



REVIEW

Is There a Role for Informal Caregivers in the Management of Diabetic Foot Ulcers? A Narrative Review

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Received: July 17, 2019 / Published online: September 26, 2019
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ABSTRACT

Successful management of diabetic foot ulceration (DFU) is crucial for preventing long-term morbidity and lowering risk of amputations. This can be achieved with a multifaceted approach involving a multidisciplinary team, with the patient at the centre. However, not all healthcare setups enable this, and the rate of

lower limb amputations continues to rise. It is therefore time to consider new approaches to diabetic foot care, capitalising on engagement from patients in self-management while supported by their informal caregivers (ICGs) to help improve outcome. The role of ICGs in DFU care has the potential to make a significant difference in outcome, yet this resource remains, in most cases, underutilised. Limited research has been conducted in this area to reveal the true impact on patient outcomes and the caregivers themselves. This narrative review aims to explore how ICGs can benefit DFU management with applicability to different healthcare setups while benefiting from established experience in the care of other chronic health conditions.

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Keywords: Chronic diseases; Diabetes mellitus; Diabetic foot ulcer; Informal caregiver; Patient engagement

INTRODUCTION

Diabetes mellitus (DM) has become one of the leading non-communicable diseases worldwide, with 425 million affected in 2017, and is expected rise to 629 million by 2045 [1]. DM has a significant impact on the morbidity and mortality of patients and is the third highest risk factor for premature death [2], with the worst

effects observed in low income countries [1]. Diabetic foot ulcer (DFU) is one of the most common long-term complications of DM and is the leading cause of hospitalisation [3, 4]. The most important risk factors associated with DFU development are peripheral neuropathy and peripheral arterial disease [5]. Moreover, the screening tools used to diagnosis peripheral neuropathy are not sensitive enough, therefore it is expected that rates of peripheral neuropathy are underestimated. A recent large cohort study reported odds ratios for developing DFU at 42.5 with Charcot arthropathy, 12.1 with peripheral neuropathy, and 14.5 with peripheral arterial disease [6]. DFU leads to devastating effects on patient morbidity and mortality which can reach 55% over a 5-year period, an outlook worse than that of some of the commonest cancers [7]. People with DM have a lifetime risk of developing DFU of between 12% and 25% [8–10], and despite well-established evidence-based treatments only 60% of DFUs heal within the first 6 months [11]. DFUs are also the leading cause for non-traumatic lower limb amputations [3], and despite national and international guidelines, amputation incidences continue to rise with an estimated rate of 135 per week in England [12]. Progression to lower limb amputation is more common in DFUs of longer duration [13]. Moreover, post-amputation mortality rates are very poor, with one case series reporting only 50% of patients surviving the first year [14] and a hazard ratio of lifetime mortality risk after lower extremity amputation of 3.0 (95% CI 2.9, 3.1) [15]. The financial burden on health services due to DFU is enormous, with an estimated direct expenditure of around £662 million on DFU management in the UK alone [16]. Moreover, the overall cost is far more than this when loss of productivity, family added costs, and deterioration in quality of life (QoL) are factored in [16].

The aim of this article is to explore the role of informal caregivers (ICGs) in the care of people with DFU. Relevant literature is reviewed and, when relevant, examples of ICG input in other conditions will be included. No human or animal subjects were directly studied in this article. This article is based on previously conducted

studies and does not contain any studies with human participants or animals performed by any of the authors.

INFORMAL CAREGIVER

As healthcare standards improve, more individuals are living with chronic illnesses and approximately one in ten adults are involved in informal care [17]. ICGs are individuals who have a social relationship (i.e. spouse, parent, child, other relatives, neighbour, friend or other non-kin) with the person cared for (older or dependent individuals) and provide unpaid care continuously or when required [18]. ICGs are sometimes referred to as “family caregivers” [19] or simply “caregivers” [20]. They are in most cases not formally trained in healthcare and they are driven by social or moral values and obligations. ICGs are recognized as an integral part of the care team in many conditions such as dementia [21], stroke [22], frailty in old age [23], or palliative care [24]. ICGs are present in all societies and ethnicities, although some variations in prevalence of ICGs [20] and utilisation of healthcare services [25] have been reported between different ICG ethnicities. The true value of informal caregiving is significant. In the USA it was estimated that the value of ICG input for elderly people with DM alone was 3–6 billion US dollars per year [26].

PATIENT ENGAGEMENT

Successful management of DFU is multifaceted and relies on a patient’s understanding and engagement with management plans. The management of DFU not only aims to heal the ulcer but also to address the factors causing the ulceration and therefore prevent further ulceration. DFU management requires optimizing diabetes control, regular attendance at podiatry clinics for specialist interventions including sharp debridement of unhealthy tissue, offloading strategies and wound dressings in addition to antibiotic cover and/or revascularization procedures if indicated [27]. Often management of DFU requires hospital

admission for intravenous antibiotic and surgical procedures. Patients are usually given complex advice for DFU management involving reduced weight-bearing and changes to personal hygiene routines. This management approach requires rest and often leads to regular absences from work and therefore reduced productivity. Adherence to such an approach can be difficult in those who are the breadwinners in their families. Consequently, patients can burden themselves with the added pressure of minimising work absences, which prolongs the DFU and ultimately increases morbidity and healthcare costs. Peripheral diabetic neuropathy can be seen in 50% of patients within 25 years of initial diagnosis with DM and the accompanying sensory loss [28] can in some patients undermine their perception of the severity of the condition and lead to varying degrees of ambivalence. Strict offloading regimes are crucial for wound healing and recovery but lead to considerable reduction in mobility, thereby impacting on patient's physical activity and daily living which in turn affect the patient's adherence. Moreover, lack of motivation, low mood, and long-term non-compliance with medical advice contribute to non-adherence and poor outcomes [29, 30]. As such, outcomes are very much affected by patients' ongoing engagement with foot care and their abilities to manage the multiple challenges they face in self-management of DFU. This is usually complicated further by reduced standards of living and lower psychological states in patients with DFU, especially when this leads to amputation [31]. It is therefore essential to engage patients and their families in any management plan. They should be included as active members of the care circuit and collaborative partners with the healthcare team [32]. Patient engagement entails involvement of individuals or others elected to engage on their behalf, in their care, with the aim that they make competent, informed choices about the individual's health and take action to support care plans set by healthcare professionals (HCPs) [32]. However, several factors can influence patient engagement in their own care including patient beliefs, level of education, health literacy, communication difficulties, cultural influences,

society and social norms, and the healthcare system setup spanning organizational policies, practices and regulations [33].

A fundamental component of patient engagement is education. The need for patient education in successful prevention as well as management of DFU is well recognised [34]. Patient education should be part of every stage of the treatment pathway [35], with evidence demonstrating reduction in lower limb amputations by as much as 49–85% through early detection and treatment of minor foot injuries [34]. However, two Cochrane systematic reviews assessing evidence from multiple randomized controlled trials (RCTs) have shown there is insufficient robust evidence regarding the impact of patient education alone [36] or as part of complex interventions [37] to effectively achieve consistent reduction in the incidence of DFU or lower limb amputation. This clearly does not devalue the importance of patient education and involvement in their own care but serves to highlight the need for further additions to the diabetic foot care pathways in order to bridge current gaps in care. One different approach to the self-management aspect of DFU care pathway is involving the wider patient support circle including ICGs.

Jeffcoate et al. recommend ICGs be included in the development of DFU management plans [11]. Although ICGs could offer a high level of support to patients with DFUs, there is a dearth of published evidence regarding the utilisation and impact of such care resources. A systematic review on wound care that explored literature between 1995 and 2013 revealed that only 1% of papers mentioned ICGs as a member of the wound care team, while 7% mentioned administrative staff [38]. One report found that 11% of ICGs played an active role in DFU management and recommended education programs for patients and their ICGs [39].

Schumacher et al. described the essential skills caregivers require to successfully support and care for the care receivers. These included, but are not limited to, language support such as interpreting, adjusting care provisions to the changing needs of the patient, assisting in decision-making or making decisions on behalf of the person cared for, accessing resources

related to the patient's condition and care plan, working with the patient and assisting them in achieving care targets even when this requires negotiating, monitoring and assisting with decision-making, in addition to providing comfort and hands-on care [40]. It is interesting to note that these qualities are essential components in DFU management.

NEGOTIATION AND MONITORING

Patients with an active DFU are less mobile and are usually advised to minimise weight bearing or to wear specific offloading footwear. Studies have shown patients wear offloading footwear for only 28% of the advised time [41]. ICGs can, and often do, play an active role in negotiating and monitoring patient self-management. A large body of evidence supports the positive influence ICGs play in patients' general diabetes self-management, with improved diabetes control and adherence to treatment advice [42–45]. It is therefore logical for HCPs to engage with caregivers to support the use of restrictive offloading devices when indicated to help improve outcome. However, we have been unable to find relevant studies on this critical topic. Painful diabetic neuropathy (PDN) affects between 10% and 20% of people with DM [28]. Inadequately managed PDN can lead to psychological stress and low mood while overtreatment can lead to drowsiness and risk of falls, which could be compounded by protective offloading footwear. ICGs can play a useful role in emotional, psychological and physical support in addition to helping in the assessment of adequacy of pain relief and potential side effects.

HANDS-ON CARE, DECISION-MAKING AND ADJUSTING TO PATIENTS' CHANGING NEEDS

Infected DFU can deteriorate rapidly with infection ascending the leg and escalating to a limb- or life-threatening sepsis [46]. ICGs are often the first persons to notice early deterioration in existing health problems or emergence

of new health issues, and in those cases they play a crucial part in accessing urgent medical care for the patient [47]. In taking such decisions, ICGs have an important role in patient's changing health needs. In a representative national survey, commissioned by the American Association of Retired People (AARP) Public Policy Institute and the National Hospital Fund, covering more than 1500 families with caregivers, approximately 35% of ICGs reported providing wound care [48]. However, fear of making mistakes was stated by 66% of caregivers and 38% expressed need for training. It is not a surprise, therefore, that 33% of ICGs find the task of wound redressing emotionally challenging [49]. Spouse caregivers are particularly vulnerable, often because of older age, low education, lower income, and social isolation [48]. Access to systematic and easy-to-follow training is therefore crucial for the wellbeing of the ICGs and the effectiveness of their care [50].

COMFORTING AND EMOTIONAL SUPPORT ROLES

DFUs and lower limb amputation have a significant impact on patients' QoL and strong association with depression [51]. Upton and South reported that patients with chronic wounds, including DFUs, have more mental health problems than patients without wounds, including increased stress, worry and depression in addition to increased feelings of isolation and debilitation [52]. Emotional support and understanding provided by ICGs have been shown to be associated with greater levels of life satisfaction in patients who have undergone lower limb amputation, while conflict with the ICG was associated with lower levels of life satisfaction [53]. Beattie et al. conducted a qualitative study on people with previous history of DFUs who were ulcer-free at the time of the study. It was evident that a history of DFU left patients with an emotional burden and sense of hopelessness. Moreover, patients did not always feel comfortable discussing this aspect of their life with friends, family members or co-workers [54]. When family and spousal indifference existed, patients with DFUs had a

much higher chance of a diagnosis of depression or severe depressive disorders [55]. This highlights the delicate emotional state of people with current or history of DFU, which if handled well by their family and caregivers can have a positive impact on their QoL and wellbeing, and negative impact otherwise.

ACCESSING CARE AND SUPPORTIVE INFORMATION

The contributions of ICGs to medical appointments are significant. Approximately 48% of patients with a chronic illness attend their medical appointments accompanied by an ICGs [56]. In these circumstances, ICGs can be an essential source of information gathering and sharing [57]. It has also been established that individuals with low health literacy were influenced by their support networks [58]. While health literacy refers to the individual's ability to obtain, process and understand necessary health information and services required to make appropriate health decisions [59], patients' misunderstanding of such crucial health information compounded by low rates of compliance with physician recommendations [60] can significantly effect outcome. In such circumstances family and ICGs can be the most important sources of knowledge to healthcare professionals as well as to the patient [57, 61].

CHALLENGES ICGS FACE

Despite the important roles ICGs play in the care and support of patients with chronic conditions including DFUs, ICGs often feel that they are not prepared for the care they provide and often receive little or no support which reflects on their confidence in providing good care [19]. In the AARP public policy survey 40% of ICGs reported that they had not received verbal or written information about the medical conditions or its management by healthcare professionals [39]. Moreover, ICGs appear to be at higher risk of mental illness and financial difficulties [62], in addition to being at higher risk of developing type 2 DM when they have

low social support at work [63]. ICGs are devoted individuals and demonstrate eagerness to get more information about the conditions they care for, which was expressed by 57% of spouses surveyed. Moreover, 41% indicated that they would take part in educational programs if offered to them [64]. Although evidence was not robust, the findings of the systematic review by Aksoydan et al. were rational and concluded that supportive interventions to ICGs can result in stress reduction and thus lead to improvement in quality of care for the person cared for [65].

RECOMMENDATIONS AND CONCLUSIONS

Despite the growing evidence regarding the difference ICGs can make to care outcomes and alleviation of struggle in patients with chronic health conditions, the role of ICGs in the management of diabetic foot complications in general, and DFU specifically, remains largely unexplored. The role of ICGs in the care of people with DFU is relevant to all healthcare settings, with higher expected impact in healthcare systems with limited resources and reach and in societies with a strong tradition of family support. Further research is needed to help better understand the optimal approach to the effective utilisation of this untapped resource. ICGs should be integrated in the DFU care pathway with early identification and involvement while preserving patient autonomy. It is important to understand patients' perceptions about, and expectations from, ICGs and their putative role in their care, in addition to the effect of the perceived powershift that may come with such an approach. Moreover, the abilities and capacities as well as the needs of different ICG groups should be studied and understood so that these can be honed to best fit into the DFU care pathway. An accurate estimate of the true cost of ICGs needs to be evaluated including the caregiver's loss of productivity and impact on their own livelihood. Provisions for appropriate training should be made available for patients and their ICGs; this training should be based on international DFU

standards with assessment of the effectiveness of ICG involvement on clinical outcomes and QoL. ICGs can bring valuable addition to the DFU care pathway and care of patients with diabetes in general and this deserves recognition from governments, health authorities and society at large.

Given the unhindered epidemic increase in incidence of DM worldwide it is expected that the burden of DFUs will also increase worldwide over the coming years and decades, as will the rate of lower limb amputations. Without mobilising all available resources in the struggles against DM and its related complications the impact of this on healthcare systems and society will be colossal. With the increasing number of ICGs stepping into support patients, it is high time to study their role in DFU management and how best to utilise their efforts, support their needs, and show them the recognition they deserve.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the support received from Dr. Ebaa Al Ozairi, Chief Medical Officer and The Kuwait Foundation for the Advancement of Science (KFAS). They would also like to thank all the staff from Clinical Services at Dasman Diabetes Institute.

Funding. No funding or sponsorship was received for this article. The Rapid Service Fee was funded by Dasman Diabetes Institute.

Authorship. All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published.

Authorship Contributions. GM, NT and AA were responsible for developing the theoretical concept, writing and editing the manuscript. SS and AH were responsible for reviewing and editing the manuscript.

Disclosures. Grace Messenger, Nehad Taha, Sabina Sabau, Asma AlHubail and Ali M. Aldibbiat have nothing to disclose.

Compliance with Ethics Guidelines. This article is based on previously conducted studies and does not contain any studies with human participants or animals performed by any of the authors.

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