Lifestyle Changes and Pressure Ulcer Prevention in Adults With Spinal Cord Injury in the Pressure Ulcer Prevention Study Lifestyle Intervention

Samruddhi Ghaisas, Elizabeth A. Pyatak, Erna Blanche, Jeanine Blanchard, Florence Clark; PUPS II Study Group

Pressure ulcers (PrUs) are a major burden to patients with spinal cord injury (SCI), affecting their psychological, physical, and social well-being. Lifestyle choices are thought to contribute to the risk of developing PrUs. This article focuses on the interaction between lifestyle choices and the development of PrUs in community settings among participants in the University of Southern California–Rancho Los Amigos National Rehabilitation Center Pressure Ulcer Prevention Study (PUPS II), a randomized controlled trial of a lifestyle intervention for adults with SCI. We conducted a secondary cross-case analysis of treatment notes of 47 PUPS II participants and identified four patterns relating PrU development to lifestyle changes: positive PrU changes (e.g., healing PrUs) with positive lifestyle changes, negative or no PrU changes with positive lifestyle changes, positive PrU changes with minor lifestyle changes, and negative or no PrU changes with no lifestyle changes. We present case studies exemplifying each pattern.

Serious (Stages 3 and 4 of four stages) pressure ulcers (PrUs) are a common and potentially life-threatening complication of spinal cord injuries (SCIs; Garber, Rintala, Holmes, Rodriguez, & Friedman, 2002). PrUs can become a psychological, physical, and social burden to patients, affecting their health, well-being, and quality of life (Gorecki et al., 2009). A PrU is an area of skin tissue damage caused by pressure, or pressure in combination with shear, and the resultant disruption of blood supply (National Pressure Ulcer Advisory Panel and European Ulcer Advisory Panel, 2009). Risk factors for PrU development among people with SCI include older age, severity and level of SCI, degree of impairment, comorbid health conditions, poor hygiene, stress, and substance abuse (Byrne & Salzberg, 1996; Chen, Devivo, & Jackson, 2005; Garber, Rintala, Rossi, Hart, & Fuhrer, 1996). Additionally, the lack of patient education regarding prevention of PrUs contributes to the recurrence of PrUs among people with SCI (Garber et al., 1996).

In addition to negative consequences to health and quality of life, PrUs are associated with increased health care costs, with one study demonstrating a 3.6-fold increase in expenditures for community-dwelling people with SCI who experienced a PrU versus those who were PrU-free (Stroupe et al., 2011). Cost-effective community interventions are clearly needed to prevent PrUs among people with SCI (Byrne & Salzberg, 1996; Garber & Rintala, 2003; Garber, Rintala, Hart, & Fuhrer, 2000).

In response to the need for efficacious community-based interventions addressing PrU prevention, Clark and colleagues (2006) conducted a 2-yr qualitative study investigating lifestyle factors contributing to the formation of PrUs in adults with SCI. Findings from this study, the Pressure Ulcer Prevention Study I
(PUPS I), suggested that the prevention of PrUs in adults with SCI may be related to everyday lifestyle choices and daily routines (Clark et al., 2006; Dunn, Carlson, Jackson, & Clark, 2009; Fogelberg, Atkins, Blanche, Carlson, & Clark, 2009). The risks encountered by this population are complex, multilayered, and individualized. The investigative team identified eight lifestyle principles that partially explained PrU risk in adults with SCI, including disruption of routine, decay of preventive behaviors, limited access to care, and inadequacy of equipment, and recommended that these principles be incorporated into a lifestyle-based intervention (Jackson et al., 2010). Additionally, the team identified response patterns to the initial detection of a low-grade PrU, many of which, such as procrastinating and avoiding social discomfort, could delay seeking treatment and increase the risk of worsening the PrU (Dunn et al., 2009).

Clark and colleagues (2007) developed a manualized community-based lifestyle intervention, the Pressure Ulcer Prevention Program (PUPP), to address the lifestyle concerns identified in PUPS I. The PUPP intervention is aimed at reducing the incidence of serious PrUs and associated surgeries, reducing medical expenses, and enhancing quality of life among community-dwelling adults with SCI (Vaishampayan, Clark, Carlson, & Blanche, 2011). The efficacy and cost-effectiveness of PUPP are presently being evaluated in a randomized controlled trial, Lifestyle Redesign for Pressure Ulcer Prevention in Spinal Cord Injury (PUPS II), in which a total of 170 participants were randomized into either a control group receiving usual care or an experimental group receiving the PUPP intervention.

The PUPP intervention spans 1 yr, divided into an intensive phase (Months 0–6), which incorporates weekly in-person and telephone intervention sessions, and a tapered phase (Months 7–12), which includes biweekly telephone sessions and two in-person visits. In addition to taking part in preplanned sessions, participants are instructed to contact their occupational therapist for immediate assistance if they detect a new PrU or experience an unanticipated event that heightens PrU risk. Delivery of the PUPP intervention is guided by a manual that incorporates both fixed and variable topics, organized into six modules: (1) Understanding Lifestyle and PrU Risk, (2) Advocacy, (3) Equipment and the Physical Environment, (4) Social Support, (5) Happiness and Personal Well-Being, and (6) Planning the Future (Blanche, Fogelberg, Diaz, Carlson, & Clark, 2011). The intervention is individually tailored by applying the variable topics in accordance with a participant’s individualized goals for reducing PrU risk.

The PUPP intervention manual incorporates eight overarching principles, which, regardless of the individualized goal addressed, are adhered to throughout the intervention (Jackson et al., 2010). For example, the principle of lifestyle trade-off states that PrU management strategies (e.g., prolonged bedrest) are sometimes in conflict with personally meaningful activities (e.g., attendance at a family function). In such cases, the benefits of engaging in the desired activity must be carefully weighed against the potential for PrU worsening.

The purpose of this article is to explore the relationship between lifestyle changes made within the context of the PUPP intervention and the development and progression of PrUs. Through the use of case studies, this article examines participants’ life histories and life choices as factors interrelated with PrU development, giving particular attention to PrU progression in real-life contexts.

Method

Research Design

We investigated the relationship between changes in lifestyle and changes in PrU status through a secondary analysis of intervention recipients’ treatment notes recorded by occupational therapist and nurse interveners. This analysis was conducted as part of the PUPS II study, in which 170 participants were randomized to either the 12-mo PUPP intervention (n = 83) or a usual-care control group (n = 87). The participants selected for this secondary analysis included all participants in the intervention group who had completed the 12-mo intervention phase as of December 2011 (n = 47). This study was approved by the Los Amigos Research and Education Institute and University of Southern California institutional review boards, and all participants completed informed consent before enrollment.

Participants

Participants in the PUPS II study were English- or Spanish-speaking adults with SCI and a history of serious PrUs. They were recruited from Rancho Los Amigos National Rehabilitation Center (RLANRC), a county facility serving primarily urban, low-income patients. Bilingual recruiters attended the RLANRC PrU management clinic each week to enroll interested patients and visited the PrU management inpatient unit to discuss the study with prospective participants before discharge. Recruitment posters were also placed in strategic locations throughout the RLANRC campus.

Procedures and Data Collection

The primary data used for this retrospective secondary analysis were treatment notes of the 47 selected intervention group participants. Participants’ treatment
notes were recorded by licensed occupational therapists and registered nurses administering the intervention. Notes were entered in an electronic database and contained participants’ background information, individual session notes, discharge summaries, and information on unusual events that may have occurred during the intervention. In total, 1,922 documents were reviewed, including an average of 40.9 notes per participant (range: 4–70). The data available for each participant included a mean of 33.4 occupational therapy treatment notes, 2.5 nursing treatment notes, 3 incident notes, 1 health history, and 1 discharge summary.

Data Analysis
Data analysis followed a four-step process. First, the first author (Ghaisas) read all the intervention notes and identified the need to classify participants on the basis of the relationship between their lifestyle changes and PrU status. Second, she organized data from 9 participants into provisional case studies to explore the relationship between lifestyle changes and PrUs. Four key patterns emerged from this process, which were reviewed with the occupational therapy interveners and members of the research team for confirmation.

Third, to validate these patterns, the first author reread the treatment notes for all participants who had completed the intervention phase by December 2011 (\(n = 47\)) and, using demographic and qualitative data, categorized them into the previously identified patterns. To accomplish this analytic process, she created data tables that included each participant’s level of SCI, number of years since injury, history of PrUs during and before the study period, positive and negative factors associated with the participant’s background, progress made healing PrUs during intervention, and a summary of lifestyle changes implemented during intervention. Finally, the interveners and three members of the research team reviewed the data tables, confirmed the categories assigned to all 47 participants, and selected exemplary cases that best represented the four identified patterns between lifestyle changes and formation of PrUs.

Results
In total, 47 cases were reviewed for this article, representing all PUPS II participants who had completed the PUPP intervention phase by December 2011. Of the 47 cases, 17 experienced no PrUs during the intervention and therefore were excluded from the analysis. Two participants had very poor adherence (<17%) to the lifestyle intervention and were excluded from analysis because of insufficient data on lifestyle changes made during the intervention. Three participants displayed irregular patterns of lifestyle and behavior change and could not be categorized. The remaining 25 participants’ demographic and clinical characteristics are outlined in Table 1. Participants’ characteristics closely mirrored those of the full PUPS II sample \((N = 170; Pyatak et al., 2013)\), with the following exceptions: More participants in this analysis were White (24%, \(n = 6\) vs. 12.4%, \(n = 21\)), and fewer were Hispanic (36%, \(n = 9\) vs. 48.2%, \(n = 82\)); fewer were female (8%, \(n = 2\) vs. 15%, \(n = 26\)); and more had complete SCIs (80%, \(n = 20\) vs. 70%, \(n = 119\)).

Four patterns characterized the relationship between lifestyle changes and PrU status:
- Positive PrU changes (e.g., healing and closing PrUs) accompanied by positive lifestyle and behavior changes

### Table 1. Demographic and Clinical Characteristics of Participants Who Developed Pressure Ulcers \((N = 25)\)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>(n) (%) or (M (SD))</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic</strong></td>
<td></td>
</tr>
<tr>
<td>Age, yr</td>
<td>45.5 (13.5)</td>
</tr>
<tr>
<td>Education (&lt; high school degree or GED certificate)</td>
<td>9 (36)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>23 (92)</td>
</tr>
<tr>
<td>Female</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Race–ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>9 (36)</td>
</tr>
<tr>
<td>Black</td>
<td>7 (28)</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>6 (24)</td>
</tr>
<tr>
<td>Other or more than one race</td>
<td>3 (12)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
</tr>
<tr>
<td>$0–$999/mo</td>
<td>14 (56)</td>
</tr>
<tr>
<td>$1,000–$1,999/mo</td>
<td>5 (20)</td>
</tr>
<tr>
<td>$2,000/mo</td>
<td>6 (24)</td>
</tr>
<tr>
<td>Residence type</td>
<td></td>
</tr>
<tr>
<td>House, apartment, condo</td>
<td>24 (96)</td>
</tr>
<tr>
<td>Assisted living, nursing home</td>
<td>1 (4)</td>
</tr>
<tr>
<td><strong>Clinical</strong></td>
<td></td>
</tr>
<tr>
<td>Years since SCI</td>
<td>20.5 (13.2)</td>
</tr>
<tr>
<td>Body mass index</td>
<td>27.8 (5.8)</td>
</tr>
<tr>
<td>No. of comorbidities(^a)</td>
<td>7.0 (2.4)</td>
</tr>
<tr>
<td>Paralysis type</td>
<td></td>
</tr>
<tr>
<td>Paraplegia</td>
<td>18 (72)</td>
</tr>
<tr>
<td>Tetraplegia</td>
<td>6 (24)</td>
</tr>
<tr>
<td>Undetermined</td>
<td>1 (4)</td>
</tr>
<tr>
<td>SCI type</td>
<td></td>
</tr>
<tr>
<td>Complete</td>
<td>20 (80)</td>
</tr>
<tr>
<td>Incomplete</td>
<td>5 (20)</td>
</tr>
</tbody>
</table>

\(^a\)Comorbidities assessed were autonomic dysreflexia, heart disease, diabetes, high blood pressure, kidney disease, liver disease, pain, spasticity, contractures, colostomy, urinary tract infections, catheter, seizures, asthma or lung disease, and referral for counseling.

Note. GED = general educational development; \(M\) = mean; SCI = spinal cord injury; \(SD\) = standard deviation.
Negative or no PrU changes accompanied by positive lifestyle and behavior changes  
Positive PrU changes accompanied by minor or no lifestyle or behavior changes  
Negative or no PrU changes accompanied by minor or no lifestyle or behavior changes.

Each pattern is exemplified by one of four case studies described later in this section.

For the purposes of this study, behavior change was conceptualized as eliminating discrete behaviors that increased PrU risk (such as prolonged sitting time or performing transfers incorrectly) or adopting behaviors that decreased PrU risk (such as performing pressure reliefs at regular intervals). Lifestyle change was conceived of more broadly as altering one’s routines of daily living, adapting the physical and social environment, and developing a mindset that was cognizant of PrU risk in everyday life situations.

Table 2 provides definitions for each pattern and delineates the number of cases in each pattern. Of the 25 cases, we found that the majority (19 cases) had adopted positive lifestyle and behavior changes and experienced improvement in PrU status. Three made positive lifestyle and behavior changes; however, their PrUs did not improve. One participant made minimal or no changes but nevertheless experienced improvement in PrU status, and 2 participants made minimal or no changes and experienced no change or worsening of PrUs.

Case Study 1. Mario: Positive PrU Changes With Positive Lifestyle and Behavior Changes

Life and Medical History. Mario was born in a city near Los Angeles to working class parents. His background story appears challenging. As a child, he was physically abused by his alcoholic father; in his adolescence, he used drugs and alcohol and dropped out of school; and by the time he was 30, he had married twice and fathered five children. Mario sustained a T1 SCI at age 35, secondary to a gunshot wound during an argument with a family member. After the injury, Mario developed depression that lasted approximately 3 yr. He later became a concert promoter and community activist, raising money for youth and senior citizens.

About 6 yr after his SCI, Mario was involved in a motor vehicle accident that left him with severe shoulder and leg injuries requiring surgery. During this hospitalization, he sustained his first PrU on his right buttock. He described this experience in the following way: “They did not turn me, and I couldn’t feel my femur . . . . I did not want to move or be moved, plus I could not move certain areas.” This PrU progressed to a Stage 4 but eventually healed without requiring surgery.

Intervention Goals and Progress. Mario began intervention 7 yr after his SCI, with a healing Stage 4 PrU. He also had fungal infections on his buttocks and thighs and frequent muscle spasms. Because of severe shoulder pain and increased weight, Mario was unable to perform pressure reliefs effectively, lessening the likelihood of closing his PrU. When he started the intervention, Mario needed surgery on his shoulder to repair damage caused by his car accident 2 yr before, but his doctors had postponed the surgery to avoid limiting his functional abilities and inhibiting PrU healing. Additional factors that increased Mario’s PrU risk included lack of accessibility to transportation, inadequate equipment, poor communication with health care professionals, inadequate transfers, poor bladder and bowel management, and the need for caregiver support for pressure reliefs and home management.

Mario was very engaged in the intervention; he independently identified all of his risk factors and collaborated with his intervener in developing a personal PrU prevention plan. The intervention focused on increasing

| Table 2. Typology of Relationship Between PrU Status and Lifestyle Change (N = 25) |
|----------------------------------|------------------|------------------|
| Lifestyle and Behavior Changes | Positive Change | Negative or No Change |
| Positive change | n = 19  
Behavior changes pertaining to PrU risk; lifestyle changes in accordance with intervention principles  
Improvement of PrU status without surgical intervention | n = 3  
Behavior changes pertaining to PrU risk; lifestyle changes in accordance with intervention principles  
No change in or worsening PrU status |
| Minor or no change | n = 1  
Minimal or no changes in prevention behaviors;  
no lifestyle changes in accordance with intervention principles  
Improvement of PrU status without surgical intervention | n = 2  
Minimal or no changes in prevention behaviors;  
no lifestyle changes in accordance with intervention principles  
No change in or worsening PrU status |

Note. PrU = pressure ulcer.
his self-advocacy skills, losing weight, learning to better manage his PrU and SCI by acquiring needed medical supplies and caregiver support, and improving his ability to monitor his skin integrity and wound healing.

Unfortunately, Mario suffered three additional major challenges during the intervention. First, his son was murdered, causing Mario to become depressed. Second, he had his shoulder surgery, which consequently restricted his mobility and posed a greater need for assistance in his daily routines while he recuperated. Third, while in the hospital after his shoulder surgery, he developed a Stage 2 PrU on his right hip.

**Intervention Outcome.** Despite his challenges, Mario was able to make lifestyle changes to enhance his health. During the intervention, he achieved most of his identified goals: improving his self-advocacy skills, losing 20 pounds by making healthy diet choices, learning to order and use adaptive equipment effectively to attend to his PrU status, and improving his ability to monitor his skin integrity and wound healing by using a digital camera. Most important, in spite of undergoing several difficult life events during the intervention, Mario was able to adopt lifestyle changes that enabled him to successfully heal his PrUs without surgical intervention.

**Case Study 2. Moses: Negative or No PrU Changes With Positive Lifestyle and Behavior Changes**

**Life and Medical History.** Moses was born and raised in a small town near Los Angeles. His biological parents divorced when he was a baby, and his mother remarried twice. Moses had one older sister and several step-siblings with whom he maintained good relations. Although Moses was considered a “good kid” who stayed out of trouble most of the time, he dropped out of high school halfway through his senior year. As a young adult, he worked several blue-collar jobs, was married and divorced twice, and fathered four children.

When he was 25 yr old, Moses sustained T7 complete paraplegia as a result of a motor vehicle accident while intoxicated. During the 30 yr between his SCI and the start of the intervention, Moses had numerous serious PrUs on his trochanters and ischial tuberosities and underwent five flap surgeries. In addition, he had a left Girdlestone procedure (i.e., removal of the hip joint) about 2 yr after his SCI, a hip disarticulation amputation of his left leg 15 yr postinjury, and a right Girdlestone procedure secondary to osteomyelitis 2 yr before entering the PUPP intervention. In the months before the intervention, Moses developed a superficial PrU on his left ischium while in the intensive care unit for a severe bone infection. This PrU worsened to become Stage 3 as a result of inadequate pressure reliefs.

Moses’ social history since his injury revealed serious challenges. Despite his divorces, he stayed in touch with all of his children and was particularly close with two of them. However, 4 yr before intervention, one of his sons, mistaken for a gang member, was murdered in a gang-related shooting. This led Moses to feelings of depression and hopelessness. In addition, he had lost part of his support system because the son who was murdered had lived with him and been an important source of emotional support. Despite this loss, Moses maintained a large social network that included his mother, his other three children, his grandchildren, and his first wife and her family.

**Intervention Goals and Progress.** At the start of intervention, Moses was 58 yr old and lived with his mother in his own living space separate from the larger household. He was well cared for by an attendant for 5 hr per day and by his extended family. Moses’s risk factors included fragile skin as a result of an extensive history of PrUs and surgeries, insufficient knowledge about how to manage his medical needs, limited literacy and writing skills restricting his ability to manage medical documents, inadequate equipment, and depression.

Moses began intervention with a preexisting healing Stage 3 left ischial PrU. Healing this wound was the major focus of the intervention. The intervener collaborated with Moses by assisting him with managing medical forms, obtaining and using equipment such as a multichamber air wheelchair cushion and a vibrating watch to monitor his sitting time, and maintaining a paper calendar to keep a log of his medical appointments. In addition, the intervener and Moses discussed adequate nutrition for tissue healing, and Moses adopted a healthy and protein-rich diet.

Moses experienced three setbacks during the intervention that challenged his health, yet paradoxically served as beneficial learning experiences. First, because of his history of osteomyelitis, Moses had to undergo a bone scan. Positioning for the bone scan caused his left ischial PrU to deepen. Second, during two consecutive visits to a wound clinic, two doctors disagreed about whether he should get “a little flap” surgery to close his PrU or a negative-pressure wound-healing device, which caused delays in implementing a successful care strategy. Ultimately, he used the negative-pressure device, which he preferred over surgery. Third, a suture line from a previous surgery opened in his buttock region. His surgeon recommended, and Moses agreed, that he undergo surgery to close both this wound and the ischial PrU.

As the intervention progressed, Moses learned different PrU management methods and incorporated them into his daily routines. For example, he began to wear an alarm watch to remind him to perform pressure reliefs in a timely manner, and he adopted the strategy of sitting up...
for shorter time periods. Moses increased his understanding of the health care system and how to advocate for himself in health care encounters. He was also able to identify his grief over the death of his son and subsequent depression and was interested in pursuing counseling once he had adequate sitting tolerance to attend weekly sessions.

Intervention Outcome. At the end of the intervention, Moses’s left ischial PrU had decreased in depth but had not healed completely and ultimately required surgery. Although Moses had adopted healthy habits during the intervention, they were not sufficient to heal his PrU, apparently because of a confluence of extenuating circumstances. Thus, he was a good example of someone who followed the intervener’s recommendations about lifestyle changes, but these changes did not translate into appreciable changes in his PrU.

Case Study 3. Raul: Positive PrU Changes With Minor or No Lifestyle or Behavior Changes

Life and Medical History. Raul was born and raised in the southwestern United States. His childhood was unstable, and he left home as a teenager to escape abuse. Two yr later, he moved in with an uncle in California and earned his general educational development (GED) certificate and a certificate in cement masonry. He moved several times over the next few years, partially for work and partially to escape gang activity. At the age of 18, Raul sustained an SCI caused by a gunshot wound incurred during gang violence, resulting in T12 complete paraplegia. After the injury, he used drugs for 20 yr; was homeless for at least 4 yr; and never held a job, got married, or had children.

Since his SCI, Raul reported having developed 15–20 PrUs on his buttocks, ankles, tailbone, and feet, all of which advanced to Stage 4 and resulted in flap surgeries. He stated he developed these PrUs because he was homeless and dirty, wore shoes without socks, had swollen legs, did not attend doctors’ appointments, did not check his skin, used drugs, did not have adequate caregiving, spent too much time in his wheelchair, and was depressed. He had a right total leg amputation because of hip osteomyelitis, a colostomy, and insertion of a supra-pubic catheter. At the start of intervention, he had three PrUs and was taking medications for hypertension, spasms, and pain.

Intervention Goals and Progress. At the outset of intervention, 30 yr after his SCI, Raul indicated a lack of willingness to make lifestyle or behavior changes. During the first session, he stated, “I know what I have to do . . . I already know this.” He appeared distracted and displayed cognitive deficits, such as poor attention, eye contact, and listening skills, along with memory deficits possibly acquired from his history of drug abuse. These limitations interfered with the intervener’s ability to build rapport and hampered progress during the course of intervention.

The intervener noted several factors putting Raul at high PrU risk. He had a manual wheelchair with a missing footrest, posing a risk of skin tears because of unsafe positioning. Additionally, his home had poor accessibility, making him prone to injury from jarring movements and bumping into things. For example, the only accessible entrance into his house required him to travel across 6 yd of dirt terrain, and the hallways and doors of his home were narrow. Moreover, Raul’s financial resources were insufficient to fulfill his equipment needs. Finally, although he performed pressure reliefs fairly regularly, he did not limit his sitting time. Raul, however, also had several strengths at the start of intervention: Access Paratransit services (which provides transportation around Los Angeles for people with disabilities), making it relatively easy for him to travel to and from medical appointments and other activities; knowledge about resources for obtaining supplies; good communication skills; and adequate understanding of health care services.

Raul entered the intervention with venous stasis ulcers on his medial ankles, unstageable PrUs on his left plantar heel and left big toe, and a Stage 2 PrU on his left ischial tuberosity. The focus of the intervention was on healing these wounds and preventing future PrUs. To accomplish these goals, the intervener tailored the program to meet Raul’s needs, including practicing transfers and reducing sitting time. When Raul developed shoulder pain during the intervention, the intervener advised him to exercise regularly and obtain an overhead trapeze for transfers, both of which Raul did. In addition, he increased his time spent lying in bed to avoid stress on his shoulders.

Despite this limited progress, overall, Raul did not make substantive changes specifically targeted toward PrU prevention and maintained an attitude of indifference throughout the intervention. The few lifestyle changes he made were in response to his shoulder pain, and their contribution to his PrU improvement was incidental. Therefore, in the context of this PrU prevention intervention, these changes were considered minimal. One explanation why Raul did not fully comply with the strategies suggested by his intervener is that although he had a fair understanding of healthy behaviors, his attention deficits limited his ability to maintain those behaviors. Moreover, he had limited social and caregiver support to help him with his daily routines.

Intervention Outcome. At the end of intervention, Raul’s venous stasis ankle ulcers had improved and the unstageable PrUs on his left heel and left big toe had healed. Raul’s behavior change (lying in bed more) in response to
his shoulder pain eventually contributed to improvement of his ischial PrU, though it did not heal completely. Thus, he was an exemplary case of someone who made minimal lifestyle changes and still improved his PrUs.

**Case Study 4. Andy: Negative or No PrU Changes With Minor or No Lifestyle or Behavior Changes**

**Life and Medical History.** Andy was born and raised in Los Angeles. At age 16, he was a victim of a drive-by shooting, causing T5 complete paraplegia. After his injury, he dropped out of high school and underwent rehabilitation for 3 mo, becoming independent in his self-care. Andy had an extensive medical history after his SCI. Between ages 20 and 30, he had multiple flap surgeries, primarily on his ischial tuberosities and trochanters, because of inadequate self-care. He had urostomy and colostomy procedures to promote healing and prevent new wounds in the buttocks area and bilateral Girdlestone procedures secondary to bone infection. A chart review revealed several more flap surgeries during his 30s, culminating with surgery on his bilateral ischial tuberosities at age 39. Because of his extensive surgical history, Andy had very little healthy tissue left and was told that he would lose his leg if he required any more flap surgeries.

**Intervention Goals and Progress.** At the beginning of intervention, approximately 1 yr after the flap surgery on his ischial tuberosities, Andy had a healing Stage 3 PrU on his right heel. Andy’s skin was fragile and uneven because of numerous past surgeries and substantial scar tissue, but he had had no skin breakdown on his buttocks since his most recent surgery. He stated that the threat of amputation had motivated him to prevent serious wounds from developing and the need for future flap surgeries. Andy lived with his mother in stable housing and reported having a supportive network of family and friends with whom he loved to spend time. He reported smoking half a pack of cigarettes per day, drinking occasionally, and smoking medical marijuana about once a day to control spasms. He loved to drive, and he cruised around his neighborhood for hours at a time.

In the first session, Andy made it clear that he was not interested in the intervention and had hoped to be in a placebo group. He received numerous phone calls during the first session, which restricted the intervener’s ability to build rapport. His attitude suggested a lack of readiness to change and unwillingness to cooperate with the intervener, both of which continued throughout the intervention. However, Andy identified his main goal in the intervention as staying in bed to heal the PrU, with secondary goals of applying for Section 8 housing assistance and obtaining his GED certificate. The intervener tailored the intervention to assist him in achieving these goals, focusing on educating Andy regarding unhealthy behaviors and the need to stay in bed to heal his existing PrU.

Although Andy demonstrated adequate knowledge of PrU prevention and health management techniques such as safe transfers and pressure relief strategies, he did not perform them enough to improve his skin’s health during the intervention. Although he understood the benefits of wearing the protective heel boot that the intervener gave him in the second session, Andy stated that he would wear it only in bed or possibly in his wheelchair, and only if the PrU on his heel did not progress as per his expectations. Additionally, he was advised by the intervener to wear sweatpants to avoid shearing; he tried them but was noncommittal about wearing them regularly. Moreover, he was not interested in adopting any system to remind him in a timely manner to do his pressure reliefs. Finally, and most important, he frequently told the intervener he had reduced his sitting time to 3–4 hr daily to heal his PrUs; however, the intervener learned from Andy’s mother during the last sessions that Andy was in fact sitting up to 10 hr daily.

Andy demonstrated a general lack of motivation and interest in maintaining healthy habits in other ways. His multiple daily car transfers were hasty and jarring, which increased the risk on his skin condition. He discussed with his physician the possibility of quitting smoking but later told the intervener that he was not really going to do so. Finally, he stated that he wished to visit the PrU Management Service clinic at RLANRC but did not call to schedule an appointment until the intervener reminded him repeatedly.

Andy’s risky practices negatively affected his PrU status. Although the PrU on his right heel closed during intervention, in that time he also developed a Stage 2 PrU on his right ischium at the site of a previous flap surgery. This PrU worsened in spite of the intervener’s efforts and regular medical care. By the end of intervention, this PrU had deteriorated to Stage 3 and resulted in a surgery referral from a PrU–SCI specialist. He also developed a small Stage 1 PrU on his left heel, which did not heal or improve by the end of intervention because he did not adhere to wearing protective boots.

**Intervention Outcome.** Andy exemplified a participant who did not change his lifestyle or behaviors in conjunction with intervention and whose wounds worsened. He did not comply with the intervener’s or other health care professionals’ recommendations or try to achieve his intervention goals. He exhibited a lack of engagement in intervention, and caring for his wounds was a low priority. Although he healed one small Stage 2 PrU on his right heel, he developed two additional PrUs that worsened and ultimately required flap surgery.
Discussion

The PUPP intervention is aimed at promoting positive lifestyles and behavior changes in people with SCI to prevent the development of PrUs. The current analysis focused on the relationship between participants’ PrU development and lifestyle changes made during intervention. We reviewed intervention data on 47 participants, identified four patterns of lifestyle changes as they related to PrU development, and presented case studies exemplifying each pattern. Table 3 provides a summary of the case studies.

The case studies may eventually help ascertain the best candidates for this type of preventive lifestyle intervention. For example, participants who showed positive lifestyle and behavior changes were motivated, could identify goals, and had some support structure in their life. Of these participants, many also ultimately healed or improved their PrUs without surgery. Participants whose PrUs did not improve despite participating in the intervention and making positive lifestyle and behavior changes typically experienced additional medical complications or fragile skin or were overwhelmed with circumstances beyond their control that heightened PrU risk. Participants who did not change their lifestyle or behavior generally lacked a sense of urgency regarding PrUs or had persistent knowledge gaps regarding the importance of skin health. They were often observed to prioritize other issues in their lives ahead of PrU management and may have been constrained in their ability to make lifestyle changes because of psychosocial challenges previously described by our investigative team (Pyatak et al., 2013).

Many participants were socioeconomically disadvantaged, lacking resources that may have enabled them to make more extensive lifestyle and behavioral changes. Although the PUPP intervention aimed to ameliorate these challenges, the scope of possible changes was limited. Because this population is subject to sizable health disparities, broad-scale social and political changes addressing these disparities would likely have a major impact on their ability to make healthful lifestyle changes.

Limitations and Future Research

Because this was a secondary analysis in the form of a limited number of case studies, definitive conclusions cannot be made regarding whether the identified patterns were causative for PrU healing or lifestyle change. However, these patterns should be considered in future research and clinical practice. In addition, these patterns, which were extracted using data on 47 participants from the set of 83 total participants in the intervention arm of PUPS II, may be revised after data collection is completed on all the intervention participants. Another limitation is that the case study information in this article was based on interveners’ notes and not collected firsthand by the authors. Therefore, because the interveners’ notes were generated for purposes other than our analysis, their use may adversely affect the validity of the findings.

Finally, this analysis investigated only participant characteristics, whereas the response to intervention ultimately rests not only on the participant, but also on the interveners’ skills. Future studies should investigate the interveners’ attributes associated with better outcomes. Moreover, a description is needed of the process variables inherent in interveners–participant interaction that may influence the degree to which the intervention is beneficial. Future work should also explore participants’ motivations for engaging in the intervention (e.g., desire to make lifestyle changes, financial incentives, social pressure) and to what extent participants believed the intervention addressed their needs and concerns related to health and quality of life.

Implications for Occupational Therapy Practice

Our findings have the following implications for occupational therapy practice:
- Lifestyle factors and PrU development are interrelated; four patterns of relationships between the two emerged from this study.

<table>
<thead>
<tr>
<th>Lifestyle and Behavior Changes</th>
<th>Positive Change</th>
<th>PrU Status</th>
<th>Negative or No Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive change</td>
<td>Mario: Lost weight, improved communication with health care professionals, learned to take charge of situations, performed regular pressure reliefs, focused on healing PrU</td>
<td>Healed Stage 4 and Stage 2 PrU</td>
<td>Moses: Learned PrU management, improved advocacy and communication skills, adopted healthy diet, enhanced understanding of health care system</td>
</tr>
<tr>
<td>Minor or no change</td>
<td>Raul: Did not change habits, changed lifestyle in response to pain but did not care for PrUs, did not limit sitting time, continued risky behaviors</td>
<td>Improved Stage 2 PrU</td>
<td>Andy: Did not change habits, did not limit sitting time, continued risky behaviors, lied to the intervener about compliance</td>
</tr>
</tbody>
</table>

Table 3. Summary of Case Studies: Relationship Between Lifestyle Change and Pressure Ulcer (PrU) Status
The four patterns were not absolute, demonstrating the complexity of the relationships.

Additional factors, such as medical complications and unanticipated life circumstances, affect PrU development and lifestyle change.

Community-based practice offers a valuable opportunity to comprehensively address lifestyle and environmental factors during intervention with people at risk for PrU development.

Conclusion
In every randomized study, it is ultimately important to identify the best and worst candidates for the intervention being tested. This secondary analysis provided a first glimpse into issues that may contribute to positive and negative outcomes of a lifestyle intervention to prevent PrUs. Through analysis of the case studies, we became aware of the complexity of participants’ lives, the impact of the environment and events outside participants’ control, and the role of the health care system in shaping participants’ lifestyle and behaviors in response to PrUs.

The four case studies were chosen as exemplars of the patterns identified in this research. By presenting these case studies, we aimed to provide a snapshot of this PrU prevention intervention in real patients’ lives and communicate the complexity of implementing a lifestyle intervention to prevent PrUs. Through analysis of the case studies, we became aware of the complexity of participants’ lives, the impact of the environment and events outside participants’ control, and the role of the health care system in shaping participants’ lifestyle and behaviors in response to PrUs.

The four case studies were chosen as exemplars of the patterns identified in this research. By presenting these case studies, we aimed to provide a snapshot of this PrU prevention intervention in real patients’ lives and communicate the complexity of implementing a lifestyle intervention to prevent PrUs. Through analysis of the case studies, we became aware of the complexity of participants’ lives, the impact of the environment and events outside participants’ control, and the role of the health care system in shaping participants’ lifestyle and behaviors in response to PrUs.

Acknowledgments
This work was supported by National Institutes of Health (NIH), Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Center for Medical Rehabilitation Research (NCMRR) grant no. R01-HD056267. The Pressure Ulcer Prevention Study I was funded by National Institute on Disability and Rehabilitation Research grant no. H133G000062. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NICHD or the NIH. The authors are indebted to RLANRC; Michael Weinrich and our program officer, Louis Quatrano (NICHD–NCMRR); the PUPS II Data Safety and Monitoring Board (Richard Salcido, chair; Tom Belin; Joy Hammel; Forrest Pendleton; Denise Tate; and Lou Quatrano); and all PUPS II trial participants, without whom the study would not be possible.

References


