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Title: Overcoming barriers to self-management: The person-centred diabetes foot behavioural agreement.

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Highlights

- 98% of diabetes management is self-care
- Effective self- foot care can prevent diabetes foot disease
- Self- foot care requires functional, interactive and critical health literacy skills
- Behavioural agreements delineate, prescribe and support individual responsibilities

Abstract:

Objective: Behavioural agreements have been proposed as a clinical strategy for improving concordance with diabetes foot self-management practices, both for individuals 'At-risk' of, and with active, diabetes foot disease. This narrative review sought to explore the potential supportive role of person-centred diabetes foot behavioural agreements in promoting protective foot self-management behaviours among 'At-risk' individuals. Conclusions: Health care professionals (HCPs) involved in diabetes foot risk stratification and management dedicate considerable time, effort and resources to the prevention of diabetic foot ulcers (DFU) and lower extremity amputation (LEA) and are uniquely placed to deliver person-centred diabetes self-management education and support (DSMES) interventions. Written, verbal and non-verbal agreements are consistent with a wider global move toward DSMES approaches, respectful of people's preferences, and supporting them to

undertake protective self-care behaviours. Practice Implications: It is theorised that clear communication of the roles of the person with diabetes, their family or carers and HCPs may improve concordance with self-management behaviours. Rather than a punitive measure or means of facilitating discharge of 'non-concordant' individuals, person-centred behavioural agreements should be framed positively, as a means of delineating, prescribing and supporting individual diabetes foot-care responsibilities. This is an area worthy of further research.

1. Introduction:

By promoting timely self-recognition of the early signs of diabetes foot disease and self-referral to specialist diabetes foot services, the severity of diabetes foot disease may be reduced [1,2]. Annual diabetes foot screening has become standard practice within the National Health Service (NHS), allowing risk stratification and tailoring of diabetes foot education and podiatric management. Throughout the United Kingdom (UK) diabetes foot patient education is supported by patient information and advice leaflets [3,4]. This terminology is problematic, however, both in its use of the term 'patient' and focus on 'education,' 'information' and 'advice.'

While both patient- and person-centred approaches place the individual, and often families and care-givers, at the centre of healthcare decisions, person-centred care considers the needs and desires of individuals beyond their 'patient' role. A further semantic challenge is the traditional language of 'education' and 'advice,' implying that self- foot care is a recommendation or choice rather than an agreed course of action. Self- foot inspection should be prescribed not advised. By handing a person with diabetes a written information leaflet, even with verbal reinforcement, this does not constitute an agreement between parties to actually undertake foot inspection or to contact relevant Health Care Professionals (HCPs) in the event of signs or symptoms consistent with diabetes foot disease.

Reliance on terms like 'education,' 'information' and 'advice' further betray a focus on functional health literacy skills, or *knowledge*, over the interactive and critical skills essential for *action*. This review seeks to explore the concept of diabetes foot education and advice further, proposing future person-centred approaches that address, not only education, but also support people with diabetes to develop the skills and abilities necessary for daily self-management. These skills and abilities primarily concern either self- or assisted-foot inspection and prompt referral to specialist services in the event of signs of diabetes foot disease.

2. Diabetes self-management education and support:

While diabetes self-management education (DSME) and diabetes self-management support (DSMS) programmes have historically been defined as separate entities [5], recently Beck and colleagues [6], p. 301, proposed a combined definition for diabetes self-management education and support (DSMES) as *"the ongoing process of facilitating the knowledge, skills, and ability necessary for diabetes self-care, as well as activities that assist a person in implementing and sustaining the behaviours needed to manage his or her condition on an ongoing basis, beyond or outside of formal self-management training."*

Previous DSMES programmes have demonstrated enhanced coping [7], empowerment and self-efficacy [8], improved quality of life (QoL) [9-13] and reduced rates of depression [14,15] and diabetes-related distress [16,17] among individuals with type 2 diabetes (T2DM). Improved adherence to diet and physical activity targets [18] and a reduction in glycosylated haemoglobin (A1C) [9,16,19-25] may also limit the onset and severity of diabetes complications [26,27] for individuals receiving DSMES.

2.1. Health literacy:

This combined DSMES concept bears striking similarities to Professor Don Nutbeam's [28] multidimensional health literacy framework, describing a continuum of progressively more challenging functional, interactive and critical health literacy skills (**Table 1**). Health literacy has been positively associated with treatment adherence, particularly non-medication adherence [29]. Understanding the signs of diabetes foot disease requires functional health literacy skills, or the ability to *"apply literacy skills to health-related materials"* [30], p. 537. In their 2015 survey, Rowlands and colleagues [31] reported 43% of 5 795 English adults studied possessed insufficient literacy skills while 61% of 4 767 English adults had insufficient numeracy skills to routinely understand health information.

While evidence is currently lacking for specific educational approaches in primary DFU prevention, a joint negotiated consultation style and family and social networks play key supportive roles in health information seeking behaviours [32]. Without first ensuring understanding, efforts to promote active engagement with personalised care planning, including mutually-agreed goal setting, are perhaps destined to fail [33]. Checking feet daily, however, demands more than just an understanding of the principles of foot inspection. Knowledge of foot inspection practices is, undoubtedly, the first step towards behavioural change but not the only relevant factor.

To undertake the daily task of self-foot inspection and timely communication of abnormal findings with family members, carers or HCPs requires interactive health literacy skills, *"needed to extract and understand information from various sources,"* and critical health literacy skills, allowing individuals to *"critically assess information and apply it to make health-related decisions"* [34], p. 3. Crucially, assistance may be required from a partner, friend, family member, carer or HCP to support daily foot inspection, communicate with specialist services and attend podiatry and associated appointments.

2.2. Diabetes foot self-management education and support:

Traditional diabetes foot education initiatives are weighted towards informing people with diabetes of the signs and symptoms of diabetes foot disease. Clinical signs and symptoms are usually presented within the context of new ulceration or infection but may also be appropriate for early signs of Charcot neuroarthropathy (CN). Imparting *knowledge* is only part of the story, however. Timely specialist management, associated with improved clinical outcomes for both diabetic foot ulceration (DFU) [2] and CN [1], is more reliant on the *actions* of individuals in recognising relevant 'danger signs.'

In isolation, DSME strategies have not robustly demonstrated lasting improvements in diabetes foot knowledge or self-management behaviours or a reduction in DFU or lower extremity amputation (LEA) rates [35]. Complex interventions have similarly failed to demonstrate effectiveness [36]. In

their 2013 review of diabetes self-care behaviours, Shrivastava and colleagues [37], p. 3. recommended HCPs *"begin by taking time to evaluate their patients' perceptions and make realistic and specific recommendations for self-care activities."*

Diabetes foot education initiatives have historically prioritised education (DSME) over support (DSMS). To illustrate this concept, diabetes educators involved in the education and management of individuals with diabetes routinely dispense advice concerning daily self- foot inspection and assessment. We routinely screen for the ability to self-care with or without assistance but do we truly consider individual preferences in how daily foot inspection will be achieved? For those with unhindered mobility and adequate eyesight, routine foot inspection may be readily incorporated into daily diabetes self-care. For individuals with limited mobility, retinopathy or other causes of visual impairment, daily foot inspection may prove more challenging, however. These individuals typically require additional support from a partner, friend, family member, carer or HCP.

Failure to effectively self-monitor may lead to more complex diabetes foot disease, unrecognised progressive infection and may ultimately precipitate LEA. At each step of this cycle, it is the patient, family member or carer who is most likely to recognise 'danger signs' first, being responsible for 98.8% of daily foot assessments for a typical 'High-risk' individual (**Table 2**). This assertion is supported by the work of Baba and colleagues [38] who found 68% of diabetes foot issues were self-identified by people with diabetes compared with only 9% for HCPs and Jordan and Jordan's assertion [39] that 98% of diabetes management concerns self-care.

Effective DSMES approaches may improve self-recognition and self-referral by providing supportive education sensitive to individual's *"health beliefs, cultural needs, current knowledge, physical limitations, emotional concerns, family support, financial status, medical history, health literacy, numeracy, and other factors that influence each person's ability to meet the challenges of self-management"* [40], p. 1372. Diabetes Educators must move away from simply focussing on 'education' and 'advice' to supporting individuals to achieve effective self-management.

2.3. The person-centred diabetes foot behavioural agreement:

Behavioural agreements have been explored as a means of promoting treatment adherence within a range of health contexts, primarily addiction, hypertension and weight management, however evidence of effectiveness remains limited [41]. Litzelman and colleagues [42] incorporated behavioural agreements into their study of 352 people with T2DM, receiving a 12-month complex diabetes foot education intervention. Behavioural agreements specified desired self-foot care behaviours and were reinforced verbally over the telephone and in writing with postcard reminders. Individuals receiving this complex intervention were significantly more likely to self-report protective self-care behaviours and presented with less severe foot disease.

While not providing definitive evidence of efficacy, this study suggests positive effects may be achieved, in terms of self-foot care and outcomes, with regularly reinforced diabetes foot behavioural agreements. Several authors have recently championed behavioural agreements for individuals 'At-risk' of diabetes foot disease [43] or with chronic DFUs [44], particularly among those with a history of non-adherence or suspected comprehension difficulties. Crucially, potential benefits associated with such agreements do not rely on fear of punitive repercussions in the event of non-adherence, such as discharge from a service.

Furthermore, diabetes foot behavioural agreements do not necessarily need to be in writing, though this may be preferable. While a verbal or non-verbal, i.e. handshake, agreement may be preferred by some, particularly individuals with lower literacy skills, written information may help reinforce the precise signs each individual, or their carer, should look for and detail relevant contact information. An example 'At-risk' person-centred diabetes foot behavioural agreement is included as **Table 3**.

3. Practice implications:

As educators, we have a duty to ensure we adequately consider the support structures available to people in our care. Critically, those unable to effectively self-care, should have adequate social care and support in place to assist daily foot inspection. Routine foot inspection is an important first step,

however, we must also support individuals and their carers to identify 'danger signs' early and know who to contact if they discover a problem. We must be mindful of individual's health literacy skills, understanding and abilities, checking comprehension through tools like the 'Teach-back' technique, as necessary [45].

The online *Foot Risk Awareness and Management Education (FRAME)* resource [46] references learning difficulties, visual impairment and arthritis as barriers to personal hygiene and foot inspection practices, however, obesity is likely to play a greater role in future. To illustrate this point, consider the daily, sometimes twice daily, application of emollient advised for individuals 'At-risk' of diabetes foot disease. While emollient application may provide an ideal opportunity for self-foot inspection [47], this practice may be difficult for individuals with limited mobility or flexibility.

Applying emollient to the dorsum of the foot may allow the person with limited mobility to moisturise their contralateral foot through rubbing the plantar surface over the dorsum. This activity does not, however, lead to inspection of the vulnerable sole of the foot. Assistance is, therefore, required in daily foot inspection to ensure any signs of foot disease are observed and then referred on appropriately. As the term 'self-foot inspection' implies, each person with diabetes is able to examine their own feet, perhaps the term 'supported foot inspection' may be more fitting, for many.

Several tools have recently been developed to assist in self-foot inspection practices, such as the *Solesee™ Diabetes Foot Inspection Mirror* [48], or early detection of localised erythema with *Siren Smart Diabetic Socks* [49]. Any device designed to support routine self-foot inspection or assessment has the potential to improve self-identification of the early signs of diabetes foot disease. Person-centred diabetes foot behavioural agreements represent another, potentially valuable, tool at our disposal and an example has been shared (**Table 3**) to support educators wishing to adopt this approach.

4. Conclusion:

Throughout this narrative review, person-centred diabetes foot behavioural agreements were discussed within the context of 'At-risk' DSMES. While further research is warranted, such agreements may potentially help individuals identify and understand their personal responsibilities and the necessity for structured support concerning daily foot inspection, timely identification of, and self-referral for, diabetes foot disease. Education and advice alone are unlikely to result in timely self-referral among this 'At-risk' population and, it is argued, skills and abilities must be further nurtured through structured, supported self-management strategies. People 'At-risk' of diabetes foot disease, inclusive of both DFUs and CN, may access medical, nursing, podiatry, orthotic and associated services regularly and receive routine diabetes foot screening, education and podiatric management. At each clinical consultation, every diabetes educator has an opportunity to reinforce the importance of daily self-inspection, with or without support, recognition of signs and symptoms of diabetes foot disease and how to contact local service in the event of foot problems.

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None

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Tables:

Table 1: Integrating health literacy and diabetes self-management education and support (DSMES) frameworks for diabetes foot self-management [5,6,28,40,50,51].

Health Literacy Level	*Educational Goal*	*DSMES Principal*	*Desired Outcome*
1 **Functional health literacy**	Communication of information	Facilitating knowledge of self-management behaviours and skills	Improved knowledge of diabetes foot risk, self- foot care practices and podiatry services
2 **Interactive health literacy**	Development of personal skills	Facilitating self-management skills and active collaboration with HCPs	Daily self- foot inspection and timely recognition and self-referral in the presence of signs and symptoms of diabetes foot disease
3 **Critical health literacy**	Personal and community empowerment	Empowering individuals to implement and sustain self-management behaviours	Improved capacity to continually monitor and critically assess foot status and contact podiatry services if required

Table 2: Example annual 'high-risk' diabetes foot management schedule.

Calendar weeks (/52):	**Foot check:** **Individual or caregiver (days)**	**Foot check:** **Podiatrist (days)**
01-12	83	1
13-24	83	1
25-36	83	1
37-48	83	1
49-52	28.7	0.3
Total days (%):		
365 (100%)	360.7 (98.8%)	4.3 (1.2%)

Table 3: Example 'At-risk' person-centred diabetes foot behavioural agreement.

Title: Our Diabetes Foot Care Agreement
Date: 19th October 2018
☐ Today we discussed the importance of applying foot cream and checking my feet daily for signs of foot injury or new redness, heat, pain, swelling, discharge or odour.
☐ If I am unable to see the soles of both feet, I will ask my nominated assistant for help.
☐ I have been assessed as being at 'High-risk' of foot ulcers or Charcot foot as I have lost feeling in my feet.
☐ We agreed that the NHS podiatry service will review my feet approximately every three months and my risk of diabetes foot disease with be reviewed each year.
☐ Should I discover a new foot problem, I will contact the NHS podiatry clinic as soon as possible on:
Name: _____
Nominated Assistant: _____
Podiatrist: _____