Response Factors Surrounding Progression of Pressure Ulcers in Community-Residing Adults With Spinal Cord Injury

Claudia A. Dunn, Mike Carlson, Jeanne M. Jackson, Florence A. Clark

OBJECTIVE. This study examined how community-dwelling adults with spinal cord injury (SCI) respond in real-life circumstances after detecting a low-grade (Stage 1 or Stage 2) pressure ulcer.

METHOD. We performed a secondary analysis of personal information profiles obtained in a previous qualitative research study. Profiles were examined to explore how individualized lifestyle considerations affected pressure ulcer risk in 19 adults with SCI who responded to an early ulcer that later progressed to a medically serious level.

RESULTS. On the basis of a total of 46 pressure ulcer events, we identified a typological framework that described eight primary response categories and seven subcategories.

CONCLUSION. The findings have significant practice implications for occupational therapists who provide services for adults with SCI living in the community. The importance of combining an initial individualized preventive intervention with structured follow-up within a person's unique everyday life setting is further explored.


Adults with spinal cord injury (SCI) are at high risk for developing medically serious pressure ulcers because of decreased mobility and reductions in skin sensitivity (Bogie, Wang, & Triolo, 2006; Correa et al., 2006; Garber, Rintala, Hart, & Fuhrer, 2000; Maklebust, 2005; Nogueira, Larcher-Caliri, & Haas, 2006; McKinley, Jackson, Cardenas, & De Vivo, 1999). The prevalence of pressure ulcers among adults with SCI ranges from 25% to 30%, with incidence of up to 40% per year (Brem & Lyder, 2004; Fuhrer, Garber, Rintala, Clearman, & Hart, 1993; Walter et al., 2002). The negative consequences of this problem are vast and long lasting. Depending on the depth of tissue injury, pressure ulcers can lead to serious medical complications such as altered metabolic functioning, urinary or bowel diversions, amputations, systemic infections resulting in osteomyelitis, or septicemia (Bogie et al., 2006; Brem & Lyder, 2004; Consortium for Spinal Cord Medicine, 2000; Correa et al., 2006; Krause, 1998; Rish, Dilustro, Salazar, Schwab, & Brown, 1997). Accordingly, the cost of treating SCI-related pressure ulcers places a great burden on the health care system (Consortium for Spinal Cord Medicine, 2000; Garber & Rintala, 2003; Hiser et al., 2006; Krause, Vines, Thomas, Farley, & Sniezek, 2001; Middleton, Lim, Taylor, Soden, & Rutkowsky, 2004). In the United States, approximately 25% of all treatment-related expenses for people with SCI are accounted for by pressure ulcers (Byrne & Salzberg, 1996).

Beyond their severe medical and economic consequences, pressure ulcers affect many aspects of function and are a deterrent to a person’s ability to pursue activities that contribute to a sense of independence, control, and productivity (Consortium...
for Spinal Cord Medicine, 2000; Larcher-Caliri, 2005). When treated at an advanced stage, the long healing process can lead to significant lost work time and a subsequent decrease in employability, interfere with the rehabilitation process, delay community and social reintegration, and cause further disability (Song, 2005). These personal costs are associated with a loss of self-esteem and seriously diminish a person’s quality of life (Correa et al., 2006; Dijkers, 1997; Hopkins, Dealey, Bale, Defloor, & Worboys, 2006; Krause, 1998; New, 2004; Tate & Forchheimer, 2002; Tate, Kalpakjian, & Forchheimer, 2002). The severity of the SCI-related pressure ulcer problem dictates that appropriate preventive measures be taken. Medical recommendations for prevention include obtaining ample bed rest; performing pressure redistribution at regular intervals with accompanying skin inspections; keeping skin dry while adhering to a personalized bowel-and-bladder management program; and using and maintaining proper pressure-redistribution equipment, such as friction-reducing mattresses or protective padding to line the inner surface of braces covering bony prominences (Catz, Zifroni, & Philo, 2005; Consortium for Spinal Cord Medicine, 2000; National Pressure Ulcer Advisory Panel [NPUAP], 2006; Wilborn, Halfens, & Dassen, 2006).

These recommendations, however, are frequently not followed. For example, people with SCI do not always understand or cognitively retain instructions for care (Consortium for Spinal Cord Medicine, 2000). Other reasons for nonadherence include misconceptions about ulcer risk factors and barriers to treatment that are perceived as insurmountable, such as lack of transportation, prohibitive cost, or travel distance (Byrne & Salzberg, 1996). One study suggested that engagement in preventive behaviors is strongly linked to a complex set of daily lifestyle influences (Clark et al., 2006). In this regard, the education that patients with SCI receive during their acute rehabilitation care is often decontextualized and may not transfer to their actual life settings.

One crucial issue for prevention is a person’s response to the emergence of a newly observed low-grade (Stage 1 or Stage 2) ulcer. A Stage 1 pressure ulcer presents as a visible alteration of intact skin, whereas a Stage 2 ulcer manifests as a partial-thickness skin loss of the epidermis, dermis, or both (Consortium for Spinal Cord Medicine, 2000). By receiving prompt medical attention and taking necessary precautions such as rest, it is possible to prevent such ulcers from progressing to more serious stages requiring surgery (Consortium for Spinal Cord Medicine, 2000; Maklebust, 2005; Nogueira et al., 2006; NPUAP, 2006). It seems likely that a person’s response at the early stage of ulcer development is affected by a wide range of daily life contextual factors such as internal attitudes, noncollaborative environments, work obligations, mental or emotional issues, competing motives, comorbidities, or lack of knowledge (Clark et al., 2006; Correa et al., 2006; Krause et al., 2001; Tate et al., 2002). At present, however, empirical evidence is lacking about how personal lifestyle issues affect responses to emerging ulcers.

The purpose of this study was to describe how adults with SCI respond in real-life circumstances after detecting a Stage 1 or Stage 2 pressure ulcer. The impetus for this examination was to explore in greater depth the particular temporal window during which decisions are made in response to early-stage skin breakdown. Gaining a deeper insight into this response process may make it possible to enhance acute rehabilitation interventions that provide consumers with information on ulcer prevention. In addition, such knowledge can be used to improve preventive approaches, such as lifestyle enhancement interventions or consumer self-help efforts, that can be directly applied within the daily life settings of community-dwelling adults with SCI.

Method

Research Design

This study was a qualitative cross-case secondary analysis. A secondary analysis (Thorne, 1994) is a reanalysis of an original data set to answer new questions. A cross-case analysis enables the researcher to recognize patterns in the data that stem from similarities and variations in individual experiences (Paron, 2002; Polit & Beck, 2004). We analyzed case profiles generated in a previous qualitative study of the daily lifestyle influences on the development of pressure ulcers in adults with SCI. The previous (i.e., parent) study is described in the next section.

Parent Study Overview

The parent study, the Pressure Ulcer Prevention Study, funded by the U.S. Department of Education’s National Institute for Disability and Rehabilitation Research, was conducted from 2001 to 2005 and involved collaboration between researchers at the University of Southern California and Rancho Los Amigos National Rehabilitation Center (RLANRC). In this study, holistic ethnography (Clark, 2000; Pelto & Pelto, 1985) was used to provide researchers access to prolonged contact with study participants in their daily life settings as a means of documenting their personal experiences with pressure ulcer risk (Tate, 2006). The research participants were 20 ethnically diverse men and women, 19 with SCI and 1 with transverse myelitis, who had been treated at RLANRC for one or more medically serious ulcers, including one previously ulcer-free participant. Data collection procedures included participant observation and unstructured interviews. On the basis of an
extensive data collection process, detailed personalized pressure ulcer risk profiles were generated for each study participant. The profiles averaged 38 pages in length and focused on participant characteristics, environmental barriers and affordances, beliefs and practices surrounding pressure ulcers, and pressure ulcer outcome histories. Because of the in-depth data collection process, the profiles contained detailed accounts of responses to specific ulcers. The methodology of the parent study is described in detail in Clark et al. (2006).

Data Collection and Analysis
The data for this study included 19 personal profiles with adequate information about one or more responses to a low-grade ulcer. Adequate response information consisted of a statement regarding the presence of a low-grade ulcer, actions taken, thoughts and justifications for actions taken, and observations about the subsequent worsening of the ulcer to a medically advanced level. One participant in the parent study did not develop a pressure ulcer and was therefore not included in this study. Data collection and analysis for this study were primarily conducted by Claudia A. Dunn. Jeanne M. Jackson also participated in data collection to provide confirmation of Dunn’s findings. As in most qualitative research studies, we engaged in an iterative process between data collection and analysis. For clarity, however, we present the procedures in a more linear fashion.

Initially, Dunn scrutinized participants’ case profiles to identify each person’s response to a low-grade pressure ulcer (Stage 1 or Stage 2) that subsequently advanced to a medically serious level. Stage 3 (subcutaneous tissue damaged or necrotic) and Stage 4 (subcutaneous tissue, muscle, bone, or supporting structures damaged or necrotic with possible undermining and sinus tract involvement) ulcers are considered to be medically serious (Consortium for Spinal Cord Medicine, 2000).

Although low-grade pressure ulcers were specifically reported as being Stage 1 or Stage 2 in only four accounts, in most cases it was possible to deduce that an ulcer was in an early stage by attending to the information provided (e.g., if a participant indicated that a small red spot was noted on his or her buttock). In other cases, participants merely described an ulcer as being at an early stage or as newly emergent without providing a physical description of the ulcer. Because it was assumed that advanced ulcers that surfaced as topics of discussion had proceeded through earlier stages of development, we retained such instances in the analysis and treated them as low-grade ulcers when discussed in the context of their early manifestation. If there was no description of a response to an ulcer before it became medically serious, no data were collected. In several cases, participants reported a succession of varying responses to a single ulcer or demonstrated inconsistent responses to different ulcers that occurred at separate times. We treated multiple simultaneous ulcers as a single unit (i.e., an ulcer event, defined as a time-specific occurrence of an ulcer or cluster of ulcers that was responded to in an identical fashion) and recorded them as such.

After identifying a response to a low-grade pressure ulcer, Dunn and Jackson created a category with a corresponding code representing the specific type of response. Using a word-processing program, they then either assigned each subsequent response to an existing category or created a new, more fitting category. For organizational purposes, they also used the typological categories to produce an informational chart, which included each ulcer incident number and stage; a response code; the circumstances surrounding the ulcer, including direct participant quotes; and any attitudes conveyed by that person regarding the ulcer.

During the course of data collection, regular meetings took place in which Dunn and Jackson discussed emerging themes in the data. Following Dunn’s initial derivation of categories, both Dunn and Jackson worked iteratively to refine categories and subcategories via the following steps. First, Jackson read all participant accounts before viewing Dunn’s categories. Jackson then reviewed Dunn’s scheme of categories and compared them against her thoughts concerning the data. They then met to discuss the respective similarities and differences. Over the course of this iterative process, they reconfigured two response categories to achieve agreement. To generate a set of concrete examples for each category, illustrative participant statements and reactions to ulcers were highlighted on hard copies of the case profiles.

To enhance rigor, Dunn and Jackson examined one randomly selected pressure ulcer event for each participant in the deep, original data transcripts to determine the accuracy of the comprehensive individual profiles. This examination was done to verify that the summarized stories were not oversimplifications relative to the extensive original data gathered and to cross-check participant quotes regarding the response to a specific pressure ulcer event. In each case, they found the shorter account to be accurate and to correspond to the participant’s self-report.

Results
The analysis included a total of 46 pressure ulcer events, as reported by the 19 participants. As noted earlier, a single pressure ulcer often led to a series of responses. As a result, some responses to a given ulcer were assigned to a single category and others were spread across more than one category. Table 1 presents the typology of response categories.
Table 1. Typological Summary of Responses to Low-Grade Pressure Ulcer Events (N = 46 Events)

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
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<tbody>
<tr>
<td>1. Lacking adequate knowledge</td>
<td></td>
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<tr>
<td>Overlooking an ulcer</td>
<td>Lack of awareness of what to look for or expect on detection</td>
</tr>
<tr>
<td>Underestimating danger</td>
<td>Identifying a skin abnormality with no knowledge of how an ulcer appears and therefore failing to recognize that an ulcer is present</td>
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<tr>
<td></td>
<td>Having an awareness of a budding ulcer with knowledge that it could exacerbate but without an understanding of the speed or severity of progression</td>
</tr>
<tr>
<td>2. Procrastinating</td>
<td></td>
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<tr>
<td>Delaying on the basis of emotion</td>
<td>Discovering an early-stage ulcer followed by a delay in seeking medical attention</td>
</tr>
<tr>
<td>Negating consciously</td>
<td>Delaying the receipt of treatment because of fear, agitation, or impatience</td>
</tr>
<tr>
<td></td>
<td>Denying ulcer existence as a means of putting off treatment</td>
</tr>
<tr>
<td>3. Experiencing cognitive dysfunction</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lacking the cognitive or behavioral facility to respond in an attentive and reasonable manner, including that caused by depression</td>
</tr>
<tr>
<td>4. Diverting attention</td>
<td></td>
</tr>
<tr>
<td>Attending to comorbidity</td>
<td>Discovering an ulcer and subsequently deciding to engage in everyday activity or a pressing life event rather than attend to healing it</td>
</tr>
<tr>
<td>Desiring activity</td>
<td>Paying attention to a competing medical condition</td>
</tr>
<tr>
<td></td>
<td>Engaging in activity for its own sake after discovering an ulcer (e.g., continuing to work, using substances, attending to the death of a loved one)</td>
</tr>
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<td></td>
<td>Delaying active pursuit of medical care as a result of diversion of attention to environmental concerns</td>
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<tr>
<td>5. Avoiding social discomfort</td>
<td>Demonstrating a reluctance to perform treatment measures because of a belief that the underlying recommended behavior would be unattractive to others</td>
</tr>
<tr>
<td>6. Being thwarted from receiving adequate medical help</td>
<td>Tolerating external conditions that prevent procuring proper or timely medical care when sought</td>
</tr>
<tr>
<td>7. Relying on self or caregiver help</td>
<td>Attempting to heal an ulcer without obtaining direct treatment from a health professional</td>
</tr>
<tr>
<td>8. Adhering to medical recommendations</td>
<td>Following advice from a medical professional, with the ulcer nonetheless progressing to a medically serious level</td>
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</tbody>
</table>

Note. An ulcer event is defined as a time-specific occurrence of an ulcer or cluster of ulcers that was responded to in an identical fashion.

Eight main categories and seven subcategories were identified. We include definitions of the categories and subcategories in Table 1, ordered according to an increasing estimated degree of conformity to optimal responding.

**Category 1: Lacking Adequate Knowledge**

Lacking adequate knowledge refers to situations in which a person did not know what an ulcer looked like or did not know what to expect on discovery of an ulcer. One subcategory, overlooking an ulcer, represented cases in which a person identified an area of skin as appearing unusual but had not previously experienced a pressure ulcer or did not know how one manifests and therefore did not recognize the area as a budding ulcer. This subcategory also included instances in which a person had experienced an ulcer in the past but nonetheless failed to properly identify a new ulcer. Rachel’s response to her first early-stage ulcer after being discharged from the hospital illustrates this category:

My mother came in here and looked, and she looked at my butt, and she was, like, “What is that?” She did not know what it was, you know, and then I didn’t know what it was, and so it ended up getting worse, because I went to [the hospital] emergency room, and they cleaned it all out and everything, and then told me, “[You have a decubitus ulcer].” And then I said, “A dem-who?” Because I had never heard the word.

The second subcategory, underestimating danger, captured cases in which a person demonstrated an awareness of a budding pressure ulcer with the knowledge that it could exacerbate but simply did not understand how severe and rapid the progression could be. One respondent, Mitch, noticed an area of skin breakdown on his hip but chose not to mention it to his doctor during a routine medical checkup. He believed that the ulcer was not big enough to require surgical care and that he could stay its progression by sleeping on an air mattress that he had ordered but not yet received. In another case, Odel shared his experience of what he perceived to be a sudden and unexpected worsening of a seemingly nonthreatening early stage of skin breakdown:

It must have been gathering and coming up for a long time. And it was deep. So, I didn’t know. They said it was like a mushroom. It was real big and deep on the inside, but on the outside, it was almost like a little pinhead.

**Category 2: Procrastinating**

In these instances, a person discovered an early-stage pressure ulcer but waited some time before seeking medical attention. Two varieties of procrastination emerged. Delaying on the basis of emotion occurred when a person initially avoided contacting a health professional because of fear, agitation, or impatience. This reluctance to receive help was commonly because of trepidation at the prospect of medical treatment or a potentially long hospitalization. Billy, for example, spoke of why he waited before seeking treatment at the onset of a pressure ulcer because of his fear of possible surgical repair:
I’m scared to look at it. . . . When I get one, you know, I’ve already had so many now, you know, and I’m scared, I’m scared to lose my legs. . . . Cause my meat [muscle] is running out, you know?

Another participant, Gary, actively avoided contact with the medical system for fear of surgery and the resulting hospitalization:

I didn’t want to come back to the hospital because I didn’t want to have surgery. So I tried to avoid it as long as possible. I was like, every time I did come, it was always a problem. I had, like, a drug test ‘cause I, I smoke marijuana. So I would always come in dirty.

The second subcategory, negating consciously, occurred when a person was aware of a budding ulcer and knew that it could exacerbate but chose to deny its presence. One person, Frank, expressed his regret regarding his refusal to acknowledge or attend to his first recognized ulcer onset when asked how long it had taken him to respond:

‘Bout 2 months, like, like a fool. Like 2 months before I came in here [to get medical care]. And to the point that I started gettin’ sick and couldn’t eat. That’s when I came. I’m sittin’ at home, me and my girl, my girl was tellin’ me to come. . . . Then I, my stupid ass, stupid butt, still didn’t go to the doctor.

**Category 3: Experiencing Cognitive Dysfunction**

In some cases, a person did not have the cognitive facility to respond in an attentive and reasonable manner. This category captured the responses of Charlie, who had incurred traumatic brain injury and evidenced difficulties with planning and long-term decision making; Billy, who had problems with sustained attention associated with attention deficit/hyperactivity disorder; and Gary, who had a bipolar disorder that led to difficulty in focusing on matters of day-to-day life. Several other people had responses that reflected cognitive or behavioral impairment resulting from severe depression. For example, as Steve described the death of his younger brother, he demonstrated severe bouts of despair. Steve expressed how his state of mind affected his pressure ulcers and contributed to his reckless decision to leave a hospital waiting area out of impatience despite having two infected ulcers in need of immediate medical attention:

I just figure the faster I die, the better off I am. . . . Now I’m thinking that there is, there is no reason, and I’m thinking that there’s no purpose. I think it’s just bulls*** . . . Because every morning, or whenever I go to sleep, I wake up and I don’t wanna see tomorrow.

**Category 4: Diverting Attention**

In some cases, a person chose to engage in everyday activity or respond to a pressing daily living concern rather than attend to a recognized ulcer. Three subcategories were distinguished, ranging on a continuum from internal to external sources of distraction. The first subcategory, attending to comorbidity, represented instances in which adjustments to comorbidities or additional physical conditions affected participants’ responses. Incontinence, diarrhea and, to a lesser degree, perspiration were key concerns that disrupted participants’ choice or ability to promptly treat a budding ulcer.

For Tom, living with incontinence sometimes created tension in deciding whether to perform pressure redistribution, which was believed to relax the bladder and cause frequent urination accidents, thereby exacerbating an existing ulcer. Substance abuse was in many instances included in this category (in addition to desiring activity) because it frequently involved an addiction that shared features with disease or compromised health. In this vein, one person, Chris, recounted a period in his life when alcohol abuse negatively affected his response to several low-grade ulcers.

Desiring activity refers to an intrinsically motivated desire to participate in activity for its own sake, despite the threat of impending skin breakdown. In response to her doctor’s recommendation for bed rest, Judy said,

I just, I cannot see me lying around. I mean, it’s just not in my vocabulary. I’m a workaholic. I love my job. I have a great job at . . . [a large] accounting department. I love doing it. I’ve been there [more than 30 years], and the thought of being gone and not being able to be productive when I’m gone for 3 to 4 months just did not please me. It just didn’t seem like something that needed to be done.

Both alcohol and drug abuse are included in this subcategory because they reflect a desire for engagement in an activity despite negative consequences. Often, substance abuse diverted attention away from the need for treatment of a newly discovered ulcer.

Attending to external exigencies referred to those times when environmental factors pulled attention away from seeking proper medical care. One participant, Alley, was advised by her doctors to remain resting in the hospital in an effort to prevent exacerbation of her ulcer. Instead, she decided to forego her doctors’ recommendation and discharged herself for a few days to be at the bedside of a dying friend. The act of supporting her friend was of such importance to her that she chose to risk the possibility of worsening her ulcer.

Alley explained,

That was the one reason I wouldn’t come back. I could not leave [Lucy to die alone]. I just couldn’t. No, I was there when she passed . . . she passed on the 4th and I came back on the 6th. So you see how soon I came?

In two other cases, in response to a low-grade ulcer a person did not follow medical advice to rest but instead felt...
forced to continue working as a means of providing financial support for family members.

**Category 5: Avoiding Social Discomfort**

In two cases, a person was reluctant to comply with treatment measures because of a belief that the recommended behavior would offend or be unattractive to others. For example, Ken developed ulcers on his left toe and foot but was disinclined to consider alternative footwear such as sandals or just socks “because when people go back to work, they should look professional.” He also chose not to wear a short leg cast or splint (to decrease friction to the area of skin breakdown), which had been successful in healing foot ulcers in the past, pointing out that “some people look and ask you. A [student or colleague] would ask what happened to your foot, and I don’t want to [talk about it] . . . . I think maybe it’s the ego.”

Dave decided against hiring a night home health aide as a result of his father’s cultural belief that it was undignified, or even unmanly, to rely on “strangers” for help or to receive “pity” from outsiders. Although in-home care was within Dave’s financial capabilities, social considerations caused him to forego hiring an attendant. As a result, he would occasionally spend nights in his own urine, which facilitated continuing skin breakdown.

**Category 6: Being Thwarted From Receiving Adequate Medical Help**

At times, a decision to obtain treatment was affected by external conditions that prevented procuring proper or timely care. In these instances, medical help was sought, but for various reasons the person was unable to receive adequate treatment. In the cases of Howard and Rachel, for example, each received what they sensed or knew was less-than-optimal treatment but experienced some constraint that led to an unintended response of tolerating that substandard care. Such situations involved staff members in long-term care facilities, inadequately trained or insufficiently committed home care attendants, or clinic receptionists who triaged patients over the course of 2 weeks to reach hospital-based health professionals by telephone. The result was that she did not acquire the advice she needed to care for ulcers on both feet, which eventually progressed to Stage 4 despite the fact that medical recommendations were followed in each case (and because of the ulcer inclusion criteria for the study), the ulcer progressed to Stage 3 or Stage 4 despite the fact that medical recommendations were followed. Physicians’ advice in these cases included complete or increased bed rest, application of DuoDerm pads (Convatec, Skillman, NJ), and use of saline solution on the affected area. In Brenda’s case, she obtained her physician’s instructions for home care over the telephone and followed environmental barriers in an institutional jail setting that impeded his efforts to obtain adequate care. Others were the victims of system breakdowns. Transportation difficulties could be another obstacle, such as when Ken’s wheelchair-accessible vehicle service failed to arrive on time, which resulted in an extended period of sitting and waiting that led to ulcer progression. On two occasions, delayed reimbursement authorization prolonged the scheduling of a needed surgical repair. In Frank’s case, after noticing an ulcer onset, he was held up for a period of 2 months as he awaited authorization for a new gel cushion and used an inadequate seating device in the interim. In another instance, Mitch lacked night attendant care for repositioning assistance.

**Category 7: Relying on Self or Caregiver Help**

In some instances, a person or caregiver attempted to heal an ulcer without obtaining direct treatment or advice from a health professional. Such self-care efforts involved the use of home remedies. Frank tried to treat a burgeoning ulcer by himself until it became dangerously serious:

> My girlfriend was saying, baby, go to the doctor. I’m like no, I’m gonna heal it. I, I’ll put peroxide out on it . . . And come to find out you don’t ‘posed to put peroxide on pressure sores. It make it worse . . . . I’m at home treatin’ it, treatin’ it to the point that I threw up one day. I said, baby, get on the phone right now. Call the ambulance, I’m going to the hospital. I got, I can’t treat myself. I’m sick real bad. I knew it. And I almost, I was to the point that my kidneys were shittin’ down. They said I . . . I was to the point of last year that I almost died.

In another instance in which self and caregiver help were combined, Mitch and his mother attempted to medicate a newly noticed “little scrape” on his right elbow without seeking medically sound advice for that specific incident. The breakdown quickly progressed to a serious ulcer, resulting in nearly a year of recovery and hospitalization after complicated elbow surgery.

**Category 8: Adhering to Medical Recommendations**

This final category includes only those cases in which the person received seemingly sound advice from a health care professional on examination of an affected area and adhered to that advice. In each case (and because of the ulcer inclusion criteria for the study), the ulcer progressed to Stage 3 or Stage 4 despite the fact that medical recommendations were followed. Physicians’ advice in these cases included complete or increased bed rest, application of DuoDerm pads (Convatec, Skillman, NJ), and use of saline solution on the affected area. In Brenda’s case, she obtained her physician’s instructions for home care over the telephone and followed...
them. She reported that “it looked like it was healing up,” but eventually the ulcer exacerbated and required surgical repair.

Discussion

This study describes factors that affect the decision-making process and resultant responses of adults with SCI on discovery of a low-grade pressure ulcer. The eight main response categories that emerged from the data analysis were lacking adequate knowledge, procrastinating, experiencing cognitive dysfunction, diverting attention, avoiding social discomfort, being thwarted from receiving adequate medical help, relying on self or caregiver help, and adhering to medical recommendations. In general, these processes can lead to a delay in seeking treatment and thereby heighten the risk of ulcer progression to an advanced level.

Our analysis builds on Clark et al.’s (2006) findings, which demonstrated that a person’s individual daily life contexts are inextricably intertwined with health-related behaviors. The results indicate that individualized contextual factors of daily life have a substantial effect on the response process that follows the discovery of a low-grade pressure ulcer. Previous research on SCI-related ulcers has focused primarily on examining incidence, prevalence, and predictive risk factors and preventive measures (Brem & Lyder, 2004; Byrne & Salzberg, 1996; Consortium for Spinal Cord Medicine, 2000; Correa et al., 2006; Fuhrer et al., 1993; Garber et al., 2000; Hiser et al., 2006; Krause et al., 2001; NPUAP, 2006). Our findings suggest that it is also important to attend to the process events that occur in the critical window of time that follows the onset of early skin breakdown.

This secondary analysis has significant clinical implications for occupational therapists as rehabilitation professionals. Early ulcer recognition and treatment information must be properly transmitted by health care providers to supply patients with the resources necessary to respond adequately to the first signs of skin breakdown, especially when reentering their homes and communities after hospitalization (Garber, Rintala, Rossi, Hart, & Fuhrer, 1996). This study’s findings indicate that rehabilitation professionals need to provide patient education about early ulcer detection and recognition, the potential severity of a budding ulcer, the urgent need to receive prompt medical treatment, the ability to self-advocate for proper medical care on the first signs of receiving inadequate treatment, and the need to effectively balance prevention practices with pressing lifestyle concerns.

The accomplishment of this objective requires increased planning, development, and implementation of pressure ulcer prevention and treatment intervention programs for patients in rehabilitation facilities (May, Day, & Warren, 2006). To have an effective impact on responses to early-stage pressure ulcers, a strong patient training component must emphasize the importance of early detection and treatment at the time of ulcer onset. As seen in this study, even when a patient adheres to a doctor’s recommendations, some ulcers may still progress to a medically serious level. Therefore, patients must understand the insidious nature of early onset and the magnitude of future risk if ulcers are not attended to promptly. Strategies for effective interventions may include the use of peer-based training and counseling, provision of resource information in a variety of formats, engagement in simulation exercises that address problem-based scenarios, and experiential techniques such as group learning from real-life situations and sharing of experiences (Carlson, Clark, & Young, 1998; University of Southern California–RLANRC Pressure Ulcer Study Team, 2007). Staff members are encouraged to build rapport with patients, which in turn will support knowledge acquisition, confident decision making, and creative problem solving in application of the information learned (May et al., 2006).

After discharge, scheduled formal follow-up sessions can reinforce approaches previously learned in a rehabilitation facility (Garber et al., 2000; Leduc & Lepage, 2002). Personalized approaches to pressure ulcer prevention and management should ideally extend to a person’s daily life context, incorporating primary caregivers and family members in an interactive learning process during and after hospitalization (Garber et al., 1996; Leduc & Lepage, 2002; Noreau & Fougeryrollas, 2000). In this regard, a professionally administered in-home occupational therapy intervention that focuses on the attempt to ensconce preventive behaviors in the client’s daily routine, such as is emphasized in the lifestyle redesign approach (Clark et al., 1997; Jackson, Carlson, Mandel, Zemke, & Clark, 1998), may propel the learning and assimilation of precautionary measures. To support such efforts, additional resources may be provided, including teaching Web sites that offer interactive tools and chat rooms; instructional DVDs, videotapes, or audiotapes; community newsletter subscriptions; or referrals to local service resources. The establishment of wound care clinics and the formation of consumer support groups can also serve as valuable continuing community resources.

Occupational therapists and other rehabilitation specialists particularly need to be mindful of the tension between pressing lifestyle concerns and adherence to a risk-reducing regime. Our findings, as evidenced especially by the diverting attention category, revealed this tension to be a consistent struggle for many participants. In view of this distraction effect, the health care provider is called on to carefully determine what, when, and how much information to deliver on the basis of the opportunities and obstacles embedded in a person’s life.
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According to our results, the complex nature of pressure ulcer response history. For example, self-report errors could result in underreporting of continued risk-taking behaviors after discovery of a budding ulcer or overreporting of adherence to doctors’ recommendations. Again, this is unlikely to bias the identification of response categories. Third, within the framework of the methodology used, it was possible to lump and split the response categories or subcategories in slightly different ways. However, we should note that there was a high level of convergence between Claudia A. Dunn and Jeanne M. Jackson in the category typology determination phase. Moreover, it seems doubtful that minor shifts in the categories would change the study’s basic outcomes because such alterations would merely provide an alternate organizational framework for the same information.

A final limitation is that because this study was a secondary analysis, the data stemmed from individualized profiles and raw interview transcripts. Therefore, there was no opportunity to pursue follow-up probing to provide a more complete description of the given response processes.

Future research would benefit from longitudinally exploring responses to Stage 1 and Stage 2 pressure ulcers that did not progress to an advanced level (i.e., exploration of “successful” responses) and documenting how the underlying processes compare with the results of this analysis. Additionally, it would be useful to determine responses using a random sample of adults with SCI. Future research should also include an exploration of the cost-efficiency, effectiveness, and patient satisfaction of interventions addressing pressure ulcer prevention and education.

Conclusion

According to our results, the complex nature of pressure ulcer progression in real-life contexts dictates the integration of proper patient care and an educational approach into the fabric of each person’s unique, multilayered, day-to-day existence. This integration calls for shifting focus away from imparting generalized preventive information and onto the detailed content of daily life by providing customized occupational therapy interventions in everyday settings. By minimizing the need for surgical repair and rehabilitation expense, the additional time and effort required to implement this recommendation is likely to prove cost effective. This approach holds great promise for occupational therapists to best promote health and facilitate long-term well-being in response to the problem of SCI-based pressure ulcers.

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