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Original Research

Application of the Five Stages of Grief to Diabetic Limb Loss and Amputation

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ABSTRACT

A potentially underappreciated member of the multidisciplinary approach to diabetic limb salvage is that of psychiatry. Diabetic patients are more likely to experience depression, and diabetic patients with depression are more likely to undergo an amputation. Also, both diabetes and depression independently increase the healthcare costs in the United States. The objective of the present investigation was to increase knowledge among diabetic foot practitioners with respect to psychiatric and other mental health patient-care issues, specifically the potential application of the 5 stages of grief to diabetic limb loss and amputation. We enlisted the assistance of a clinical professor from the psychiatry department at our institution to review the 5 stages of grief, provide context specific for application to diabetic limb loss, and offer clinically relevant guidelines for surgeons to better understand and communicate with their patients at each stage. The 5 stages reviewed were denial, anger, bargaining, depression, and acceptance. We hope that the present review will increase the body of knowledge with respect to relevant psychiatric issues and the diabetic foot and provide a starting point for increased awareness with respect to this important, yet underappreciated, aspect of patient care.

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A multidisciplinary team approach to the diabetic foot has been widely recognized to lead to increased rates of wound healing, decreased major limb amputation levels, lower healthcare costs, and improved patient care (1-11). However, a potentially underappreciated component of this team is that of psychiatry. As an objective example, patients with type 2 diabetes mellitus worldwide have as much as a 30% greater risk of experiencing depression compared with those without diabetes, even without a specific history of the lifechanging events of diabetic foot disease and amputation (12-19). With the global prevalence of diabetes increasing, it has become important to understand the ramifications of both diabetes and depression as independently increasing healthcare costs (20). Additionally, the combination of these 2 diagnoses has been shown to lead to an increased risk of developing multiple diabetic comorbidities, including retinopathy, nephropathy, neuropathy, and amputation (13,15,16,21-28).

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Also suggesting the potential underappreciated mental health aspects of diabetic foot disease, similarities have been noted between the grief caused by the loss of a body part and the grief caused by the death of a spouse (29,30). Surviving spouses and amputees were found to have similar psychological reactions to their respective loss that were evident over the course of an entire year. Although it is socially acceptable to extend sympathy and patience to someone grieving the loss of a spouse, we might not have the same degree of empathy with our patients who have undergone amputation. As such, the widely accepted stages of the grief model used for death could have potential relevance within the treatment of lower extremity amputation (30–34). Dr. Elizabeth Kübler-Ross first described the stages of grief model in her classic text *On Death and Dying*, published in 1969 (35). These stages were (1) denial and isolation, (2) anger, (3) bargaining, (4) depression, and (5) acceptance (Table).

The objective of the present investigation was to increase the knowledge among medical professionals working with the diabetic foot with respect to the mental health patient-care issues, specifically, application of the 5 stages of grief to diabetic limb loss and amputation.

Materials and Methods

Because the initiating investigators of the present study were foot and ankle surgeons without specific mental health training, we enlisted the assistance of a clinical

TableSummary of the 5 stages of grief as related to diabetic limb loss

Stage of Grief	Clinical Definition	Tips for Surgeons to Recognize and Help Patients With This Stage
Denial	A conscious or unconscious decision to refuse to admit that something is true; in patients with diabetic foot disease, this could be the diagnosis of	Be as specific and explicit as possible with respect to the diagnosis and treatment recommendation
	diabetes, sequelae of the disease process, the severity of a clinical situation, or the need for a recommended intervention	Reinforce the diagnosis and treatment recommendation with second opinions and family meetings
	Several forms of denial exist, including denial of fact, impact, awareness,	Repeat the diagnosis and recommend treatment with each patient encounter
	cycle, and denial	Have the patient repeat back the diagnosis and treatment recommendation to you
Anger	An emotional or physical act in which the patient attempts to place blame Patients often report a lack of trust with their treating physician	Spend extra time with the patient in an attempt to identify a specific cause for the anger
	Physicians themselves could develop anger as a response	Repeatedly ask if the patient has any questions about their clinical situation, so they are as informed as possible throughout the process
		Be open and honest about the postoperative course and potential or likely long- term effects and complications
Bargaining	A negotiative process in which patients attempt to postpone or distance	Remain firm regarding the treatment recommendations
	themselves from the reality of a situation	Do not actively participate in turning your recommendation into a negotiation
Depression	A feeling of loss of control or hopelessness with a situation Diabetic patients are more likely to experience depression, and depressed	Increase the control the patient feels in their life with family meetings and amputation support groups
	diabetic patients are more likely to undergo amputation	Actively recognize depression in patients using screening tools and appropriate referrals to mental health professionals
Acceptance	A feeling of stability or resignation as the patient becomes an active participant in their life	The factors identified leading toward better adjustment to amputation include time, high levels of social support, prosthetic satisfaction, lower levels of stump or phantom pain, and an optimistic personality

professor from the psychiatry department at our institution to review the 5 stages of grief, provide context specific for application within diabetic limb loss, and offer clinically relevant recommendations for surgeons to better understand and communicate with their patients within each stage.

We also performed a basic published data review regarding patient responses to diabetes, depression, and limb loss. This information is likely relatively well known to practitioners within the mental health professions but not as familiar to foot and ankle surgeons. We performed a search of the PubMed database, without date restrictions, and included combinations of the search terms "diabetes," "diabetic," "grief," "denial," "anger," "bargaining," "depression," "acceptance," "mental health," "amputation," "limb loss," "wound," and "infection." The reports were considered relevant for inclusion within our review if they contributed to the subsequent discussion about patients' emotional responses to diabetes and limb loss. The corresponding author (A.J.M.) made the final decision with respect to inclusion.

From the onset, it is important to note that these stages should not be viewed as distinct, isolated, or independent events but, rather, as a spectrum with a degree of overlap as the patient progresses from the index diagnosis toward acceptance. For example, a patient does not have to have completely left the denial stage before developing signs of anger. A patient could also experience single or multiple feelings at any given time.

Results

Denial

"Denial" is refusing to admit that something is true (35). This can be a conscious or unconscious process and can actually reach levels of psychosis. For patients with diabetic foot disease, denial could come in the form of the diagnosis of diabetes itself, certain sequelae of the disease process, the severity of a specific clinical situation, or the need for a recommended intervention, among others. Although most physicians will likely recognize the concept of denial, they might not appreciate that it has several specific subsets (35). Thus, "denial of fact" is a denial of personal responsibility, such as refusing to believe a diagnosis or the severity of a clinical situation. "Denial of impact" is refusing to accept the consequences, such as a failure to modify one's diet and lifestyle or refusing to implement preventative or treatment strategies. "Denial of awareness" leads to patients who actively or passively avoid appropriate treatment. "Denial of cycle" occurs when patients resume harmful behaviors that will lead to predictable outcomes and subsequently fail to appreciate the consequences of their decisions and actions. Finally, "denial of denial" involves thoughts,

actions, and behaviors that untowardly give the patient confidence that nothing needs to be changed in their personal behavior and can be somewhat self-delusional.

Denial can be easy to recognize but difficult to treat with effective intervention. Strategies involve being as specific and explicit as possible with patients about their diagnosis and one's recommendation. If, for example, extensive osteomyelitis has been diagnosed and a partial foot amputation is recommended, but the patient could also consider long-term antibiotics, one should be clear as possible with respect to the diagnosis and recommendation. As an illustration, consider: "Mr. Feynman, your diagnosis is very easy. You have an infection of your foot that involves the bone. Not only has the bacteria spread to your bone, but it has also essentially killed a portion of your foot to the point that there is dead bone in your foot. Although we have powerful antibiotics that treat infection, they cannot bring dead bone back to life. My recommendation is that we remove any dead or dying tissue from your body by way of amputation to give the antibiotics the best chance at fighting the remaining infection and try to save what is still alive. I want to be clear that my recommendation is that you undergo an amputation of your toes. Although you might have other options, I am confident that this gives you the best chance of keeping the remainder of your foot and making a recovery from this serious infection."

Denial can also be combated by presenting the treatment recommendations using several different formats. This can most easily be accomplished in the form of second opinions and family meetings. Family meetings, in particular, can reinforce the diagnosis with the patient and can prevent them from bringing their denial into other areas of their life outside the healthcare system. Patients in denial might attempt to "wall off" potentially bad health news from their family members and their home life, essentially sheltering themselves with the diagnosis. Additionally, patients cannot always physically see what is happening with their feet, particularly on the plantar aspect. Thus, using a mirror during the patient encounter or showing any photographs of the affected tissue can help the patient understand the diagnosis. Finally, one can have the patient repeat the diagnosis using their own words and repeat it during each patient encounter. This will help ensure that the patient appropriately understands and is processing the information one is providing.

Anger

"Anger" can manifest itself emotionally or physically and is a stage likely to be outwardly recognized by physicians (35). Patients look to place blame and might direct this toward the doctor, the nursing staff, the hospital, previous treatment interventions, themselves, the disease process, family members, friends, social situations, and so forth. Those working with the diabetic foot should be mindful that they themselves could become unconsciously angry in response to this behavior, especially because it is likely to become increasingly difficult to effectively communicate with patients during this stage. Physicians and staff should attempt to be extra tolerant with patients during phase and should spend more time communicating with the patient to identify a specific cause for their anger. The identification of a specific cause, in contrast to general and nondirected anger, could lead to a quicker resolution.

Through cross-sectional patient-reported studies and logs, it has been observed that a number of amputees, whether minor or major, note a "lack of trust" associated with their physician postoperatively and a general feeling of having been provided with "misinformation" (32,36). This could be particularly true for patients undergoing amputation secondary to diabetic foot disease. A study has shown that patients who have undergone vascular-related amputations demonstrated more anger and hostility than did patients with trauma-related amputations (21,31).

One specific area in which foot and ankle surgeons might be able to improve their communication is with respect to the serial nature of the planned debridements and amputations and a realistic appreciation of the potential long-term complications and recurrence rates. In most situations, diabetic foot infections will be treated with planned serial debridement before definitive closure. Thus, one must be explicit with patients during the consent process if multiple procedures are likely to be performed. Also, an explanation of the rationale for the serial debridement procedures should be provided. Additionally, both minor and major limb amputations will rarely be "one and done" procedures, such as we sometimes intimate. How often have we all told a patient that an amputation is the "definitive procedure" and that a patient can simply have an amputation and "just be done with it"? However, recurrence and complication rates are high, and we should be honest with our patients and ourselves with respect to their risk of developing a new issue. Borkosky and Roukis (37) recently followed up patients who had successfully healed from a partial first ray resection. They found that within 2 years, 42% had required an additional amputation, 69% had developed subsequent lower extremity ulcerations, and more than 90% had been prescribed multiple antibiotic courses (37). Brown et al (38) studied the outcomes of nearly 300 below-the-knee amputations and found that 25% of the patients did not return to ambulation and 24% had undergone operative revision. None of these statistics seemed overly "definitive."

Interestingly, the anger stage has also been associated with relatively increased patient energy, which has the potential to be channeled into something productive, such as strength development with physical therapy and rehabilitation (31).

Bargaining

"Bargaining" represents an attempt by patients to postpone or distance themselves from the reality of a situation (35). This has typically been thought of as bargaining with a higher power, such as a religious figure. However, the treating physician could certainly qualify when amputation is imminent. It is important for physicians to be aware of this stage and to not participate in the bargaining process, because this will essentially enable the patient to avoid the important discussions and decisions that need to be made. Physicians

are encouraged to remain firm in their recommendations and to not turn the process into a negotiation. This has the potential to come in several forms with respect to the diabetic foot: "Can't we try antibiotics for a little longer?...", "Can't we try a lower level of amputation?...", "Can't we try just one more debridement?...", "Isn't there anything else we can try?...", and so on. It is our ethical duty as physicians to recognize when a limb cannot be saved and be aware of the potential emotional, physical, and financial burdens placed on patients by an unnecessary continuance of unsalvageable situations.

As an illustration, consider "Ms. Descartes, I am confident in my diagnosis and treatment recommendation. I know this is a lot to take in and that it is not good news, but I am convinced that this is the best thing for you in terms of your overall health. You certainly have some time to think about it and are free to seek other opinions, but my recommendation is not going to change and I am not willing to compromise your care."

Physicians should also be mindful of bargaining internally with themselves when treating the diabetic foot. If we are being honest with ourselves, we can likely all identify times when we have delayed the recommendation of a major amputation by attempting another futile intervention or performing a knowingly fruitless debridement. Diabetic foot surgeons with empathy might feel as though they are also "losing" the limb in a sense and negotiate with themselves accordingly.

Depression

"Depression" presents itself with feelings of hopelessness and a loss of control and is a major factor in diabetic foot disease (35). One study has identified that patients with the diagnosis of depression had a 33% increased incidence of a nontraumatic major amputation compared with patients without depression (21). Depression has been shown in various studies to range from at least 10% to perhaps greater than 30% in diabetic patients, both type 1 and type 2, and the rates could be particularly high in elderly patients with diabetes and females with diabetes. Interestingly, these studies have not shown an increased incidence of major depressive disorder in patients with undiagnosed diabetes mellitus or in those with impaired fasting glucose, indicating that some factor about knowing the diagnosis leads to the increased risk (14,15,21,39,40). One could certainly appreciate the potential for a feeling of "loss of control" associated with the diagnosis of a chronic health condition.

Depression often goes hand-in-hand with feelings of isolation; thus, treatment can be directed toward attempts to pull patients out of self-imposed seclusion. This can be done in the form of amputation support groups, if available, or even simply by speaking with another patient who has undergone an amputation. An attempt should also be made to increase the specific feelings of control the patient experiences within their life. Family members can review with the patient what important roles they need to continue to play within their social structure. The patient does not need to feel "wanted" but specifically "needed" by others.

Several screening tools for depression exist that surgeons should be aware of and ought to consider implementing within their practice (33,41). One of the most simple is the Patient Health Questionnaire (PHQ), which can be completed as either a series of 9 (PHQ-9) or 2 (PHQ-2) questions. The PHQ-2 variant simply asks the patient: first, during the past 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless?; and, second, during the past 2 weeks, how often have you been bothered by having little interest or pleasure in doing things? Although brief and basic, this has been shown to be a sensitive and specific screening tool that any surgeon could administer within a short period to determine whether a higher level of mental health care might be valuable (41).

Acceptance

"Acceptance" can be described as a feeling of resignation and stability as the patient becomes a ready and active participant in their life (35). The patient is likely to take ownership of both themselves and their actions. Factors that have been associated with a better adjustment to limb loss include an increased period since the amputation, greater levels of social support, greater levels of satisfaction with their prosthetic, lower levels of stump or phantom pain, and an optimistic personality (31).

In a study following up patients after both minor and major amputations, it was noted that patients could feel increasingly depressed for up to 2 years after the procedure before progressing back toward their baseline (31). Physicians should be particularly cognizant of stump or phantom pain and prosthetic satisfaction, because these are modifiable and treatable factors. In a study by Livingstone et al (32), many patients reported a feeling of "damaged trust" from physicians because they had not been truly informed of the extensive aftercare required after an amputation. A relationship with a prosthetist should be initiated as soon as possible to enable the patient to have an active role in this postoperative process. Also, surgeons should be explicit with respect to an expected time table of recovery, including healing benchmarks along the way. Furthermore, it was noted by Connell et al (30) that high levels of perceived social support correlated with decreased depressive levels associated with major amputation. Similarly, many studies have correlated acceptance and progression through rehabilitation after major amputation with a positive self-image and coping strategies associated with increased self-worth (31,32,34,42,43).

Discussion

The present review was primarily intended to increase awareness of an important and potentially underappreciated aspect of the treatment of diabetic foot disease. Although the stages of grief we have described are neither universal nor definitive, they can provide insight into predictable patterns of patient behavior and actions that can affect a patient's prognosis. It is important to be aware of and recognize the important mental health considerations that diabetes with depression will have on general and foot-specific health. Also, foot and ankle surgeons are often the first line of care that can recognize a potential problem. We hope that our study will serve as a starting point for physicians to improve their knowledge with respect to psychiatric considerations of their practice and patient care.

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