The Lived Experience of Diverse Elders With Chronic Wounds

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Abstract
A previous study described the phenomenon of 16 financially stable Caucasian elders living with a chronic wound. The purpose of this study was to extend this research and describe the phenomenon of living with a chronic nonhealing wound in elders of color and in financially fragile circumstances. A purposive sample of 11 elders (nine older than and two disabled persons younger than 65 years of age) was selected who met the following inclusion criteria: having a chronic nonhealing wound present longer than 8 weeks; absence of mental health issues or cognitive deficits; able to communicate in English; and being from a diverse racial/ethnic background (not Caucasian). Seven male and four female elders were interviewed. Interviews were tape recorded and transcribed. Using phenomenological analysis, the researchers derived 10 themes and 24 associated subthemes incorporating physiological, psychological, and social concerns. Diverse elders had some experiences in common with Caucasian elders — notably, tolerating pain, missing normal mobility, living with chronic illness, and explaining causes of wounds. They also had different experiences including encountering losses, considering costs (both emotional and financial), and changed social roles. Unlike wealthier white elders, the diverse elders did not describe distrust of caregivers or altered sleeping or eating patterns. The results of this study provide a window on the lived experience of having a chronic wound.

Key Words: qualitative study, chronic wounds, lived experience, elderly, race


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Previous research1 using Colaizzi’s2 approach to phenomenology described the experience of elders living with a chronic wound (ie, a wound that fails to heal within 4 to 8 weeks). The sample interviewed lacked the perspectives of diverse elders so an extension study was planned because wounds, skin problems, and poor healing plague many older Americans, including elders of color. Statistics on chronic wound prevalence vary but reports indicate that 0.2% to 1% of the population in developed countries has venous ulcers, 0.5% from pressure ulcers, and up to 15% of persons with diabetes may develop a wound.3 Risk factors for the various ulcers differ but most are more common in elders.

In addition to advanced age, pressure ulcer risk factors include diabetes, malnutrition, altered mentation, incontinence, selected medications (eg, steroids), renal failure, and peripheral vascular disease.6 Venous ulcer risk factors include multiple pregnancies, prolonged standing, obesity, deep vein thrombosis, and vein damage.6 Arterial ulcer risk is affected by high cholesterol and lipid readings, hypertension, peripheral cardiovascular disease, and cigarette smoking; up to 20% of persons 65 years of age and older are affected by peripheral arterial disease.7

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Neuropathic ulcers are most commonly associated with poorly controlled diabetes mellitus, although they may be related to other causes including spinal cord disease and Hansen’s disease.5 Diabetes currently affects 23.6 million Americans (February 2009); 23% of all people age 60 years or older have diabetes.6 Minority groups are disproportionately affected. The prevalence of diabetes (diagnosed and undiagnosed) in non-Hispanic Blacks and Mexican-Americans is about 70% to 80% higher than in non-Hispanic whites.9 As many as 15% of all patients with diabetes will suffer a diabetic foot ulcer.10

Given projected increases in elders (up to 88 million by 2050) and persons with diabetes4,11 — the population of diverse elders is projected to increase to nearly 35 million Americans by 205011 — healthcare clinicians need to understand the chronic wound experience. Quality wound care demands comprehensive knowledge. Clinicians need to understand wound healing, wound etiology, asepsis, topical products, microbiology pharmacology, ethics, and psychosocial factors.12 With the increasing prevalence of elders and chronic wounds, increasing diversity, and accelerating complexity of care, increased knowledge and understanding of the chronic wound experience especially among elders from diverse races and ethnicities are vital for caregivers and health professionals.

Study Purpose
The purpose of this phenomenological study was to explore the lived experience of diverse elders with a chronic, nonhealing wound and describe what it means for them to live with a chronic wound. To explore this phenomenon, the investigators asked these research questions: 1) What is the lived experience of having a chronic wound? 2) What are the meanings and essences of the phenomenon? A secondary purpose of the study was to sensitize healthcare professionals and other caregivers to the chronic wound experience.

Literature Review
Phenomenology. Phenomenology has been described as the philosophical study of essences put into existence. It is also a research method.13 The lived experience of everyday life is the central focus of phenomenology and the person is viewed as integrated with the environment. The self shapes and is shaped by the world. Phenomena occur when a person experiences them. Phenomenology endeavors to take a fresh look at phenomena uncontaminated by scientific theories or a priori “common sense.”14 The ultimate goal of phenomenology is to describe lived experience, not explain it.15

The phenomenological approach used reflects Colaizzi’s2 method belief that phenomenology permits researchers to construct a phenomenon as people experience it. Through interaction between the researchers and the participants, meaning is created. The researchers selected phenomenology because it is a useful approach for addressing a highly subjective area such as the chronic wound experience and associated feelings and emotions. Quantitative and qualitative research approaches have been used to explore individuals’ chronic wound experiences. Although existing research has increased in the last decade, literature focusing on the chronic wound experience is remarkably modest, especially in light of increased wound incidence and prevalence worldwide.

A clear theme from recent literature on managing wound pain16–22 is that clinicians need to understand patients’ experience to gain their cooperation in care management and to support wound healing. Pain has been repeatedly identified as an important concern for patients with leg ulcers.1,23,24 In addition, the literature has included a stronger focus on therapies for more common (pressure, venous) as well as less common (eg, malignant fungating wounds, vasculitic sickle cell ulcers) wounds.25–29 Most of the literature focuses on chronic wounds within a larger context — that is, how the chronic wound affects the sufferer’s family30 and the effect of home care nurse-patient interactions on patient stoicism31 — and includes unusual approaches to leg ulcer management (eg, larval therapy).32

Chronic wounding: qualitative perspectives. Several qualitative clinical studies have been conducted; meta-analyses and meta-syntheses on chronic wounding have summarized the available literature published until 2005. Briggs and Fleming33 synthesized published qualitative research studies exploring experiences of living with a leg ulcer. Eight phenomenological studies, two grounded theory, and two descriptive studies met their inclusion criteria. The researchers identified five common themes: physical effects of leg ulcer, describing the leg ulcer journey, patient-professional relationships, cost of a leg ulcer, and psychological impact.

Other qualitative studies addressed chronic wounds. Ebbeskog and Emami34 conducted an interpretive phenomenological study to describe the lived experience of older patients with venous leg ulcers to examine their concerns about care interventions. Among the 12 women and three men who
participated, emerging themes included “being cared for with a skillful touch,” “feelings of belonging, continuity, and affinity,” and “being suppressed into a state where one loses control, leading to feelings of discomfort.” The participants wanted skillful, confident care delivered by gentle nurses in a sharing atmosphere.

Hopkins et al35 used a Heideggerian phenomenological approach to explore the experience of older people living with pressure ulcers. Analysis of the transcribed interviews of the eight participants revealed three main themes with associated subthemes: “pressure ulcers produce endless pain” (constant presence, keeping still, equipment pain, treatment pain); “pressure ulcers produce a restricted life” (impact on self, impact on others, consequences) and “coping with a pressure ulcer” (comparison, acceptance). The pilot study, though small, suggests that the issues of pain and life restrictions should be considered when providing pressure ulcer care.

A qualitative approach was used in an international chronic wound study. Mudge et al35 used focus group methodology and narrative analysis of transcribed discussions to study wound-related pain experiences in French, British, and Canadian patients (N = 23) with chronic leg ulcers (eg, venous, diabetic). Although pain was an important issue for all participants, specific cultural differences emerged. French patients expressed particular concern with body image, the British group was uncomfortable with medication use, and the Canadian patients were anxious about financial loss and apprehensive of the healthcare system.

Watson-Miller36 conducted a qualitative study on persons with diabetic foot ulcers. Using hermeneutic phenomenology, she interviewed six patients about their lived experience. Pain was a common concern and the presence of odor was a major problem. Constant physical foot care was wearing and burdensome and participants also had psychological issues such as anxiety and worry. Family issues were an important concern with feelings of increased dependence and feelings about changed family roles. Conversely, most patients felt supported by their families.

Chronic wounding: quantitative perspectives. Traditionally, venous ulcers were viewed as less painful than other ulcers19,21-23; the reality is very different. Using a quantitative perspective, Briggs et al34 studied pain and pain mechanisms in a longitudinal cohort of community dwellers with leg ulcers of varying etiologies. The researchers found that ulcer type, size, leg position, and duration of ulceration did not predict pain severity; rather, participants who reported symptoms associated with neuropathic pain had higher pain scores and less ulcer healing at 6 months.

Edwards et al37 conducted a randomized controlled clinical trial to determine the effectiveness of a new community nursing model of care on quality of life, morale, depression, self-esteem, social support, healing, pain, and functional ability of clients with chronic venous leg ulcers (N = 67). Patients in the experimental nursing model, which included social and peer support, demonstrated significantly better outcomes in quality of life, morale, self-esteem, wound healing, pain, and functional ability (P ≤0.5) than patients in the traditional model of care.

Franks et al38 studied quality of life in 113 elderly persons with leg ulcers (mean age 76 years) over 48 weeks. Initial improvements in pain, wound healing, and energy were not sustained over time. The researchers submit that the positive effects of treatment on health-related quality of life may not be sustained for the longer term. They speculate that this finding may be associated with general deterioration in the health status of elderly patients as they age, independent of the ulcer experience.

Slonkova and Vashku39 studied 30 patients with leg ulcers (venous and mixed venous-arterial) in the Czech Republic regarding quality-of-life issues using a quantitative style questionnaire. Major findings included pain, altered sleep patterns, restrictions in leisure activities, and the need to wear larger clothes. Patients also reported bad moods and depression.

Table 1. Patient demographics and clinical variables (N = 11)

<table>
<thead>
<tr>
<th>Age</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;55</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>55-64</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>65-74</td>
<td>3</td>
<td>27</td>
</tr>
<tr>
<td>75-84</td>
<td>4</td>
<td>37</td>
</tr>
<tr>
<td>85+</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Mean</td>
<td>X = 68</td>
<td></td>
</tr>
<tr>
<td>Mode</td>
<td>= 69</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>47-90</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>64</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>36</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>10</td>
<td>91</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Married</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td>Widowed</td>
<td>5</td>
<td>46</td>
</tr>
<tr>
<td>Ulcer etiology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Venous</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>Arterial</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Diabetic</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Surgical</td>
<td>3</td>
<td>27</td>
</tr>
<tr>
<td>Pressure</td>
<td>3</td>
<td>27</td>
</tr>
<tr>
<td>Multifactorial (&gt;2 etiologies)</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Current employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>8</td>
<td>73</td>
</tr>
<tr>
<td>Disabled</td>
<td>3</td>
<td>27</td>
</tr>
<tr>
<td>Previous employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Truck driver</td>
<td>1</td>
<td>N/A</td>
</tr>
<tr>
<td>Cook</td>
<td>1</td>
<td>N/A</td>
</tr>
<tr>
<td>Homemaker</td>
<td>3</td>
<td>N/A</td>
</tr>
<tr>
<td>Not reported</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

Changes in pressure ulcer care practice are being driven by patient satisfaction and expectations. Although the delivery of skillful, confident care by gentle nurses is important in the prevention of pressure ulcers, we must consider the experience of older people living with pressure ulcers, especially those with chronic venous leg ulcers (eg, venous, diabetic). This is important in the prevention of pressure ulcers, especially those with chronic venous leg ulcers (eg, venous, diabetic). This is important in the prevention of pressure ulcers, especially those with chronic venous leg ulcers (eg, venous, diabetic).
Price et al40 studied dressing-related pain in patients with chronic wounds using a cross-sectional survey. They sampled a total of 2,018 patients from 15 different countries suffering from 10 different wound types (venous, arterial, mixed, diabetic, pressure, surgical, trauma, burn, unknown, other) about their perceptions of wound pain. Many patients reported poor pain management. Pain was scored as the most difficult of six symptoms associated with living with a chronic wound. More than 40% of the patients indicated that pain at dressing change was the worst part of living with a wound.

Using a descriptive study design, Shukla et al45 studied Indian patients with chronic wounds for 1 day. The study group comprised 50 patients with wounds of varying etiology (eg, pressure, diabetic, venous, tuberculosis-related). Using a short questionnaire, researchers asked about several areas affected by having a chronic wound (physical activities, feelings and emotions, household duties, leisure time, and social relations) and general activities. The results demonstrated that patients’ quality of life was altered, with middle-aged persons having higher scores (more satisfactory quality of life) than those in younger or older persons. Men were more satisfied with quality of life in terms of physical activities, leisure, and general activities. Wound size affected responses. Patients with smaller wounds had more positive responses than patients with larger wounds.

Sibbald et al42 evaluated the use of a foam dressing incorporating ibuprofen in persons with leg ulcers compared to local standard wound care practice. The comparative block randomized prospective design involved 24 patients in a Canadian wound clinic. The foam dressing group (n = 12) reported diminished pain between dressing changes. In addition, decreased pain was associated with increased healthy granulation tissue, decreased peri-wound erythema, and better exudate control in the foam group versus the control group.

Case series design43 also has been used to study pain in venous leg ulcers patients. Ten patients were treated with foam dressings with ibuprofen. The finding that the ibuprofen decreased wound pain was helpful but notably, these patients experienced persistent severe wound pain along with intermittent bursts of intense spontaneous pain.

Quantitative mixed method approaches were used to address other psychosocial issues. Jones et al44 used a questionnaire and depression scale to examine the presence of anxiety and depression in people with chronic venous leg ulceration (N = 196) and also completed interviews with 20 people living with a chronic venous leg ulcer. Odor and exudate with leakage had substantial adverse effects on patients’ psychological state, including feelings of disgust, self-loathing, and low self-esteem.

A literature review19 on management of venous leg ulcer patients investigated the effectiveness of lifestyle and pain-related interventions, such as leg ulcer exercises, leg elevation during bed rest, and the use of an eutectic mixture of local anesthetic (EMLA) for reducing leg ulcer pain. The researchers submitted that patients felt that daily pain relief was lacking.

Stevens45 and Vuolo46 addressed wound pain management in literature reviews. Both noted the strong impact pain has on chronic wound patients’ lives and that key sources and triggers include dressing changes, use of negative pressure wound therapy (NPWT), larval therapy, and wound cleansing, as well as emotional triggers such as malodorous wounds.

Other non-research articles addressed critical themes in chronic wound. Green47 targeted the issue of chronic edema and possible associations with wounds and body image. Implications for healthcare professionals included the importance of allowing patients the opportunity to discuss feelings about body image.

Selected studies and articles addressed various chronic illness health issues and other illness foci in diverse subjects and those of lower income levels.48,49 However, no study was identified that purposely targeted the chronic wound experience in diverse elders.

**Study Design**

This study used phenomenological design to describe living with a chronic wound. Data sources included interviews and field notes. Interviews were tape recorded and transcribed verbatim.
The purposive sample (N = 11) was selected using the following criteria: having a chronic non-healing wound present longer than 8 weeks, absence of diagnosed mental health issues or cognitive impairment, having the ability to communicate in English, and being from a diverse racial/ethnic background (not Caucasian). A notable finding from participant background was that as a general trend, diverse elders had developed their chronic wounds at younger ages than the sample in the 2005 Beitz and Goldberg study. Thus, the researchers consciously chose to loosen the definition of elderly because the findings diverged from initial expectations and the pertinent participants had extensive experience with chronic wounding. The term elder was defined more broadly to include two diverse disabled middle-aged participants younger than 65 who had extended experiential knowledge of chronic wounding, experienced multiple chronic illnesses (>5), and reported severe financial strain. These patients had been forcibly retired from work by their wounds and been placed on disability. However, the mean age of the final sample was 68 years with 82% of the participants older than 65 (see Table 1).

Participants were contacted initially via nursing administrators at their respective facilities. Verbal and written information was provided at the first meeting with participants. Interviewing continued until saturation of themes was obtained. Theoretical saturation usually signals completion of data collection on a particular phenomenon.

Interviews were conducted on site at three Living Independently For Elders (LIFE) care program centers, a nursing home with an assisted-living facility, and a wound care center. All sites purposefully represented demographic locales serving low income populations. All participants were racially or ethnically diverse and all were from lower socioeconomic classes based on their self-described financial status (“poor”, of “limited means”, or “financially insecure”). All were receiving some form of federal/state financial assistance. Wound care was provided by healthcare professionals, mostly nurses.

Ethical considerations. La Salle University’s Institutional Review Board (IRB) reviewed and approved the study. The researchers gained access to the sites via their healthcare administrators who reviewed the proposed study, noted the IRB approval, and agreed to participate. Participants were informed that their consent could be withdrawn at any time during the study. Confidentiality was ensured by using code numbers instead of participants’ names. At the end of the study, all tapes were destroyed.

Data collection. Participants signed consent forms and also consented verbally on tape before interviews began. The researchers completed a brief demographic questionnaire (gender, age, race, marital status, type of wound, previous employment). A quiet area was used so participants could reflect on their experiences and audiotaping could be conducted. One or both of the researchers conducted the interviews. Each interview consisted of the following semi-structured, open-ended requests for information:

Table 3. Theme clusters and themes of original study: “The Lived Experience of Having a Chronic Wound”

<table>
<thead>
<tr>
<th>Living with pain</th>
<th>Experiencing altered sleeping habits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explaining nature of the pain</td>
<td>Getting a good night’s sleep</td>
</tr>
<tr>
<td>Disliking pain of wound treatments</td>
<td>Seeking elusive sleep</td>
</tr>
<tr>
<td>Intervening to ease pain</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Losing mobility</th>
<th>Changing eating patterns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changing agility</td>
<td>Eating well</td>
</tr>
<tr>
<td>Re-seeking beautiful life</td>
<td>Diminishing appetite</td>
</tr>
<tr>
<td>Seeking independence</td>
<td></td>
</tr>
<tr>
<td>Wearing down chairs</td>
<td></td>
</tr>
<tr>
<td>Enforcing stillness</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Receiving care</th>
<th>Explaining causes of wounds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trusting caregiver relationships</td>
<td>Reflecting on wounds history</td>
</tr>
<tr>
<td>Accepting care passively</td>
<td>Feeling guilty</td>
</tr>
<tr>
<td>Distrusting disrespectful caregivers</td>
<td>Reporting traumatic events</td>
</tr>
<tr>
<td>Disliking wound care</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Contending with chronic illness</th>
<th>Healing and recuperating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing illness</td>
<td>Savoring improvement</td>
</tr>
<tr>
<td>Losing vitality</td>
<td>Voicing frustration</td>
</tr>
<tr>
<td>Adding another burden</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Living and aging</th>
<th>Adapting and maladapting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Losing spouse</td>
<td>Rolling with punches</td>
</tr>
<tr>
<td>Tolerating diminishing abilities</td>
<td>Keeping active mentally/physically</td>
</tr>
<tr>
<td>Reflecting on having a lovely life</td>
<td>Feeling upset</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dealing with wound treatments</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Immobilizing wounds</td>
<td></td>
</tr>
<tr>
<td>Tolerating treatment apparatus</td>
<td></td>
</tr>
<tr>
<td>Altering usual drug therapy</td>
<td></td>
</tr>
</tbody>
</table>

Note: Elders were all Caucasian and financially stable/wealthy (N=16)
• Please describe your experiences of living with a chronic wound.
• Please include anything that you think would help us understand what it is like to be a person living with a chronic wound.

Prompting questions were used if needed, including:
• Can you tell me more about that?
• How did you feel when that happened?
• Is there anything you wish to add?

In addition to taping, the researchers observed body language and topic avoidance and made brief field notes. Interviews usually lasted from 45 to 60 minutes. Importantly, participants were not asked, “As a Black, Hispanic, or Asian person, what is it like to live with a chronic wound?” The researchers did not want to impose any preconceived perspectives on the participants — they wanted them to speak freely and honestly about the wound experience phenomenon as it was lived.

Data analysis. Colaizzi’s suggested steps from phenomenological researchers begin their inquiry by uncovering their presuppositions about the phenomenon. This exercise gives researchers a basis from which they can structure their questions and sensitize themselves to “unexpected” findings. The presuppositions identified by the investigators from clinical practice and previous research included the following beliefs: a chronic wound affects interpersonal relationships, self-image, and views of the healthcare system. In addition, aging may affect the lived experience of chronic wound.

A contract transcriber transcribed each audiotape. Researchers initially reviewed a hard copy of the transcript and made notations. Data analysis took place in stages, beginning with a review of audiotapes and transcripts. Following Colaizzi’s suggested steps from phenomenological data analysis, the researchers:
• Read all the participants’ descriptions to acquire a sense of what was said and of the whole interview; played the audiotapes repeatedly to sensitize them to latent meanings;
• Returned to participants’ descriptions to extract significant statements and phrases pertaining directly to the phenomenon and organized descriptions into thematic structures with indicator statements;
• Formulated meanings from significant statements and phrases and identified meanings throughout the analysis;
• Repeated the previous steps for each participant’s description, organized the aggregate formulated meanings into theme clusters, and searched for themes that fit together under major themes;
• Used the theme clusters to exhaustively describe the experience and wrote and reviewed the full description of the experience;
• Returned the descriptions to the original source and returned many times to original transcripts to ensure accuracy;
• Validated findings with participants and incorporated new relevant data. The researchers returned the descriptions to participants who discussed their agreement with the description.

A wound care expert with qualitative research experience was used to peer check the audit trail of selected interviews. An audit trail was maintained involving all field notes, transcriptions, themes, theme clusters, and descriptions.

Qualitative rigor: reliability and validity. Descriptive validity was ensured by audiotape recording the interview, verifying transcript accuracy, and creating an audit trail. The researchers bracketed their possible biases. Inter-rater reliability was protected by independent analysis of selected transcripts by the researchers. A colleague with expertise in phenomenology provided a comparative analysis of selected transcriptions to the audit trail. These strategies were built into each phase of the study while it was conducted to support qualitative validity and reliability.

Results

Eleven (11) persons (seven men and four women), nine greater than and two less than 65 years of age participated (see Table 1). Common themes inherent in the diverse elders lived experiences of having a chronic wound (leg ulcer) were organized into theme clusters and subthemes (see Table 2). The description includes the context of wound-related care history of wound development and its impact on the individuals’ lives. Theme clusters derived from the data included: tolerating pain, missing normal mobility, receiving care, living with chronic illness, explaining causes of wounds, trying to heal, adapting to new living, considering costs, encountering losses, and changing social roles.

Tolerating pain. Similar to the earlier study, pain was a very strong theme of the chronic wound experience. Participants described various forms and the constancy of pain and reflected on their need to take pain medicine. One participant commented, “I had what you call nerve pain or phantom pain. Some called it ischemic pain.” The effect of pain on lifestyle was devastating. One participant had pain “for a whole year and just stayed away [from life] the whole entire year.” Although pain at dressing changes was a common focus of exploration, some patients described pain from their wounds as ongoing, making comments such as, “I’m constantly in pain. Constantly in pain.”

Conversely, most patients stated their pain, though constant, was “well managed.” A subtheme was the need to take pills for pain management. “The doctor gives me pain medicine – Percocet,” one said. The pain subsided for most participants. “Today the pain is really minimum — on a scale of one to ten, it’s a one,” said another. In general, good pain management was a contrast to the earlier Beitz and Goldberg study where poor pain management was a major issue for elders.

Missing normal mobility. Altered mobility was a major focus in the earlier and current study. Many participants
described episodes of depression as their mobility became affected. One commented, “I’m less energetic and I get really depressed a lot.” Some missed going to church as they had in the past.

Walker and wheelchair use was a theme described by all participants at some point. They found devices helpful but undesirable because they represented immobility. One said, “I do not like this wheelchair at all.” Being in a wheelchair gave several participants insight into the problem of lifelong altered mobility. “Now I understand how an actual handicapped person feels. I give them the utmost respect,” one said. The inability to walk normally was hard work. Several of the participants described the fatigue of being nonweight-bearing.

Several participants described a transition in their wound experience. They decided that they “would not be held back.” “I go to New York and Myrtle Beach,” one said. For some, a motorized wheelchair made life easier: “I take my scooter down to Atlantic City.”

Receiving care. Participants in the study described their experiences of wound care as generally positive even though it took time for some to fully understand the treatment. One remarked, “I thought they were a little bit rough the way they treated the wounds when they first started which I later learned that the way they were treating was to my advantage.” Participants also developed trust in the facilities where they received care over time. One said, “At [my] hospital, I think they did miracles with me. I didn’t like the hospital at first because I lost a daughter there … and I wasn’t too crazy about [that] hospital. But after getting there and the nurses and doctors were so good and patient with me and they worked with me. I couldn’t help but now give them all the praises in the world to the hospital and the staff.” Conversely, one participant had a bad experience. “They took me to the hospital … of all places,” one said. “Four weeks after that I went on vacation; all my toes started to swell. My foot started to get sore and my whole toe area was swelling up on me. It was circulation trying to come down to Atlantic City.”

Descriptions of wound therapies of various types were mostly positive. Participants were provided topical enzymes, NPWT, topical antibiotics, surgical sharp debridement, and special types of dressings. Most understood what was being done to their wounds but some did not. One commented, “I don’t know the name of the stuff. They put it on my wound. It doesn’t do much.” In general, participants felt involved in their care and did not feel as distrustful as in the earlier study.

Living with chronic illness. A very strong theme described by participants was living with chronic illness. Subthemes included managing illness for the long-term and dealing with the added burden. Only one participant described not having any major chronic illness. All others described disorders including diabetes mellitus, hypertension, heart disease (including coronary artery bypass grafting), arthritis, cardiac arrhythmia, gastro-intestinal reflux disease, chronic obstructive pulmonary disease, peripheral vascular disease, and other illness. All described the need to manage the chronic illness in some way. “I have juvenile diabetes,” said one participant. “I’ve had it over 30 years. I take insulin plus medication for blood pressure, hypertension, and high cholesterol.” Others described trips to the hospital. “I went to [the] hospital emergency room,” one explained. “I was dizzy.” One participant even described a life-threatening event along with the wound, saying, “I had a heart attack about a year ago. I was in a coma for 3 months.”

Most of the participants described the chronic illness as another added burden to deal with along with the wound. Their burdens included constant dressing changes while receiving multiple medications, staying on special diets, doing finger stick blood sugars, and the like. The burden of the wound along with the chronic illness was overwhelming for many participants, at least initially. One said, “My diabetes is pretty good now, hemoglobin A1c is down now a lot from where it used to be but the endocrinologist wasn’t satisfied earlier.” The wound and the chronic illness were both improving. However, the chronic illness challenge was always present. “Diabetes does play a lot on emotions because it does affect everything in life and everybody,” one said. Having a wound or wounds augmented this challenge.

Explaining causes of wounds. Participants also described a variety of causes for their wounds. Subthemes included history of the wound’s progress, feeling guilty, and describing trauma. Wound histories varied — some had a wound for several months while others had the wound for years. “It’s off and on,” one said. “I guess [I had the wound] since December, but originally I broke my ankle.” Others had surgeries that became complicated: “I healed up after the [leg bypass] surgery,” one said. “Four weeks after that I went on vacation; all my toes started to swell. My foot started to get sore and my whole toe area was swelling up on me. It was circulation trying to come back to where it was and heal the toe. It never happened, and all the toes swelled and that was it.” One participant did not know the cause of a heel wound, saying, “I don’t remember what caused it. It just kind of came on.”

Some participants felt guilty about their wounds’ development. “I had a gunshot wound in my spine,” one related. “It’s five bullets in there. They took the bullets out and it healed and then some years later it opened back up. I’ve been dealing with it ever since. I was messed up then.”

A commonality among almost all participants was the experience of trauma to a body part. They described postsurgical complications, fractured bones, serious falls, passing out in the bathtub, prolonged immobility, and gunshot injury. Some wounds were present for several months while others were present on and off since 1983.

Trying to heal. All participants described attempts to heal their wounds. Two subthemes included valuing improvement and voicing frustration. Participants described valuing any improvement. “I went through hell and I’m glad it’s over with,” one remarked. “I’m glad I’m back on the right track.” Another said, “They say it’s getting better so I can get up and walk around.” Another commented, “I went through hyperbaric, I was trying to save my toes which was last June. I hung in there, it was very painful but worth it.” Participants also
described efforts to stay wound-free. One said, “I’m doing everything I can not to get any more [wounds].”

Participants also voiced frustration about trying to heal. “I just want to get it done,” one said. “That’s the problem I got, getting this sore to heal. I just want this thing to heal cause I’m about tired of it.” The healing rate was slow for some participants. “It’s not healing fast enough,” one said. “They tell me it’s healing but I can’t get there.” Another said, “Most definitely I am worried about it… if they got to go through surgery, do the surgery, cut all that dead tissue out of there. Sew it up, you know what I mean… I want to get it over with.”

**Adapting to new living.** Participants described the need to adapt to new ways of living as a consequence of their wounds. Subthemes included “Taking one day at a time” and “Growing up.” The chronic wound experience involved receiving services that required trips to wound healing centers or elder care centers or being institutionalized in hospitals or long-term care settings. Participants described “getting used to” care services. Almost all mentioned letting go of anger and adapting. “I take one day at a time,” said one. “I leave everything in God’s hands.” Another remarked, “I was real angry. It was bottled up inside. After a while I got myself together.”

Other participants described a maturational experience because of the wound. “I wasn’t supposed to be here sitting talking to you right now,” one acknowledged. “That’s how many times I’ve been on the death boat dealing with this injury… I guess everything turned out for the best. I changed my life around… I’m back on track.” Another described a similar process, saying, “While in rehab I got back on track. I started doing work and all.” Yet another described getting over depression and growing up: “I said 2008 will be the year that I’m gonna get out of this chair. I am not gonna sit here and feel sorry for myself. I am going to grow up and get up.”

**Considering costs.** Respondents also described the costs of the wound experience. Subthemes included emotional costs and financial challenges. The chronic wound experience sometimes caused a change in lifestyle. One participant described the need to be institutionalized for care and wanting to get home: “No place like home.”

Financial challenges were also a reality for study participants. One had to purchase an expensive motorized wheelchair, explaining “I paid for it myself – it was expensive.” The chronic wound also changed income levels. One commented, “I made aluminum doors — the money was good; had to give up working.” Even those with support were challenged. “Right now I’m going through court ‘cause I’m trying to get my disability,” said one. “All they want to do is give me 40% disability… I’m trying to get 100% but I’m dealing with 70%.”

Worrying about finances was an issue for participants.

**Encountering losses.** The chronic wound experience involved losses directly associated with the wound but participants also experienced other kinds of losses. The major subtheme was struggling against loss. Some losses were physical. One participant had to use a bedpan or commode due to loss of independent mobility and felt “awkward” as a result. Other participants described the loss of independence. “I have to depend on my husband greatly,” one said. “He takes me places. He brought me in today and takes me around.”

Life cycle losses also affected the participants. “I live alone, me and my two cats,” said one. “I lost my husband several years ago. I have to depend on friends for help.”

**Changing social roles.** The chronic wound experience was initially associated with major changes in social roles. Subthemes included “being a lady of leisure” and “I’ll never work again.” One person said, “I’m not the full person I used to be.”

Both male and female participants described altered social roles due to the wound. “My son does everything,” one woman remarked. “I’m a lady of leisure now. He does all the cleaning and shopping.” A male participant explained, “My daughter and my grandkids live with me. They are very good and very patient with me… I also have an aide that comes out everyday.”

The effect on family is evident. A participant explained, “For my son it [the wound] kind of plays a role in his life because he’s not used to seeing his Mom in a wheelchair and down. Sometimes he feels a little self-conscious when he sees his friends see his mother is in a wheelchair.”

The wound also affected employability. Even before the age of 65, several participants were unable to go to a job. “That’s right, I’ll never work again,” one said. “I don’t miss working now but I did earlier on.” Another participant, a former truck driver, could not work due to the wound: “I have to use the shift and the clutch.” The wounds on his feet prevented him from being able to drive the truck.

Many participants described some variation on the experience of being “less than” previously due to the wound. One participant reflected on her marriage and the changes the wound precipitated. “It kind of plays a role in our marriage too. I know I’m not the full person I used to be. I don’t feel like it…. I won’t be walking the same…. I need the walker and maybe need assistance from the cane…”

**Discussion**

The chronic wound experience of diverse elders was similar to and different from those described in the earlier phenomenological wound study.1 Analyzing the chronic wound experience generated physiological, psychological, and social themes. Many themes were similar to the earlier study (see Tables 2 and 3); others were unique to this study (Encountering Losses, Considering Costs, and Changing Social Roles). Conversely, some themes were present in the earlier study but not present in the current results (see Table 4).

Pain and altered mobility were the major themes described and reflect findings from other studies on chronic wounds.33,35,36 These results are not surprising given the enormous impact of chronic wounds on the quality of daily living. Pain (both acute and chronic) and the inability to walk pervade studies about long-term wounding.24,25 A striking dif-
ference between the current and previous study was the fact that the diverse elder group had much better pain management experiences. The difference may be due to clinician reluctance to prescribe opioids and strong pain medications for older elders (previous study mean age was 86.5 with a range of 75 to 98), but more effective therapy is prescribed for younger elders who are perceived as less vulnerable to overdose or other negative side effects. Alternatively, the younger group of elders may have been more assertive in demanding better pain management. Also, it may be true that knowledge about pain in these wounds has increased since first study.

Participants were generally positive about their care encounters and wound interventions. This was particularly true for participants whose wounds improved. Also, the nature of the wound center and the outpatient independent living centers may provide a more positive style of patient-clinician interaction than a nursing home setting, with more perceived personal control.

An influential factor strongly present in both the current and the 2005 study was chronic illness. Wound care issues almost always occurred in the context of chronic illness(es). At times, the participants felt overwhelmed and burdened with multiple challenges. Findings of this study are similar to those of Ironside et al, whose phenomenological study of community-dwelling persons (n = 10) found that chronic illness was pervasively influential. Persons with chronic illness need to discuss issues with caregivers and families to generate deeper understanding of their experiences.

The participants also were very verbal about what caused their wounds and their attempts to heal. A common thread in their descriptions was the role of trauma (eg, surgery, fracture, or accident). Some felt guilty to a degree; others did not. In addition, all participants had lengthy courses of treatment to try to heal the chronic wound. The participants were thankful for the opportunity to heal but were also “tired” of the effort because it may have involved travel for special therapies, long-term wound treatments, and hospitalizations.

The resilience of the human spirit is evident in participants’ descriptions of adapting and their changed social roles. Their perspectives were similar to findings in other publications. Participants felt that they had adapted to changes created by the wound but that their families had to change as well. Generally, participants felt supported by family.

One issue that was a new finding in this study was the theme of “costs.” Although the diverse elders had access to care for wound therapy and daily living supports, several participants described financial strains, a familiar challenge that had affected several individuals for years. Because these the diverse elders had wounds at younger ages, the reality of “medical bankruptcy” presented a deep fear of having to spend personal finances to the point of being totally dependent on disability, Medicaid, or Medicare. The emotional costs were also disagreeable in that some participants had to give up their homes for care institutions such as nursing homes. Briggs and Fleming also identified these “cost” issues in their phenomenological study of persons with a leg ulcer and the inherent struggles faced. Participants lost aspects of their lives (eg, continence or toileting independence) or significant others. All described how these struggles added to the wound burden.

Notably, racial diversity did not explicitly affect the experience of chronic wounding other than the participants were younger when they developed their wounds. Whether this finding was a reflection of the diverse nature of the settings where care was provided or a reflection of the diverse urban locations is unknown. Whether these findings would occur again in diverse elders in other geographic areas and other care settings also is not known.

The results of the study should be viewed with an awareness of participant characteristics. Participants were mostly African-American. Only one Latino and no Asian elders with wounds were interviewed in the settings where the study was conducted. This perhaps reflects the reality that much elder care in the latter two communities occurs at the family home. All participants were of limited means but were receiving state/federal financial assistance for their healthcare and all the settings where participants received care were protective of and solicitous in providing quality wound care. Participants were very complimentary in general about professional caregivers. Results may differ for elders of other races and/or ethnic groups or for elders who are living in isolated settings or sparsely populated rural areas, as well as for persons totally dependent on family members at home for care. Nevertheless, the outcomes provide a window on the lived experience of having a chronic wound.

Conclusion

Chronic wounds are a disruptive life experience for many Americans, especially elders. As America ages and becomes increasingly diverse, more older persons of color will require care. The main findings of the study suggest that wound care, altered mobility, chronic illness challenges, encountering loss, explaining wound causes, attempting to heal, adapting to new living issues, and altered social roles are experienced while facing both emotional and financial costs. Ethnic/racial background did not appear to alter these experiences.

Clinicians should take note of the findings and their implications for practice. Chronic wound care should include ongoing thorough pain assessment with excellent pain management. Frequent reassessments are critical. If possible, clinicians should target increasing mobility as appropriate even if immobility has been the status quo. Innovative devices may free people from being handicapped. Opportunities for wound patients to express their frustrations and feelings regarding healthcare relationships, chronic illness issues, dealing with loss, and adapting to new lifestyles and social roles should be available. One approach could be the use of support groups or peer support from persons who have experienced the phenomenon. Blogging offers another way for patients to share issues.
Future research should increasingly investigate the chronic wound experience of diverse patient groups. Notably, analysis of Latino elders experiences is needed.

Research targeting the identified themes should be conducted, especially studies that analyze intervention effectiveness. Given the pervasive ongoing negative effects of chronic wounds on quality of life, efficacy studies that elucidate what does and doesn’t work are imperative.

The results of this study add to the body of knowledge guiding care for persons enduring a chronic wound. Armed with this knowledge, nurses and health clinicians can intervene for optimal holistic care.

References

