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How can we improve adherence?

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Abstract

Many patients with wound healing difficulties are also coping with the management of a chronic disease or chronic condition that requires them to make life-style behaviour changes, e.g., managing glucose levels through diet and exercise, regular foot inspection. Many find it difficult to make such changes, and often experience feelings of powerlessness when faced with a life-time of behavioural and psychological change. This paper will explore the importance of understanding the patient difficulties associated with adherence to a regime, and how life changes can be difficult to maintain over sustained periods of time. However, the paper will also discuss the importance of this topic in trying to understand the clinical evidence base for treatment – as many clinical trials investigating treatments for the diabetic foot do not include information on the extent to which patients in the trial conformed to the trial protocol. The paper gives an overview of recent developments – including lessons we can learn from other chronic conditions where permanent life changes are required - in particular the need to keep health messages simple, tailored to the individual and repeated frequently. The evidence to date suggests that no one single form of adherence intervention will work with all patients; this is not surprising given complex and multifactorial nature of adherence and the myriad of barriers that exist that patients and health care professionals need to overcome.

Introduction

This is an overview paper that attempts to tackle key issues related to adherence to treatment, particularly for patients with (or at risk of) diabetic foot ulceration. This is a complex topic with a vast literature across the full range of chronic conditions; however, the evidence to support appropriate interventions in patients with diabetic

foot problems is limited although there is increasing recognition of the importance of this area. The paper is organised in sections, each focusing on one key aspect of this issue: What is adherence?; Why do patients find adherence difficult?; To what extent does adherence affect treatment efficacy?; Recent findings and lessons from other chronic conditions; and, What makes a difference?

What is adherence?

A dictionary definition of adherence usually results in phrases such as ‘sticking to’ or ‘following rigidly’. However, for the purposes of this paper the definition from the World Health Organisation (WHO) [1] is a good place to start:

“the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes - corresponds with agreed recommendations from health care provider” (2003, pg 3).

This particular definition was used by the WHO scientific group working on adherence to long term therapies, and fits the nature of the experience for patients with Diabetes, which requires long term changes to life style, and the preventative action that is required to avoid the complications of the condition. Of particular note is the way in which this definition differs from the term ‘compliance’, which is still used by many health professionals. The key difference is that adherence requires patients to agree to the recommendations for behaviour change or therapy regime, and is based on an assumption of joint responsibility for health outcomes.

Why do patients find adherence difficult?

Many health professionals will anecdotally report that they find the experience of working with patients to ‘stick to’ preventative health behaviours similar to ‘hitting your head against a brick wall’. There is often exasperation as staff feel that have repeated messages endlessly, in different formats and at different times, and yet, patients find it difficult to ‘stick to’ agreed plans. Interviews with staff working in this area often suggest that the barriers to adherence include a lack of awareness of the complications of diabetes, examples of communication break down, a lack of easily available tools to help patients or staff, and gaps in the health care system resulting in the inability to give this issue the time it needs in order to be successful. Based on qualitative data, researchers have shown that patients and podiatrists view these issues from different perspectives with podiatrists focusing on a clinical agenda, while patients find it difficult to adhere to advice on a daily basis and often choose to prioritize their lifestyle and/or emotional well being over foot care [2,3]. The use of ‘strategic non-adherence’ (i.e., balancing the importance of life quality with the

costs/benefits of adherence) has been previously noted in both diabetes and other chronic conditions [4,5]. One thing is clear, and has been known for a substantial amount of time: knowledge alone is not enough – it is a necessary but not sufficient condition for adherence to take place [6].

The WHO [1] has proposed that there are 5 interacting dimensions that affect adherence, stressing that it is a complex issue with no single solution. Many patients face more than one barrier when faced with long-term, life-changing health conditions. The 5 dimensions are: social and economic factors; therapy related factors; patient related factors; health system related factors; and condition related factors. All five dimensions should be considered when designing interventions: there is strong evidence that a single factor approach will have limited impact, given the way in which these factors interact and influence each other [1]. Each of these dimensions has multiple elements, demonstrating the multifaceted nature of the problem. In considering the problems faced by patients with (or at risk of) diabetic foot ulceration elements of each of these dimensions can easily be identified. For example:-

- the social demographic(s) of patient groups is linked to poverty, health literacy and access to health service;
- the therapy itself is often complex, requiring skill in monitoring both the diabetes and the associated complications, and requires significant changes to lifestyle;
- the patients themselves are often elderly, with multiple conditions including visual, hearing and cognitive impairment, an inability to understand both complex health messages and how to access complex health systems;
- health care systems have often not caught up with the changing presentation of patients with chronic conditions, the need for consistency of care, and easy referral routes at key times;
- the condition is chronic and patients tend to deteriorate over time, there is also increasing evidence that depression levels are higher in this patient group than previous reported.

Patients with diabetic foot ulcers need to be involved in their foot care, yet they do not routinely comply with diabetes or foot care recommendations [7], and their beliefs about their ulcers and treatment can influence the extent to which they participate in preventive foot care or seek appropriate and timely help [8]. Fife et al suggest that three factors determine 'compliance' with performing basic wound care from an

evidence-based medicine perspective: complexity, cognitive effort, and the compensation system. They also argue that the 'disconnect' between strong clinical trial evidence (e.g for Total Contact Casts) and what happens in routine practice needs to be explained and addressed [9].

Healthcare systems need to consider ways in which self-management can be built into a framework of care – particularly knowing the extent of the projected increase in the elderly [10], many of whom will present with wound problems and the anticipated world wide increase in diabetes and associated complications [11,12]. These increases will coincide with a reduction in the percentage of skilled healthcare professionals as a proportion of the population due, to the forecasted balance of numbers in the workplace compared with the proportion of the population of retirement age [10].

One of the real challenges in researching this topic, or providing evidence of the efficacy, is the lack of a gold standard in measuring adherence [13]. Evidence to date suggests that if you ask the providers whether or not patients are adhering to treatment, they tend to *overestimate* adherence [14] – while many patients will not admit to non-adherence as it is seen to be socially unacceptable; however, when they do admit that adherence is a problem, they are likely to be honest in their descriptions [15]. Methods tend to fall into two groups: subjective methods, which rely on self-report, diaries, or questionnaire; or more objective measure such as tracking biomedical markers, electronic markers or other devices (e.g., e-assessment methods, APPs for mobile devices, pedometers, pressure sensors), or remaining dosage. These methods are either inaccurate or expensive to implement, resulting in data that do not reflect the multifactorial nature of adherence. For accurate data that is affordable, we need to use a range of methods and triangulate the resulting data.

To what extent does adherence affect treatment efficacy?

There is evidence that adherence to chronic disease management is *vital* to achieving improved health, outcomes, quality of life and cost effective health care in a range of chronic conditions [16-18]. In a systematic review presented at the May 2015 ISDF Conference by van Neeten *et al* [19], which focused on prevention, one of the key discussion points focused on the fact that studies (regardless of method used) consistently reported that those who did not adhere to treatment (regardless of the intervention under investigation) presented with significantly worse outcomes

(regardless of outcome used). This suggests that adherence to treatment may be one of the critical underestimated factors in the efficacy of a wide range of treatments. If studies do not inform readers about the extent to which patients adhere to the interventions under investigation, then there is a real potential to over or under estimate treatment effects rather than attributing improved outcomes to adherence, consistency of care and/or getting the basics right.

This review confirms the work of earlier systematic reviews on patient education and preventing diabetic foot ulceration [20] that have concluded that simple patient education alone cannot lead to clinically relevant reductions in ulcer or amputation incidence. Future research will need to focus on evaluating the effectiveness of more comprehensive and complex interventions (including patient education) that may be needed for sustained behaviour change [21].

Recent findings and lessons from other chronic conditions

Research in this area is complex, patchy and often inconclusive, but certain lessons can be learnt. There is substantial evidence that we often overestimate the health literacy of patients, such that there is a strong negative correlation between the complexity of a regime and an individual's ability to stick to the regime: the more complex the regime, the more difficult it is to stick to it over time [22].

Aretja et al (2005) [23] have used the mnemonic of SIMPLE to help clinicians formulate regimes that reflect the elements of a regime that need to be taken into account:

Simplifying regimen characteristics:- e.g, trying to match the regime to the patient's life style

Imparting knowledge:- e.g., ensure the information meets the needs of the patient

Modifying patient beliefs:- e.g., think about cultural as well as individual beliefs

Patient and family communication: - e.g., active listening, provide clear, direct messages

Leaving the bias: e.g., make sure you work to the patient's level of understanding, leave your biases behind

Evaluating adherence: e.g., work with the patients to find a way to see what works for them.

This method allows clinicians to develop adherence interventions within a framework that continually reinforces the need to keep messages simple.

A study by Bostock and Steptoe (2012) [24] involving 7857 patients in England, all aged 52 years and over demonstrated that one third of these adults had difficulties in reading and understanding basic health information on the use of aspirin. This study provided detailed evidence that poorer understanding was associated with higher mortality. Ferguson et al (2015) [25] in a study of 280 adults with poorly controlled diabetes, report that almost 40% reported that they were managing to control their diabetes either 'well' or 'very well'; this was exacerbated by low health literacy where 61% inaccurately believed they were controlling their diabetes well. Margolis et al (2015) [26] have also demonstrated in a study of 41 patients that those patients with lower health literacy scores were less likely to volunteer to be part of a clinical study, and at the time that they seek care, their wounds are less likely to heal. These studies provides a strong reminder of the importance of health literacy, literacy and numeracy skills when designing health messages.

What makes a difference?

Many of the key findings about how to formulate health messages, together with the evidence that underpins the recommendation, can be found at the following web site: <http://www.cdc.gov/healthliteracy/ScienceSays> provided by the Center for Disease control and prevention [27].

Many of the recommendations focus on simplifying messages and include practical suggestions, including:

- Using pictures wherever possible (NB: make sure the pictures are culturally sensitive)
- Use plain language / written and oral
- Use headings, and present the information in small 'chunks'
- Whenever possible use vignettes, examples, personal stories rather than statistics
- Try to use absolute risk (10 out of 100)/ use the same time frame and denominators
- Present essential information by itself, if at all possible
- If several points must be made then put the essential information FIRST but do not include more than 5 pieces of information in a session

- Always use ratings where higher scores equate to 'better' (e.g. quality /outcomes)

Although this section only focuses on the importance of health messages, this is often the area where clinicians feel that they have the greatest role to play. However, we must not forget that simplification of the health care system is also paramount as patients often feel that they are 'passed around' complex health systems, with limited communication between departments and are not sure who/where is the best source of advice.

Conclusion

There is increasing evidence that adherence is a complex issues that requires complex interventions that require whole scale changes to how we provide care. Treatment for diabetic foot ulceration requires access to complex health systems, and patients need to understand the importance of following treatment recommendations in order to avoid (or delay) a deterioration of their wound. However, such changes take a substantial amount of time and expense. In the interim there are ways in which clinicians can support patients in adhering to agreed treatment plans that focus on clear and simple messages that are tailored to an individual's life style, health literacy level and understanding of accessing care. Such messages may well need to repeated often, with subtle changes to reflect that way in which an individual's life changes over time. We all need to be prepared to amend, repeat and reinforce messages in order to support patients over a life-time of behavioural change.

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