Evolution of the diabetes caregiver: tying together limb salvage and patient education

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Practice points

- The prevalence of diabetes, diabetic foot complications and subsequent limb loss continue to be an escalating problem throughout the developed world.
- Diabetic foot complications are still the leading cause of diabetes-related hospitalizations in the USA today.
- Diabetic patients often feel helpless in the face of this illness, especially if they are uneducated about the disease.
- The ‘diabetes caregiver’ can be any one of the following: podiatric surgeon, vascular surgeon, interist, endocrinologist, plastic surgeon, physical therapist, and so on. Anyone involved as part of a multidisciplinary team in the treatment of diabetes will take on this evolving role.
- If the patient were to be treated as an equal by their diabetes caregiver and educated on both the nature and treatment of peripheral neuropathic complications, many of these complications might be averted.
- Although there is currently little objective evidence directly correlating patient education to amputation prevention, the potential link cannot be underemphasized, particularly when loss of limb and/or loss of life are involved.
- In the arena of diabetic limb salvage, it is essential to empower the diabetic patient early on and to understand one’s own role as not only a specialist, but as more importantly an evolving diabetes caregiver.

SUMMARY: The prevalence of diabetes along with its associated foot complications is an increasing dilemma throughout the developed world. Over the past two decades, a new breed of healthcare providers has evolved with a focus on treating these diabetic patients, specifically in the arenas of wound care and limb salvage. Notably, diabetic patients themselves are becoming more involved to take on a larger role in the self-management of this disease. As such, we take a closer look at the ‘diabetes caregiver’ as part of a multidisciplinary team and highlight the importance of educating and empowering our patients to help establish a new standard for providing top-tiered diabetic foot care and amputation prevention.

Almost 25 years ago, representatives of both government health departments and patient organizations from all over Europe met with diabetes experts in Italy to establish what is now known as the Saint Vincent Declaration. This declaration called for a 50% reduction of lower limb amputations as a principal target for patients with diabetes throughout Europe. Two general...
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goals for people with diabetes were presented: sustained improvement in health experience and a life approaching normal expectation in quality and quantity; and prevention and cure of diabetes and of its complications by intensifying research effort [1]. Today, it is estimated that every 30 s a limb is lost to diabetes somewhere in the world [2]. The USA alone houses approximately 26 million patients living with diabetes — a number predicted to triple in the coming years. Clearly, the worldwide situation is still far from reaching target; and yet, the goals set forth by the Saint Vincent Declaration still ring as true today as they did over two decades ago. A plethora of research has been devoted to understanding diabetes as a disease and, specifically, how it affects the foot [3]. The pathological trifecta of neuropathy, ischemia and infection has long been established as a catalyst of diabetic foot complications. Organizations such as the Infectious Diseases Society of America (IDSA) and the International Working Group on the Diabetic Foot (IWGDF) have provided treatment protocols and guidelines specific to the diabetic foot [4]. Healthcare providers today are well equipped to understand and treat diabetic foot infections [3]. Research efforts and the implementation of evidence-based medicine are seemingly at an all-time high. Despite this, the prevalence of diabetes, diabetic foot complications and subsequent limb loss continue to be an escalating problem throughout the developed world. Diabetic foot complications are still the leading cause of diabetes-related hospitalizations in the USA today. Hospitals and medical centers are forced to carry this heavy burden. Above all, it is the patient who suffers the most, feeling helpless in the face of his or her own illness. As such, we as diabetes caregivers must embrace a practical approach to limb salvage by focusing on the vital role of diabetes education via a team-based effort, with the patient being placed front and center.

Once a month, there is a meeting of the Amputee Support Group at MedStar Georgetown University Hospital’s Center for Wound Healing in Washington (DC). These meetings bring together members of the DC metropolitan community, as well as patients of the clinic, who have had prior lower limb amputations. Physicians attending these meetings will experience a sense of pride at how positive patients seem to remain despite having undergone such life-altering surgeries. However, while there are plenty of inspiring survival stories filled with ‘battle scars’, ‘newfound spirituality’ and ‘kitchen makeovers’, every now and then a newcomer patient will break the glass with a simple yet profoundly disturbing statement: “I wish I had known”. Known that bread is actually a type of sugar. Known that the tingling in her toes was a sign. Known that the blood on her sock was not just a fluke. Known that she was buying the wrong size shoes. Known that her skin would no longer heal the way it used to. Known that yes, there was a direct correlation between her high blood sugar and that sore on her heel. Known that she should have seen her doctor sooner. Known that she was not alone.

When patients hear the term, ‘the diabetic foot’, several frightening images often come to mind. What patients fail to initially understand is that problems associated with the diabetic foot are multifaceted. There is rarely a simple explanation or solution, and there are plenty of myths and misgivings about diabetic foot management. To improve standards of diabetic care and outcomes of limb salvage, patients must become more actively involved in their disease management. Most patients will rely on their primary care physician as the hub of information. However, in the world of healthcare, we as providers tend to develop tunnel vision. We become focused on our respective fields and slowly develop a daily routine. We may refer our patients to other specialized caregivers when necessary, but even we may be confused as to whom the appropriate specialists are. General surgeons may send a patient with a foot ulcer to the podiatric surgeon. The podiatric surgeon in turn may recognize ischemia and refer the patient to a vascular surgeon. In the absence of confirmed vasculopathy, the vascular surgeon may have little to offer the patient. On top of everything, the endocrinologist has lost said patient to follow-up. A lack of a unified multidisciplinary team not only confuses caregivers, but also sends mixed and confusing signals to the patient. It is imperative to win and maintain a patient’s confidence from the start to ensure appropriate care. Too often there is a lack of follow-up and too many patients end up falling through the cracks. Medical schooling and training has taught us that diabetes does not discriminate. Therefore, we as diabetes caregivers should not discriminate in turn. We have a responsibility both towards ourselves and towards our patients to become active educators on a multidisciplinary team.

The need to share the burden of caring for the
diabetic foot has been well discussed, but too few studies expound upon the role of the patient in the caregiver team [7]. A 2006 editorial in the Calicut Medical Journal from Hyderabad (India) accurately paints diabetic patients as “victims of a number of problems specific to their disease that result in augmented amputation rates from the complications of neuropathy and infection” [6]. The author appropriately urges for more forceful implementation of novel therapeutic strategies, wider availability of multidisciplinary foot care teams, and improved scientific research to reduce the burden of diabetic foot complications. But the real weight of the diabetic foot burden falls on the patients, and they rarely have a do-it-yourself guide to diabetes management. Even with the help of a diabetes educator, patients frequently become overwhelmed. How can these patients transition from the role of victim to that of savior? Why is it viewed as acceptable for patients to become casualties of their own illnesses? This is where the essential connection between diabetes education and limb salvage comes into play. For example, a patient presents to an endocrinologist complaining of numbness in the toes. If this patient were to be treated as an equal by their diabetes caregiver (in this case, the endocrinologist) and educated on both the nature and treatment of peripheral neuropathic complications, many of these complications might be averted. Although there is no objective evidence to date directly correlating patient education with amputation prevention, the early empowerment of the patient cannot be underestimated. Similarly, an educated podiatric surgeon can teach his or her patient about the detrimental effect that increased abdominal fat has on trying to reduce blood glucose levels. A plastic surgeon can reinforce the importance of wearing appropriate shoe gear. Gone are the days of worrying about ‘turf wars’ – instead, we should gladly adopt the role of the diabetes caregiver and use our respective specialties as only parts of the treatment toolbox for limb salvage.

In response to the realization that multidisciplinary efforts are the future of diabetes care, we are thankfully seeing across the globe a rise in the number of ‘amputation prevention centers’. A recent study out of Dublin (Ireland) aimed to quantify the cost–benefit and sustainability of a multidisciplinary foot protection clinic (MDFPC) [5]. The team of caregivers at the Adelaide and Meath Hospital (Dublin, Ireland) MDFPC included specialists in the areas of vascular surgery, endocrinology, podiatry, orthopedics, and orthotics and tissue viability. Between 2006 and 2010, a total of 221 lower limb procedures were performed. These included both major and minor debridements and amputations. The number of major amputations decreased from 12 during the control period to seven in the study period (after establishment of the specialty clinic). The study found an overall savings of €114,063 per year associated with the introduction of the MDFPC. Authors concluded that an aggressive, coordinated approach to diabetic foot care is both cost effective and clinically efficient in reducing the burden of foot-related complications in the diabetic population. Although this is a small single-center study, it is a practical quality assessment on the part of the authors. Such multidisciplinary efforts are crucial to improving the standards and outcomes of diabetes care. Although a daunting task, perhaps future studies will further incorporate the role of the patient and find ways to objectively measure quality of life.

In light of the increasing prevalence of diabetes globally, some may argue that the rise in the number of amputation-prevention centers has yet to drastically alter the frequency of amputations in the diabetic foot. A study out of Ankara (Turkey) in 2004 presented an interesting response to such an argument [8]. The authors had previously reported the lower extremity amputation rate and significant risk factors for patients admitted to Hacettepe University Hospital between 1992 and 1996. In January 2000, a diabetic foot care team consisting of an infectious disease specialist, orthopedic surgeons, endocrinologists, plastic surgeon, radiologist and a diabetic foot nurse was assembled. To determine whether a change had occurred in the rate and risk factors of lower extremity amputations after the establishment of this team, medical records of 66 diabetic foot patients admitted to the hospital between 2000 and 2002 were retrospectively analyzed. Although the overall amputation rate increased from 36.7 to 39.4%, data on the specific type of amputation (e.g., partial ray vs below-knee) suggested that the amputation profile had changed. The authors stated that the implementation of a diabetic foot care team had “relatively decreased the rate of major amputations in an attempt for limb salvage to improve the quality of life of the patients.” As previously mentioned, it is certainly difficult to objectively measure quality of life. For example,
several prosthetists will argue that a below-knee amputation actually affords a higher quality of life for the patient compared with a partial ray amputation. Again, patient education and participation in such discussions is crucial.

There have been several studies demonstrating the high mortality rate of patients following a lower limb amputation. In fact, many patients view amputation as a complete failure of management as opposed to a treatment option. It is difficult for them to see how the act of choosing to amputate a limb could in any way be considered a life-saving procedure. Many surgeons treating diabetic foot infections encounter this difficult patient conversation all too often. What we commonly fail to master is how to educate a patient based on his or her own specific situation. This is an example of poorly translating knowledge derived from clinical research into our routine clinical practices. Rather than grouping all patients who have had an amputation into a single population, it is essential to examine which clinical factors can predict decreased post-amputation morbidity and mortality. A 2005 study out of Greenville Hospital System in South Carolina demonstrated the significant effects of age and preoperative function on postoperative outcome in 553 patients [9]. Patients older than 70 years of age had triple the mortality of those younger than 50 years, and those who were not mobile preoperatively were at twice the risk of death postoperatively. It should be noted that not all of these patients were diabetic; however, the authors saw no difference in the diabetic versus nondiabetic patients. Although expounding upon such topics may seem uncomfortably macabre, this is the only way to educate patients and force them to take the reins.

Rarely can a patient find a single provider capable of managing all aspects of care for the complicated diabetic foot. Each healthcare provider involved in the treatment of diabetes must play his or her role in patient education and limb salvage. Although this may at times seem overwhelming, particularly in the face of the staggering statistics associated with diabetes, steps are constantly being taken to improve the current situation. A 2010 multidisciplinary study in the USA focused specifically on a conjoined model involving podiatric medicine and vascular surgery, as well as three separate programmatic models of diabetic foot care that could be implemented both in the developed and developing worlds [10]. The authors advocated a team of dedicated specialists to prevent lower extremity amputation in diabetic patients. Ideally, such a team would consist principally of podiatric physicians and vascular surgeons (the ‘Toe and Flow’ model). Additional members would be an infectious disease specialist, orthopedic surgeon, plastic surgeon, diabetologist, general surgeon, pedorthist/prosthetist and other invaluable nonphysician team members such as a certified wound and ostomy nurse, diabetes specialty/registered nurse, licensed practical nurse, medical assistant, diabetes educator, nutritionist and physical/occupational therapist. We would also argue the addition of a psychiatry/mental health specialist and spiritual guidance counselor as needed. The study also presents three modeled tiers of care based on specific conditions in a community or region: basic, intermediate and center-of-excellence. The goal of the basic model is to provide a local community with preventative and basic curative diabetic foot care, usually with a general practitioner or podiatric surgeon at the core. An intermediate model of care is usually hospital based and thus may be equipped to deliver more advanced assessment and diagnosis than the basic model. More clinicians would be involved at this level. Last, the center-of-excellence model is usually based out of a large teaching hospital, maintains an extensive and active multidisciplinary team, and oftentimes serves as a model to teach and disseminate information regionally, nationally and/or internationally. Large research studies are also usually carried out at the center-of-excellence models. Wherever a patient may be, access to one of the aforementioned models is key to ensuring adequate quality care.

**Conclusion & future perspective**

For the patient with a diabetic foot ulcer, the difference between being treated with simple wound care versus radical amputative surgery oftentimes solely boils down to his or her own education and involvement along the path of treatment. Even the most significant advances in medical technology cannot replace an informed and enthusiastic practitioner in the world of limb salvage. In the years to come, the field of diabetes care will ideally evolve exponentially and new cutting-edge treatment options will become available. We may someday be able to predict an amputation before even clinically diagnosing an underlying etiology. Regardless,
the current state of affairs has taught us that despite our best efforts, we are far from achieving the aforementioned goals. As we progress in our understanding of diabetes as a multifaceted disease, learn to shift focus to educating and empowering the patient, and solidify the importance of a multidisciplinary team of diabetes caregivers, providing top-tiered diabetic foot care to our patients will inevitably become the new norm.

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