not believe they personally had many treatment considerations to make (hence the low uncertainty). When the intervention encouraged them to take more of an active role, their decision conflict may have increased as a result of a new perception of a greater number of choices/decisions where they had perceived fewer previously.

We attempted to make sense of these findings through suggesting that patients with a diabetic foot ulcer may display what we term in psychology as a low internal health locus of control (see the original paper for more information on our reasons). This term is used to describe individuals who place low weighting on the influence of their own actions on their health. They may place far heavier weighting on the role of external influences in their recovery, such as the need for healthcare professionals to manage their health and hold most of the responsibility. In practice, this could present as a group of patients who attend and/or over-engage in NHS foot appointments, but may not recover as would be expected through poor self-care. However, these concepts must be explored further and tested directly in this patient group as our explanations were hypothetical based on our indirect findings in this pilot study, and therefore must be interpreted in this context.

Future directions for psychological research and the diabetic foot population

Despite a national push for psychological research in the diabetic foot population, there has been little research to explain why patients with a diabetic foot ulcer do not fully engage with their foot treatments and self-care regimens. Research to explore this area is pivotal in shaping the development of future interventions which aim to support and improve patient engagement and adherence. To date, most diabetic foot research in this area has focussed on developing education-based interventions; there seems to have been an assumption that poor patient knowledge is the main driver behind poor engagement. However, systematic review evidence has indicated that education interventions have little impact on influencing patient engagement with foot care (Dorresteijn et al., 2014). This does not provide support for a direct link between increased knowledge and better foot-related adherence, and is in line with wider health psychology literature which shows that education alone is rarely fruitful in promoting behaviour change without the addition of other behaviour change techniques (Michie et al., 2011). Some psychological research has found that certain patient illness beliefs independently predict foot self-care, such as a strong belief in one's ability to personally control their foot recovery and a patient believing that they have a good understanding of foot ulcers (Vedhara et al., 2014). This is also in line with the suggestions made in our study (McBride et al, 2016), that the patient's personal controllability beliefs may play a key role in negating their behaviours. Developing and testing practical interventions aimed at exploring and targeting these beliefs could act as a good starting point for future research attempting to improve adherence to foot self-care.

It is also worth noting that the degree to which patients' want to be involved in diabetic foot care is currently unknown. This is particularly important as, without this information, it is

difficult to assess the best approach to take. If patients perceive little value in their own involvement, finding ways to increase their motivation to engage with foot care pathways may be most appropriate. Alternatively, if they do want to be involved but there are barriers preventing this, that might suggest that the best way forward is assessing what these barriers are and finding ways of addressing them in practice. From the results of our pilot study (McBride et al., 2016) we argued that this population may benefit more from interventions aimed at increasing motivation to engage with foot care pathways. This was because patients appeared to be very confident in their own ability to engage with healthcare professionals and take an active role in treatment decisions, yet this confidence did not seem to translate into actions. However, as already highlighted, this area needs to be explored further and tested with primary focus in future studies.

A final point, which follows from the possibility of a lack of motivation to engage in treatment pathways, is the need to be mindful that poor engagement in treatments and/or foot self-care is unlikely to be an active choice for this patient group. Instead, it likely stems from of a number of factors which may have contributed to learned behaviours of not engaging over time. Typically, the average patient with a foot ulcer is at a progressed stage in the diabetes pathway where acute symptoms may be presenting for the first time. As a learned experience for the patient, this means that they have likely had diabetes for a number of years and interacted with the NHS on numerous occasions. They may not have associated any notable consequences as a result of not fully engaging with their diabetes care, given acute symptoms rarely occur in the early stages of type-2 diabetes. Some patients may therefore believe that their efforts towards engagement with care have had little impact on their health outcomes. This would provide them with little motivation to learn the independent skills necessary to successfully self-manage their diabetes (Leventhal et al., 1992). Thus, by the time patients present to the diabetic foot clinic they may be representative of a sub-group who have particularly struggled with self-management. This is undoubtedly a huge challenge for healthcare professionals involved in the management of diabetic foot care. It also portrays a profile of an extremely vulnerable group of patients who are strongly in need of extra support.

Conclusion

As a health psychologist new to working with the diabetic foot population, the lack of psychological research into the behavioural aspects of diabetic foot care, to date, surprises me. Increased health psychology focus could help support healthcare professionals and patients in managing the behavioural elements of foot care. Research to investigate psychological aspects and develop and test interventions suitable for implementation in practice is urgently required. As a general starting point, it would be useful to explore reasons why this particular patient group struggles with foot treatment adherence and foot self-care, building on some of the concepts discussed in this article. This would help shape more effective patient programmes and intervention tools for use with this population in the futu

References

ARMSTRONG, D. G., LAVERY, L. A., KIMBRIEL, H. R., NIXON, B. P. & BOULTON, A. J. 2003. Activity patterns of patients with diabetic foot ulceration: patients with active ulceration may not adhere to a standard pressure off-loading regimen. *Diabetes Care*, 26, 2595-7.

DORRESTEIJN, J. A., KRIEGSMAN, D. M., ASSENDELFT, W. J. & VALK, G. D. 2014. Patient education for preventing diabetic foot ulceration. *Cochrane Database Syst Rev,* 16.

- JEFFCOATE, W. J. & HARDING, K. G. 2003. Diabetic foot ulcers. *The Lancet,* 361, 1545-1551.
- LEVENTHAL, H., DIEFENBACH, M. & LEVENTHAL, E. A. 1992. Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, 16, 143-163.

MCBRIDE, E., HACKING, B., O'CARROLL, R., YOUNG, M., JAHR, J., BORTHWICK, C., CALLANDER, A. & BERRADA, Z. 2016. Increasing patient involvement in the diabetic foot pathway: a pilot randomized controlled trial. *Diabet Med*, 25, 13158.

- MCINNES, A., JEFFCOATE, W., VILEIKYTE, L., GAME, F., LUCAS, K., HIGSON, N., STUART, L., CHURCH, A., SCANLAN, J. & ANDERS, J. 2011. Foot care education in patients with diabetes at low risk of complications: a consensus statement. *Diabet Med*, 28, 162-7.
- MICHIE, S., ASHFORD, S., SNIEHOTTA, F. F., DOMBROWSKI, S. U., BISHOP, A. & FRENCH, D. P. 2011. A refined taxonomy of behaviour change techniques to help people change their physical activity and healthy eating behaviours: the CALO-RE taxonomy. *Psychol Health*, 26, 1479-98.
- NICE. 2015. *Diabetic foot problems: prevention and management* [Online]. Available: https://www.nice.org.uk/guidance/ng19/resources/diabetic-foot-problems-preventionand-management-1837279828933 [Accessed 04.08.2016].
- ROBBINS, J. M., STRAUSS, G., ARON, D., LONG, J., KUBA, J. & KAPLAN, Y. 2008. Mortality rates and diabetic foot ulcers: is it time to communicate mortality risk to patients with diabetic foot ulceration? *J Am Podiatr Med Assoc,* 98, 489-93.
- VEDHARA, K., DAWE, K., WETHERELL, M. A., MILES, J. N., CULLUM, N., DAYAN, C., DRAKE, N., PRICE, P., TARLTON, J., WEINMAN, J., DAY, A. & CAMPBELL, R.
 2014. Illness beliefs predict self-care behaviours in patients with diabetic foot ulcers: a prospective study. *Diabetes Res Clin Pract*, 106, 67-72.
- WU, S. C. & ARMSTRONG, D. G. 2006. The role of activity, adherence, and off-loading on the healing of diabetic foot wounds. *Plast Reconstr Surg*, 117, 248S-253S.