A forever healing: The lived experience of venous ulcer disease

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A phenomenological study was conducted to determine the lived experience of healing a venous ulcer for patients in an ambulatory surgical clinic. In addition to seven tape-recorded, transcribed interviews, weekly participant observations were made for 1 year. Interviews and field notes were transcribed and analyzed for themes by using van Manen's approach. Four major themes emerged from the analysis: (1) "A forever healing process" refers to the extended time over which healing occurs. (2) "Limits and accommodations" refers to the patterns of limitation related to mobility and activity restrictions due to pain and disfigurement. (3) "Powerlessness" describes the resignation about the inevitability of wound recurrence. (4) "Who cares?" refers to variation among the patients in assuming responsibly for managing their ulcer. Understanding the lived experience of venous leg ulcer disease allows care providers to provide empathic care. Patients can be encouraged to be active members of the treatment team and to assume responsibility for care and lifestyle choices. (J Vasc Nurs 1997;15:73-8.)

Venous ulcers, leg ulcers attributable to chronic venous insufficiency, are notoriously slow to heal, requiring effort over time by the patient as well as the health care team. Treatment costs in the United States are estimated to be \$775 million to \$1 billion per year. Leg ulcers are a common problem among the elderly, with incidence rates of 10/1000 in Scandinavia, and 3.3/1000 in Australia. The persistence and recurrence of venous ulcers presents a management challenge to the patient and the health care team.

The management of venous ulcers requires a consideration of both the physiology and the psychology of healing. Venous leg ulcers result from an incompetent venous system in the legs, which results in altered capillary pressures and permeability in the lower legs. To help venous leg ulcers heal, there must be adequate nutrition, appropriate wound dressings, and external compression of the lower leg to assist the venous return of blood from the leg. Conservative treatment usually involves at least weekly dress-

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ing changes to support wound healing, with additional treatment for any wound infections that might occur. It also involves treatment over a long period and requires patients to make lifestyle changes such as activity limitations.

A team approach to care has been suggested, involving physicians, nurses, physical therapists, and the patient. 4 The most important member of the treatment team is the patient, and little is known about patient experience of venous ulcer disease. A recent report of psychosocial impact of chronic venous ulceration in the elderly in New Zealand showed that leg ulcer patients experience greater pain, mobility problems, and health concerns than a matched control group, according to an interview protocol closely following certain quantitative instruments.5 This study also showed lower self-esteem and higher levels of negative affect in the leg ulcer group. Measures of loneliness, relationships, and life satisfaction showed no significant difference between ulcer and control groups. Following a literature review on venous leg ulcer disease and the experience of illness in general, no published report of a study from the patient's perspective of the experience of venous ulcer disease was found.

RESEARCH QUESTIONS

What is the lived experience of healing a venous ulcer for patients treated in an ambulatory surgical clinic?

METHOD

Because little is known about patient experience of living with venous ulcer disease, a phenomenological approach was chosen. The study was conducted in an ambulatory surgical clinic population in a urban teaching hospital. Patients are referred to the clinic from the emergency department or the walk-in clinic. In a few cases private vascular surgeons refer patients to the nurse-managed clinic for weekly dressing changes. Physicians are available for consultation for nonhealing ulcers or for wound infections. The nursing staff delivering direct care have been present for more than 10 years, providing continuity of care for weekly dressing changes and for recurrent ulcers. Nurses are also available by telephone if patients have questions about their care between visits. Appointments are made for one morning a week, and on that morning most of the patients treated are patients with leg ulcers, allowing for focused attention on the specific disease area. Appointment times are flexible as many patients rely on public transportation or senior service vans for transportation.

Fifty-four patients whose wounds were managed with weekly dressing changes in the clinic were invited to participate in a study of wound healing. Thirty-seven patients

TABLE I

SAMPLE INTERVIEW QUESTIONS

Tell me about your first experience of leg ulcers

What did you think was happening?

What did you do?

What has this condition cost you?

Are there any positive aspects to your leg ulcer condition?

What advice would you give a person experiencing their first ulcer?

Are there things about having a leg ulcer that people do not understand?

Tell me about them.

agreed to participate. The study involved the weekly measurement of wound size, using acetate tracings, the collection of an activity/pain log, and retrospective chart reviews to determine concomitant conditions, numbers of previous ulcers, and related emergency department and hospital admissions. Participant observations were conducted over 1 full year during clinic visits where patients came for weekly dressing changes. The clinic nurses changed the dressing, usually with an Unna's boot. During waiting time and dressing changes, the investigator made notes on the problems and concerns expressed by patients. Field notes were recorded by the principal investigator, an experienced qualitative researcher. Weekly participant observations with study participants allowed the researchers to follow the course of healing over time. The weekly visits also allowed for clarification of emerging understanding by the principal investigator. Activity and pain logs were collected weekly for 12 of the patients and served as a focus for exploration of daily experience with leg ulcer disease. The other authors managed the wound care and provided background information. Seven patients were interviewed in a private room using an open-ended set of questions. Sample interview questions are listed in Table I.

Interviews and field notes were transcribed and analyzed for themes using van Manen's approach to phenomenological analysis. Van Manen states that the "aim of phenomenology is to transform lived experience into a textual expression of its essence in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful." Interviews, field notes, chart data, and pain and activity logs were all coded for themes. Themes were then collapsed into categories, and the data were then reread to determine the depth of evidence available for each of the categories. To validate conclusions, patients and staff were presented the major categories and asked for response to the major ideas. Additional literature was reviewed to provide perspective on emerging understanding.

Qualitative studies need to demonstrate different standards

of rigor than quantitative studies. Lincoln and Guba⁷ list credibility, transferability, dependability, and confirmability as standards against which qualitative studies may be judged. In this study credibility was enhanced by the prolonged contact between researchers and subjects, triangulation of interview with observation data, and direct testing of findings with study participants. Findings are transferable to situations that match study situations as judged by closeness of descriptive findings to a new situation. Consistency and confirmability of findings were tested by rereading the data to test for fit of the final themes by the study authors.

RESULTS

Four major themes—"a forever healing process," "limits and accommodations," "powerlessness," and "Who cares?"—emerged from the analysis of patients' experiences in healing leg ulcers. The themes are applicable to all the patients interviewed even though each of them may have experienced his or her ulcer differently.

A forever bealing process

Venous ulcer healing extends over lengthy periods. In the larger sample of 54 patients, for the 38 ulcers that healed, the mean healing time was 31.37 weeks, and more than half of the patients were experiencing their second, third, or fourth ulcer. When asked about their first leg ulcer experience, many patients could not even remember their first ulcer experience. "It's been so long." The constant prevalence of the ulcer was referred to as an important aspect of living with the condition. "It's like having something that you cannot get rid of. It seems like it to me. It's like...In fact, I wonder if it will ever heal." Another man living with the condition for years said, "It's like a forever healing process, not getting better, not getting worse."

For healthy people or those experiencing an acute illness, healing has a positive connotation. Health, wholeness, and restoration are concepts related to healing. For the venous ulcer patient, healing raises issues that are not all positive. For them, healing means a constant attention to improvement or worsening, a constant awareness of bodily sensations, and a constant need for health care provider attention. Patients experiencing an acute illness or an illness that has the possibility of rehabilitation, see healing as a time of focused attention, of temporary interruption in life activities. For the ulcer patient the chronicity of the healing changes the nature of the healing experience. Healing is costly in terms of life energy for anyone. For the venous ulcer patient, the cost of healing continues for an extended time. The leg ulcer patient experiences different dimensions of healing. The result of healing for ulcer patients is not the same as healing for a surgical patient. The current ulcer might heal, but the underlying condition causing the ulcer remains present, because the leg has permanent changes. One patient commented, "If it heals, it is never going to be the same....It's not the scar. It is the feeling. It is always going to be tender."

The presence of chronic pain is unique to leg ulcer pa-

tients. The pain of the venous ulcer has dimensions of chronic pain in that for most people it extends longer than 6 months, but unlike many chronic pain conditions, where the cause of the pain is not readily demonstrable, for the venous ulcer patient the open ulcer is a constant irritation, a constant reminder of the threat to tissue integrity. Four patients were able to complete daily pain logs over several weeks' time. Two patients rated their pain as 2-3/10 for the weeks that they recorded their pain. Two patients reported pain at 6-9/ 10 for the 3 weeks that they recorded. These patients did report a gradual decrease in pain with time. One patient who did not record daily reported, "There's an awful lot of pain." Pain reported by patients varies in intensity. One patient described the pain as a paper cut that doesn't go away. Staff in the clinic noted that ulcers closer to the thin skin over the medial malleolus seemed to be experienced by patients as more painful than ulcers higher on the leg. Some patients appeared during dressing changes to have more pain than others. One man reported his understanding that "I cannot take pain killers because I am on Coumadin. So all I can take is Tylenol....I took three before I left [to come to clinic] and I'll take three more." As the ulcer heals, itchiness is a frequent complaint. Patients tolerate the discomfort by interpreting it as a sign of healing. On the other hand, itchiness sometimes is the first sign of recurrence of an ulcer for patients whose ulcers had healed.

Limits and accommodations

Leg ulcer patients describe limitations to their mobility and activity that are at times profound. When asked what area of her life had been affected by ulcer disease, one woman responded, "What area of my life? My whole life. I cannot do anything I want to do. I cannot go any place. [after a pause, and with sadness] I kind of got used to it." This response comes from a resourceful woman of 76 who had made accommodations in her life such as adapting her sewing machine to an elbow control so that she could sew with her feet propped up. Activity is limited by the ulcer pain, which is frequently associated with leg and ankle edema. "There is no problem telling me don't stand or don't do something else. Because it is still very sore and it hurts, I get an awful lot of pain." This woman was told by a physician who had checked on her healing progress to keep her feet elevated. After he left she indicated to the investigator that this advice was unnecessary. "He knows it from his books. I know it in my skin." On the other hand, not everyone is as limited as this woman. Another woman, less restricted by her ulcer reported that she was heading to Florida after her Unna's boot change. "I went last year with the boot on. It was wonderful....Once the boot goes on, you have to slow down a little bit, but I can get out and see people."

Several patients could not work and were receiving disability payments. One man, when asked to describe his plans for the day, replied, "As a matter of fact, I am going to see my lawyer this morning from Social Security disability. I cannot do nothing, not with my condition....Who would want to hire me like this?" This man had been a truck driver before

his leg ulcer developed. With the leg ulcer and the Unna's boot, "I cannot shift, cannot use the clutch. It hurts....I cannot even go out to a restaurant." When asked what the ulcer had cost him, one man reported, "Not much. A job." He had previously been employed as a convenience store clerk. The acceptance of limitation exhibited by this patient is remarkable. He had resigned himself to his loss. Another woman responded that what the ulcer had cost her was "freedom."

In addition to the self-imposed restriction that pain and swelling cause, there are treatment-imposed limitations on activity. The Unna's boot itself must be kept dry, so patients are limited in how they bathe. The boot is bulky, so patients are limited in how they dress. The bulk of the boot also affects gait patterns. Patients are taught to spend parts of each day with ankles elevated above heart level. Several patients in the study were homeless, and that caused a particularly difficult set of circumstances for one man. He noted that his ulcer opened up when his compression stocking "got ripped up," and he had no money to obtain a new one. "All these problems developed after being on the street or because of being on the street." When asked if he was able to find a place where he could get his legs up during the day, he responded, "They kept the shelter open because of the bad weather. There was only standing room. There were no seats available." Homeless people need to remain mobile to be able to access food and shelter. Good nutrition, an important part of wound healing, is difficult to attain for the homeless. Leg ulcers are a limitation to mobility. Getting to the clinic was a problem for one homeless woman who would appear at the clinic on days when other types of patients were being seen. This was disruptive to the staff and other patients.

Body image changes are part of venous ulcer disease. When asked how the ulcer limited him, a young man with a strong family history of venous ulcers responded that he couldn't go swimming. "I cannot really go swimming anywhere, really. I don't think anyone would appreciate me coming into a hot tub with a sore on my leg." A woman reports, "I cannot wear [any] clothes. I can only wear one pair of shoes. I can hardly get that pair on this one [leg]. It does cut the pleasure out, and I try to not let it worry me. It is part of my life and I just live with it." This represents an acceptance of the accommodations necessary to the condition. Another man reported that the condition was embarrassing. "I like to go swimming and I embarrass my family." The need to hide the body was reported by most patients. Open wounds are aesthetically displeasing in our society. The clinic was the only place patients could come and be told that their legs "look good." Ulcers for many patients are malodorous, particularly if they are draining or infected. This limits the social contact in which patients choose to participate. This could contribute to an objectification of the leg ulcer described by many patients. They treat their ulcer and in some cases their entire leg as if it does not belong to

Nonhealing leg ulcers prompt fear of loss for many patients. A woman, when asked what she most feared about

ulcer disease, remarkably replied, "I'm not really worried too much. The doctor was saying if you don't do this [skin graft] that they are going to cut your foot off." She had accommodated to the presence of her fear. Another man reported that one time he went to the emergency department and the nurse said he had a bad foot. He was worried that he would need an amputation. Not healing carries a threat. Patients are susceptible to wound infections that can result in delayed healing or even hospitalization. The incomplete understanding of their condition makes patients subject to more fear than they might need to experience. One man asked if a leg ulcer could lead to gangrene. The likelihood of amputation is not as powerful for venous leg ulcer patients as it is for patients with peripheral arterial disease, but with an inadequate understanding of the underlying conditions, patients are unable to evaluate their risks.

Powerlessness

Patients often feel a resignation about slow wound healing and the inevitability of wound recurrence. They describe a lack of understanding of what causes the ulcers and an uncertainty about whether the ulcer will ever heal. "I've resigned myself that I will always have it." The condition also causes an element of uncertainty, in that one never knows when the ulcer might heal or recur. "I wonder if it will ever heal" and "Now it is just maintaining them. They seem to get better for a while and then they get worse again" are typical comments. One man who had limited cognitive abilities but who lived independently with a disabled brother, reported:

It off-and-on hurts, the throbbing, the fluid drains when it wants to. It drains automatically. Sometimes it just doesn't do anything at all. It don't drain at all for a day, and the next day I have a lot of drainage and throbbing and irritability hurting it on the walk. Sometimes I don't have any walking pain at all. It kind of works on its own.

When asked if the ulcer runs his life, he said, "It looks like it is beginning to. I have to take care of my foot more than I have to take care of myself. I cannot do the things that I used to do in the past." Patients do not develop a sense of being able to control the outcome of leg ulcer healing. They describe being subject to the uncontrollable nature of the condition. The limitations in their lives go beyond activity limitations. Patients express an inability to alter the course of events in their lives related to their healing.

One aspect of being able to control a phenomenon requires understanding it, or having the opportunity over time to observe what affects the phenomenon. This group of patients was not able to describe what causes leg ulcers. Patients frequently look for a reason for the ulcer. "Could that break and that fracture have something to do with this?" Another man wondered if a knee problem caused the leg ulcer. He noted that when the knee collected fluid, the ulcer drained more fluid. Patients are also sometimes confused by the term *ulcer*. When asked what he thought made the leg ulcer happen a man responded, "Well, I do not think it is no Isic] stomach ulcer...I don't have any trouble with my stomach or digesting food." Laypersons may be confused by what

health care providers think of as a simple term such as *ulcer*. Not understanding their own conditions leads patients to a kind of powerlessness. Patients come to the clinic for dressing changes. They have learned that the Unna's boot eventually supports wound healing, but they do not describe an understanding of how it helps.

Who cares?

Ownership of the treatment plan is a potential difficulty for any patient-provider relationship. In this study patients varied in assuming responsibly for managing their leg ulcers. Many patients report a disconnection from or objectification of the ulcer. The Unna's boot itself, in completely covering the leg, may support this disconnection from the ulcer. The patient who describes that "I take care of my ulcer more than I take care of myself," implies that the ulcer is separate from himself. Others come to clinic and depend on staff to do all ulcerrelated care. One staff member remarked, "He acts as if it were my ulcer." This lack of ownership of the condition could be related to a sense of powerlessness to affect healing. Healing is so slow that progress is difficult to measure. The study protocol included measuring ulcer size weekly, which provided patients with direct feedback on progress. They were eager to hear their wound size as it was measured.

Deciding to enter treatment can be a problem for some. One man self-treated an ulcer for months with normal saline wet-to-dry dressings, as he had been instructed to do with an earlier ulcer treated elsewhere. A woman described, "I thought I could cure mine myself." This woman reported, "Next time I get this feeling I am coming right in. I am not going to wait, even overnight. My leg has been very very painful." Realizing that help is needed is difficult for many people. "My mother was never in the hospital in her life....She never stood inside the hospital door. Can you imagine? Look at us! The younger generation." Needing chronic medical help for her condition challenged this woman's view of herself as an adult.

Not understanding their condition can lead to delayed help seeking. One man reported "I did not know what it was. I knew it was a hole in the side of my leg, but I didn't do anything. I was stupid. Finally, it hit a blood vessel and then I finally went to the emergency room. I did not have a choice then." Another man reported that his first ulcer started as draining fluid:

The blister broke and fluid just started draining out of my foot and I was wondering what it was. So I did not pay much attention to it and just changed socks. I had white socks on and put a Band-Aid on. I just let it go for 2 months. I was trying to figure out why there was so much fluid there and after having the fluid in the knees and all the fluid that was draining out of my right foot. The next thing I noticed was the throbbing pains and my leg ulcer was starting to bleed. So I noticed blood was on my sock and it was time for me to go the hospital or call the doctor.

Efforts at self-care prove ineffective; professional care is required. Still, care is delayed until the condition worsens and the ulcer is larger or becomes infected.

Families are affected by the activity limitation and pain experienced by leg ulcer patients. During the time he was being treated for an ulcer a young man's fiancee became pregnant. "Now I take care of her, and she takes care of me." He also reported that his ulcer resulted in anxiety for his family. "They worry about me." Most people, however, report that caring for the ulcer is something that they do alone. The homeless man described earlier stated, "Everyone from my normal life has disappeared. All of a sudden, I have become like an exile. I have not spoken to any relatives in over 2 years now, or they haven't spoken to me. It is frustrating. I get more help from strangers, people I don't know at all." Care provided by the clinic staff is one positive aspect of having a leg ulcer reported by several patients. "I get to see you nurses," said one man, with a wink.

Preventing the next ulcer has its cost, as well. Patients in this clinic are fitted for compression hosiery when their leg ulcer heals. One man felt that the elastic stocking irritated his leg. "It cannot have any edges on it." The compression hosiery are sometimes uncomfortable. "I think the elastic stocking does a lot. You see what happened in the hot weather this summer, I did not wear them. I have a feeling that is what brought this on. You see, with the heat it is very hot." Clinic staff noted an increased incidence of leg ulcers during the autumn months, perhaps because patients go without compression stockings in summer. Self-care is required of all ulcer patients. "You favor it. Even after it is all over, I favor it. I sometimes wrap it. I will wear a stocking." Preventing or noting an early recurrence requires vigilance on the part of leg ulcer patients even after wound healing has occurred.

DISCUSSION

The process of healing for the venous leg ulcer patient has conditions that make it different from healing in other circumstances. This healing never ends, in that the leg needs continual protection from trauma and from capillary hypertension; therefore healing is not a temporary condition of attention and care. The wholeness expected at the end of the healing process is denied these patients. The experience of the body in venous leg ulcer disease is similar in some respects to conditions described by Morse et al.8 in their phenomenologic study of comfort. The diseased body in the case of venous leg ulcers is comforted, in that a diagnosis can be made and treatment begun. The unpredictability of the leg ulcer condition, though, contributes to an experience of the "disobedient body." The response to unpredictable conditions described in the comfort study is acceptance and compensation. Several examples of this acceptance and accommodation arose from interviews with leg ulcer patients. A degree of normalcy is regained for those who can transcend the limitation of their illness and take action to direct their life experience.

Further, in comparing with the work of Morse et al., 8 the leg ulcer patients are vulnerable because they must present themselves for frequent dressing changes in order to heal. They are dependent on care givers to provide bodily care in

the form of dressing changes that can be painful. One response to the experience of violation of the body can be to objectify body experiences, and this was reported subtly by several patients. They hid their condition with clothing and described the leg ulcer as somehow separate from the self. The pain of the ulcer is described as being endured because there is no alternative. Patients clearly describe a resignation to a changed body when they experience venous ulcer disease. Fear of recurrence is always with them. Some patients were free of ulcers for 4 or 5 years, but this illness-free time is like a cancer remission. Patients maintain vigilance in detecting the next ulcer.

Criddle9 described the process of healing from a surgical procedure in a phenomenologic study. For her informants, healing meant first a focus on overcoming pain and regaining mobility. Additionally, it involved mental and attitudinal changes that helped patients seek purpose, independence, and an integration that balanced physical and mental demands. Finally, informants reported incorporating their surgical experience into their life as they returned to their connection to the world. Criddle9 summarized the experience of healing from surgery as active participation, achieving balance, and evolving beyond. In contrast, leg ulcer patients have difficulty evolving beyond their condition because their condition stays with them. The means of increasing activity as a reentry to normal life described in the surgical study is denied leg ulcer patients because their mobility is limited for a long time, both by the pain and by the treatment. Some leg ulcer patients reported not being too limited in what they chose to do, such as vacationing, but even that required accommodation in dressing changes and activity level.

Many aspects of living with venous ulcer disease correspond with the concept of uncertainty. Mishel¹⁰ describes uncertainty as occurring "in situations where the decision maker is unable to assign definite values to objects and/or is unable to accurately predict outcomes because sufficient cues are lacking." In a later consideration of uncertainty in illness, Mishel¹¹ describes a probabilistic worldview that allows for an incorporation of uncertainty into positive views of chronic illness. In realizing that nothing is ever totally determined, an acceptance of life's uncertainties can be gained. Health care providers can support patients in seeing all events as probabilistic, or they can delay patients' reevaluation if they persist in a deterministic mode of searching for cure. Venous leg ulcer patients live with the uncertainty of recurrence of ulceration. Many express an accepting view of "If it happens, it happens." The difference between acceptance and fatalism is hard to distinguish. Certain lifestyle issues—such as activity level, leg elevation, and compliance with compression hosiery application when healed-might affect the course of venous ulcer disease. Other, less directly related activities—such as weight loss, stopping smoking, and healthy eating—might contribute to wound healing. Care providers must balance the concern for supporting lifestyle change with their own uncertainty about what factors prevent recurrence of open leg ulcers. Helping patients understand disease as a probabilistic condition can help patients be free to choose lifestyle accommodations that allow them to have a meaningful and enjoyable life. Further research will determine whether the experiences of chronic venous leg ulcers is unique or whether it shares characteristics with other chronic vascular or other conditions.

Leg ulcer patients in this study rated pain as one of the major problems related to leg ulcer disease. This stands in contrast to published reports of venous ulcer disease. "The ulcers are generally not painful unless accompanied by infection." ¹² Further research needs to be conducted to determine the prevalence of pain in the venous ulcer patient and to determine whether the kind of pain venous ulcer patients experience necessitates unique approaches to management.

Venous ulcer disease is not as life-threatening as coronary artery disease or peripheral arterial disease. It is a condition that is well suited to management by nurses in that it is often treated conservatively, it requires prolonged treatment, and it requires of patients some accommodation in their daily living. Understanding the patient experience of living with the condition can assist care providers in being empathetic to patient problems. Care providers treating patients for venous ulcer disease can meet patient needs by providing education about causes for ulcers and rationales for treatment. Furthermore, before leg ulcers develop, any person who health care providers note on routine examination to have early signs of venous insufficiency should be taught to seek care if they have any skin ulceration, however small. Ulcers often begin with scaly, eczematous skin. Patients should also be taught that wound care for venous insufficiency must include compression therapy. Several patients' ulcers in this clinic had been managed by dermatologists with normal saline dressings without compression for up to a year with no progress in wound healing. After being treated with Unna's boots, the ulcers responded well and healed.

By understanding the nature of the personal experience of healing venous ulcers, nurses can anticipate patient problems and provide more sensitive care. What distinguishes nursing from other health professions is an attention to human responses to illness. Phenomenologic studies of patient experience further our understanding of nursing. This study has described patient experiences of pain, powerlessness, and disability. Models of nursing care activities that increase patients' understanding of the normal course of the healing process can be tested to determine whether they decrease fear and assist patients in making necessary accommoda-

tions to their condition. We need to test whether nurses can encourage acceptance of the ulcerated leg as a part of the person's life and whether that acceptance results in greater freedom and function.

Patients can be encouraged to be active members of the treatment team and to assume responsibility for care and lifestyle choices even if they require frequent dressing changes by health care providers. Patients who experience venous leg ulcers experience a combination of pain, loss, and limits in their lives that extend for a long time. Helping patients to see that caring for themselves is a part of their life can increase their sense of meaning and joy in life.

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