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RESEARCH PAPER

Qualitative study of principles pertaining to lifestyle and pressure ulcer risk in adults with spinal cord injury

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Abstract

Purpose. The aim of this article is to identify overarching principles that explain how daily lifestyle considerations affect pressure ulcer development as perceived by adults with spinal cord injury (SCI).

Method. Qualitative in-depth interviews over an 18-month period with 20 adults with spinal injury and a history of pressure ulcers were conducted using narrative and thematic analyses.

Results. Eight complexly interrelated daily lifestyle principles that explain pressure ulcer development were identified: perpetual danger; change/disruption of routine; decay of prevention behaviors; lifestyle risk ratio; individualization; simultaneous presence of prevention awareness and motivation; lifestyle trade-off; and access to needed care, services and supports.

Conclusions. Principles pertaining to the relationship between in-context lifestyle and pressure ulcer risk underscore previous quantitative findings, but also lead to new understandings of how risk unfolds in everyday life situations. Pressure ulcer prevention for community-dwelling adults with SCI can potentially be enhanced by incorporating principles, such as the decay of prevention behaviors or lifestyle trade-off, that highlight special patterns indicative of elevated risk. The identified principles can be used to theoretically drive future research or to guide innovative lifestyle-focused intervention approaches. Public policies that promote short-term preventive interventions at critical junctures throughout a person's life should be considered.

Keywords: *Spinal cord injury, pressure ulcers, qualitative research, lifestyle*

Introduction

Upto 95% of adults with spinal cord injury (SCI) incur at least one advanced pressure ulcer (Stage 3 or Stage 4) in their lifetime [1–3]. Such ulcers have profound negative effects on the individual's health and ability to live a full and satisfying life. For example, they can result in serious infection or death [4], and their treatment commonly requires prolonged rest periods which interfere with the capacity to sustain an engaged lifestyle [5]. Because the average cost of surgical repair and resulting hospitalization can exceed \$150 000 per ulcer [6], this problem exerts a heavy toll on society's health care resources.

Previous research has documented numerous medical, demographic, and lifestyle variables that predict pressure ulcers within the population with SCI. Examples of such risk factors include a history of previous pressure ulcers [2,7], urinary tract infection [8,9], substance abuse [10–12], smoking [10,11,13], poor nutrition [8], low education [7,10], unemployment [7,10], and decreased activity level [8,9]. The statistical isolation of these risk factors through quantitative research has provided insights that can be used to support clinically oriented assessment and intervention efforts [2]. However, a recent review suggests that additional evidence is needed to more adequately document the degree of ulcer-risk associated with psychological and

behavioral factors (e.g. depression, unhealthy lifestyle) which, though difficult to quantify, are relevant to primary and secondary intervention efforts [14].

To provide information that complements the knowledge on risk that has emerged from quantitative studies, our research team attempted to document how a confluence of lifestyle considerations such as unanticipated moment-to-moment decision making, activity choices, and individualized risk profiles influenced the development of pressure ulcers within everyday living contexts [15–17]. Toward this end, we acquired detailed descriptions of individuals' pressure ulcer histories which included information about such risk-relevant influences as personality traits, attendant care, adherence to preventive medical recommendations, employment and social participation, substance abuse, and use of specialized equipment. In a previous publication, we described various models that focused on how such variables combined, in a temporal sequence, to instantiate and shape outcomes when pressure ulcer risk episodes in everyday life occurred [16]. In this article, we report on eight broad-based thematic principles pertaining to pressure ulcer risk that we found operated ubiquitously within the lives of the research participants. As a set, these principles are intended to provide an organized, overarching understanding of the key lifestyle issues that, in part, account for the pressure ulcer phenomenon in adults with SCI.

Methods

Design

A qualitative research approach was used to elucidate a set of basic principles that explain pressure ulcer development [18]. The principles largely transcend the level of specific quantifiable variables (e.g. presence of urinary tract infection) and instead reflect more widespread considerations that affect risk in real-world contexts that involve lifestyle and activity.

Participants

Nineteen participants with SCI and one with transverse myelitis were recruited from the Pressure Ulcer Management Clinic at Rancho Los Amigos National Rehabilitation Centre (RLANRC), a leading rehabilitation facility in the USA. Purposeful sampling was used to achieve maximum sample variation with respect to age, level of injury, gender, and ethnicity. All participants were selected based on the following criteria: (1) 18 years or older; (2) a

diagnosis of tetraplegia or paraplegia; (3) at least 1 year post-injury and completion of a rehabilitation program; (4) previous treatment at RLANRC for one or more Stage 3 or Stage 4 pressure ulcers; and (5) residence within a 90 mile radius of downtown Los Angeles. Once identified, each potential participant was approached by a member of the RLANRC study team who explained the purpose and requirements of the study, provided a Patient's Bill of Rights and obtained a signed written consent form approved by the institutional research boards at the University of Southern California and RLANRC.

Fourteen males and six females ranging in age from 28 to 77 years (mean = 43.7), nine of whom had tetraplegia and 11 had paraplegia, were enrolled in the study. African-American (eight); Asian-American (one); Caucasian (six); and Latino/Hispanic (five) ethnicities were represented. The participants were from lower (8), middle (10), and upper (2) socioeconomic strata. For the purpose of confidentiality, pseudonyms were used and nonessential information (e.g. race or age when irrelevant to pressure ulcer history) was altered to mask the identity of the research participants when reporting study results.

Data collection methods

Two senior investigative team members and four research assistants collected the data. Each interviewer was paired with one to eight participants. Racial/ethnic matching between the researcher and the participant was achieved in all but one case.

For each participant, multiple in-depth audio-taped interviews, 3–23 in number (average = 11.5) and ranging from 1 to 4 h each, took place on a monthly or twice-monthly basis. Health care professionals, friends, or family members were also recruited for interviews with the permission of the participant. The interviews were loosely guided with utmost priority given to the opinions of the participants. Interview sites were chosen by the participants for their convenience and comfort. Most interviews occurred at the individual's home or at the RLANRC, with a few sessions occurring in the community. When appropriate, participant observation was undertaken, in which the researcher made direct observation of the participants' actions during the enactment of their daily routines, excursions, and any in-home or hospital-based therapy sessions.

Data collection occurred in two phases. The first phase, which typically lasted 4 months, was dedicated to gathering information about the participant's life history, pressure ulcer history, activity patterns, personal strengths and challenges, folk beliefs about the development of pressure ulcers,

daily routines, environmental affordances and constraints, social world, and pattern of risk. This information allowed the researcher to gain a full appreciation for the broad context that influenced the individual's construction and interpretation of his or her past and present experience with pressure ulcers. During the second data collection phase, which typically lasted 10 or more months, the researcher and participant carefully explored the manner in which life changes affected daily activities and risk for pressure ulcers. In addition, moment-to-moment daily events were examined in relation to pressure ulcer risk. The interview schedule was intensified when an unanticipated event in the life of a participant (e.g. change in the living environment or the emergence of a pressure ulcer) arose that was of significance to the study.

Data analysis

All audiotapes were transcribed verbatim. Interview material was then entered into Atlas.ti® [19], a qualitative computer program for organizing data. Twice-monthly data analytic meetings were held by all six researchers to clarify interviews, review transcripts, and deliberate over the findings. On three occasions the investigators met with a consumer board, consisting of five individuals with SCI, to review the findings and receive consumer-based input. Data collection and analysis occurred recursively, a requisite feature of qualitative research. For data analysis two primary strategies, thematic and narrative analysis, were employed.

Thematic analysis. Data driven and theory driven analytical strategies were applied to the data in an effort to identify themes pertaining to pressure ulcer development [18,20]. Using data driven analysis we meticulously searched transcripts and field notes to extract meaningful concepts. Concepts that emerged were noted, compared across cases, refined, and fleshed out into thematic codes. In addition, quotes that reflected the participants' experiences pertaining to those codes were recorded. After we gained a solid grasp of the raw interview data, we turned to theory driven analysis by reviewing previous research studies in an effort to extract additional concepts. Data and theory driven analysis resulted in 15 major categories and 134 subcategories relevant to ulcer risk within the stream of daily life, which were defined and maintained in a data codebook. As expected, all themes identified through thematic coding were not represented in each story, but emerged across the set of stories considered as a whole.

Narrative analysis. The purpose of narrative analysis is to analyze participants' stories as a means of providing complex and nuanced understandings of the relationship of multiple interconnected lifestyle considerations (e.g. personal, environmental, social), as they manifest, develop, and transform over time in individuals' lives [21]. Narrative analysis occurred in three steps. Initially, the researchers flushed out the participant's stories with emphasis on plot, development of character, crisis moments, and transitions. Second, preliminary individualized personal activity profiles were developed that covered the following topics: personality; occupational/daily lifestyle history; pressure ulcer history; life context (e.g. physical environment, social connections, caregiving situation, finances); activity patterns; personal strengths; personal challenges; values and belief system; and folk theories about pressure ulcers. Third, based on a careful review of the original transcripts and the individual profiles, narrative stories were written for each individual. Once written, the researcher who interviewed the participant re-read the narrative to verify its accuracy and make any necessary corrections.

At this point the thematic codes and narrative accounts were reviewed and principles related to the daily life concerns that contributed to pressure ulcer development were identified. In an iterative fashion, these principles were then confirmed by gathering supportive examples and quotes from the data. During this process of confirmation the principles were adjusted as needed to accurately reflect the data.

Results

Eight principles were identified. Each principle reflects a key theme that helps explain how or why pressure ulcers emerge within the daily life contexts of community dwelling adults with SCI. The eight principles are presented and defined in Table I. Each of the principles is discussed below. Excerpts from the data will be provided to illustrate and support the description of each principle.

Principle 1: perpetual danger

According to Principle 1, the threat of a pressure ulcer never subsides. For example, even when an individual's pressure ulcer prevention routine is favorable an unexpected circumstance can cause an ulcer to develop.

This principle is illustrated in the life of Robert, a 42-year-old male who sustained an incomplete C7 SCI following a car accident. Robert was pressure

Table I. Principles pertaining to lifestyle and pressure ulcer development in high-risk adults with SCI.

I. Perpetual danger	The threat of incurring a pressure ulcer is continually present in the lives of adults with SCI
II. Change/disruption of routine	Pressure ulcers often result from the introduction of a change or disruption in an individual's life or aspect of his/her in-place system of pressure ulcer avoidance
III. Decay of prevention behaviors	Pressure ulcer prevention behaviors often undergo intentional or unintentional decay over time
IV. Lifestyle risk ratio	Pressure ulcer risk is related to the overall ratio of liabilities to buffers within an individual's life
V. Individualization	Lifestyle considerations, in addition to their general effects, combine in unique, individualized ways in affecting a person's risk for pressure ulcers
VI. Simultaneous presence of awareness and motivation	The simultaneous presence of proper awareness (attention and knowledge) and motivational commitment is a crucial factor in a person's ability to avoid pressure ulcers
VII. Lifestyle trade-off	There commonly exists a tension between the need to live a full, personally meaningful life and the need to avoid conditions that can incur pressure ulcers
VIII. Access to needed care, services and supports	Pressure ulcers often result from the inability of institutions or health care service providers to adequately meet at-risk individuals' needs in an effective or timely manner

ulcer-free when he went to visit his family in Mississippi. However, his return trip became a nightmare when he was stranded at the airport for over 19 h due to flight delays. He reflects, '... and I stayed in one airport for twelve hours, and I slept maybe six or seven hours in one position and that's not good, by me missing those two flights that was it'. As Robert stated, one unforeseen circumstance, missing two flights, completely disrupted the effective pressure ulcer prevention routine that he maintained. As a result, Robert developed a pressure ulcer that eventually required surgical intervention and a 4-month hospital stay.

Further illustrating the ubiquitous nature of the pressure ulcer threat, unexpected events that happened as integral parts of daily routines were common and often were devastating to skin integrity. For example, Billy who was injured at age 21 by a bullet, developed a pressure ulcer by unknowingly sitting on a pager left under his bed sheets. Ken, injured at the age of 19 by a stray bullet from a drive-by shooting, was adamant about dressing professionally in public, a strategy he used to distract attention from his wheelchair [22]. Unfortunately, wearing a new pair of dress shoes for a mere 3-h period resulted in ulcers on his feet. The great diversity of causes of skin breakdowns underscores the seriousness and unpredictability of pressure ulcer risk in the lives of individuals with SCI.

Billy and Ken's experiences also highlight the episodic nature of pressure ulcer risk. In each person's life, a series of interconnected life-situational episodes unfold within the stream of time (e.g. getting out of bed, getting dressed, bathing, driving to work, sitting at a desk all day). Each episode involves shifting circumstances that have the potential to produce physical changes in relation to the skin. Consequently, life involves a countless series of windows that, combined, generate an ever-present threat for the development of pressure ulcers. For Ken, the window of opportunity was the simple act of

donning his shoes, a task he does daily. However, the shifting circumstance in this episode was the fact that he had new shoes which were unknowingly abrasive to his skin. In Billy's case, the window of opportunity was transferring from his chair to the bed. In principle, he could have moved to many places on his bed but during this episode of shifting circumstances he happened to sit on a pager which resulted in a pressure ulcer.

The moment-to-moment decisions required by people with SCI during these endless episodes of shifting circumstances can have a huge impact on pressure ulcer outcomes. For example, one morning Gary, a 25-year-old male whose spine was injured 6 years earlier in an automobile accident, had settled himself on the living room couch in preparation for a much needed restful day. As his two roommates left the house they goaded Gary into coming with them on a jaunt. Tempted by the memories of their past adventures, and a burning desire to be active, Gary said 'why not'? In that single moment Gary, without much thought, headed off with his friends. Unfortunately, the trip led to an excessive amount of riding around town in his wheelchair, which caused a pressure ulcer. Had Gary decided to remain on the couch it is highly likely (but not certain) that he would not have incurred an ulcer. As this principle of perpetual danger suggests, there is always a risk that one could acquire a pressure ulcer, albeit the risk is greater when a risky rather than conservative decision is made. Gary's situation also evokes the question: 'Was a conscious decision made'? It is more likely that Gary thoughtlessly jumped into his wheelchair on a whim in the same manner he had done on numerous previous occasions. On many of those occasions he had eluded pressure ulcers, which provided him with a false sense of security. This false sense of security seems to have overridden any consideration about perpetual danger.

Further underscoring the principle of Perpetual Danger is the finding that skin breakdown can occur

even in the presence of conditions that appear to be ideal or unchanging. In several instances, participants were puzzled when their previously effective pressure ulcer prevention routines suddenly broke down for no apparent reason. At the age of 14, Mitch acquired a C6 SCI in a car accident. Mitch experienced confusion when he began to develop a pressure ulcer 23 years following his injury. According to Mitch, 'the worse place you can have them (pressure ulcers) is on your butt'. For this reason he habitually laid on his stomach in bed using his elbow to prop himself up. Although this strategy had worked for him over the years, 1 day he noticed slight red shadings on his elbow that matured into a full-blown pressure ulcer. His pressure ulcer was unanticipated because his health practices, psychological approach, and social/environmental profile remained constant. It is suspected that the small increments of wear and tear on his elbow that unnoticeably progressed over 23 years as he aged created an opportunity for a pressure ulcer.

Mitch's experience is consistent with the literature, which notes that the risk of pressure ulcers increases ~50% between 1 year post-injury and 20 years post-injury [23]. Common age-related changes in the skin such as capillary thinning, absence of sensory input, and loss of the epidermal and dermal interdigitation can cause the development of pressure ulcers and delayed wound healing [24,25]. These changes in skin often go unnoticed until a critical point when red spots unexpectedly appear. At this point, a re-examination and change of daily habits are critically needed [23,26,27]. However, persons such as Mitch are often bewildered by their red spot. Unaware of the effects of aging they continue to rely upon longstanding pressure ulcer prevention habits that were previously effective. Yet, those same habits which kept them ulcer-free in the past may hinder their ability to respond in an effective manner as their body ages.

Principle 2: change/disruption of routine

This principle reflects the finding that pressure ulcers can oftentimes be traced to changes that disrupt existing equilibrium in risk-relevant conditions. When such a change event occurs, the alteration translates into consequences that result in physical pressure on the skin. Thus, by its very nature, change has the potential to create disruptions that can lead to new windows of opportunity for the development of pressure ulcers.

Judy demonstrated this principle when her longstanding pressure ulcer risk equilibrium was disrupted by a change in her daily attendants. Judy sustained a spinal injury in a car accident at the age

of 43. After 3 months of rehabilitation, she left the hospital with a very positive risk profile that included successful employment, high SES, a strong social network, an accessible home, a 'can do' personality, strong self advocacy skills, good attendants, and consistent adherence to a carefully conceived pressure ulcer prevention plan. The disruption in Judy's pressure ulcer prevention routine occurred while she was on an out-of-town business trip. Because her personal attendants were unable to accompany her, she hired per-diem help for the duration of her trip. Although the new attendants were generally knowledgeable in the care of persons with SCI, they did not have a good sense of Judy's overweight body. As is customary, they adjusted Judy's dress to be free of wrinkles. However, while transferring her they inadvertently sat Judy on one small crease, which led to an ulcer. Thus, a specific change event (a shift in attendant care) translated into skin abrasion and an eventual muscle transfer surgery.

Principle 2 also incorporates the notion of 'cascading,' or a chain reaction in which the occurrence of a pressure ulcer is followed by increased risk for subsequent pressure ulcers. For example, Helen, who sustained a T5 SCI following a gunshot wound, formed an ulcer on her right hip which required surgery. Because the surgery left her unbalanced with a lateral lean to the right, a trunk support system for her wheelchair was ordered to enable her to sit upright. However, a second pressure ulcer developed when this new device disrupted her sitting balance and caused her to shift excess pressure to another part of her body.

For another participant, a downhill cascade was rooted in social and emotional considerations. Brenda, an adventurous woman who sustained a work-related SCI, had recently moved in with her boyfriend to escape emotional and potentially harmful family issues. However, the move necessitated a change in care attendants. Her previous attendants befriended Brenda, going beyond their expected duties of preparing meals and housecleaning. With their assistance Brenda was able to escape her stifling apartment and engage in social activities with a cadre of friends. However, her new attendants were more conventional in their approach toward caring for Brenda. She received good basic care but spent most of her days alone while her boyfriend was at work. Removed from social activities, Brenda became depressed and as a result began to engage in late night binging on cookies and ice-cream. Attempting to alleviate depression by eating led to a serious and dangerous weight gain. Suddenly, she found herself dependent on a breathing machine due to her obesity, which intensified her initial problem of confinement her to her home. Finally, prolonged time in bed led to a pressure ulcer. The causal effect

of Brenda's seemingly positive life-change – moving out of a dangerous family situation – was a downhill ride ending with a pressure ulcer.

Principle 3: decay of prevention behaviors

Principle 3 reflects the notion that, for a variety of reasons, the performance of prevention techniques such as pressure releases or skin checks may over months or years attenuate slowly in a subtle manner, often beneath a patient's awareness. A variety of considerations may contribute to such long-term decay including ongoing life distractions, overconfidence, forgetfulness, depression, or fatigue. Consistent with this principle, in certain instances, it became visibly apparent to the researchers that study participants were failing to perform selected preventive procedures, despite claims to the contrary. Ken, for example, insisted that he was performing pressure reliefs every 15 min, but would typically continue for 1 h or more during interview sessions without doing any reliefs. More than likely a long-term decline in diligence, evidently operating beneath his awareness, contributed to this lack of performance.

For some individuals, effective pressure ulcer prevention techniques decayed over time in the face of daily living influences. For example, Frank, who sustained a T4 injury, recovered from his SCI with a new outlook on life. A gunshot wound to his spine literally transformed him from a man consumed in gang activity to a man whose priority was to care for his girlfriend and child, buy a home, and become a gang counselor. Part of his new lifestyle was to respect the advice of doctors and other health professionals. He intently followed good pressure ulcer prevention techniques and experienced favorable outcomes. However, 3 months of intense family stress diverted his attention and consequently his successful prevention ulcer routine slowly disintegrated. Reflecting back he states, 'I got a little careless at the end, I guess. Everything was running fine, but like I said, I had a lot of problems at the time. I remember I had the attitude [that] I didn't care at the time . . . I stopped treating myself a little bit and I paid for it'. After surgery and a long hospital stay he asserted with confidence, 'If I stick to my plan, I shouldn't do nothing wrong. But once I slip from the plan – which I'm not trying to do – I'll be back in there [the hospital]'.

Principle 4: lifestyle risk ratio

This principle addresses the additive contribution of various liabilities or buffers that affect pressure ulcer

risk. Lifestyle considerations such as physical frailty, urinary track infection, lack of adherence to preventive recommendations, poor nutrition, poor problem solving, an unhealthy living environment, unstable attendant care, and inadequate finances have been the focus of previous investigations as correlates of pressure ulcers [2,7,10,11,13] and were also identified as risk-relevant factors in our study [6]. Key liabilities and buffers have been conceptualized as having a predictable direction of effect common to most people. For example, in most situations a solid support system is considered a buffer that reinforces pressure ulcer prevention, whereas aging skin is a liability that contributes to pressure ulcer development. The pressure ulcer histories of many of our participants underscore the additive contribution of such influences to overall risk.

However, our data also demonstrated that in some cases a particular lifestyle consideration was not exclusively a liability or buffer, but could either increase or reduce risk depending on its relationship to other variables in a given individual's life. A common example consisted of the ability to engage in a desired activity such as attending parties or working. Although such activities had buffering effects (e.g. due to reducing depression or enhancing the ability to hire high quality attendant care), they also had the potential to elevate risk by leading to unrelieved pressure due to long periods of sitting. This finding of varying patterns of influence underscores the complexity of lifestyle considerations in affecting ulcer risk.

Similar to the danger of viewing liabilities and buffers as static categories is viewing an individual's lifestyle risk ratio as static. Pressure ulcer risk is continuous and fluid, and as such an individual's lifestyle risk ratio changes throughout life. Although it may be important to determine the degree of risk for pressure ulcers at one point in a person's life, such as when the individual is in therapy, individuals with SCI must attend to fluid and complex changes in lifestyle risk ratios over periods of time to remain ulcer-free.

Principle 5: individualization

This principle reflects the uniquely styled interactive nature of lifestyle considerations in affecting pressure ulcer risk in specific life contexts of persons with SCI. Risk-relevant liabilities and buffers do not merely affect pressure ulcer risk in a simple, additive manner. Rather, such risk influences contribute to complex, dynamic systems [27–29] which are different in composition from person to person. In this regard, both the role and potency of an identifiable

risk-relevant element can vary among different individuals and also across time for the same individual. Ken's situation exemplifies this principle. Following his injury Ken was tormented by a lack of purpose in his life. He could not escape the depression that obscured any hope for a meaningful life. However, with the assistance of friends he managed to change his attitude and follow the advice of a social worker who told him, 'You can do it Ken. Be strong. Don't let them beat you up. You're young, it's all up to your mind'. Subsequently, Ken enrolled in a community college and achieved a favorable lifestyle ulcer risk profile. He had accessible housing, appropriate equipment, a strong base of social support, and a sense of future purpose driven by his spiritual beliefs. However, the most potent influence in keeping him pressure ulcer-free was his mother. Although she lived abroad, she would routinely visit the USA and live with Ken for long periods of time. Irrespective of all the other buffers in his life, when his mother was present he would remain pressure ulcer-free and when she was not present he was at relatively high risk of getting a pressure ulcer. In this sense, Ken's mother took on a primary and very potent role in Ken's health. If one simply added up his liabilities and buffers – equating the potency of his mother's presence with, for example, accessible housing – Ken's risk profile could be misunderstood. By taking into account the specific role and potency of a cardinal buffer – his mother – a more accurate account of his life-risk ratio is provided. Thus, to sufficiently understand how an individual's lifestyle affects his or her pressure ulcer outcomes, it should be stressed that the exact function, as well as the degree of impact of each given factor, has a personalized role within the wider constellation of lifestyle influences.

This principle also highlights the participants' efforts to individualize their pressure ulcer prevention regimes to fit their particular lifestyles. Alma was 5 years old when she sustained a SCI in a fall from a balance beam. At the age of 42, her time was consumed with work and recreational activities. She stated, 'There (the rehabilitation hospital) the demands are really hard. They request that you relieve pressure every 15 minutes'. She goes on to say, 'in meetings, I just can't see doing it, during lunch, or even in the movie or in a play or sporting events. These events are 3, 4 hours long. Every 15 minutes, just to lean forward seems harder. It's awkward, and it's not really socially acceptable in my mind, 'cause you can't do it without drawing a lot of attention and people ask a lot of questions. The requirements are too demanding, if you want to live life'. Rather than perform the recommended releases, Alma takes ½ h breaks every 4–6 h. This allows her to maintain her busy schedule of working

and socializing while attending to her skin. It is significant to note that the key ingredient of Alma's personalized pressure relief system is her conscientious daily routine of skin care and response to redness.

Some participants indicated that they had become intuitively attuned to non-conventional bodily sensations that warned them of impending problems. Despite some current research that suggests it is possible for people with complete SCI to experience sensations below the level of the lesion [30], conventional theory denies this possibility [31]. In our study, a few participants stated that they could feel the pain of a beginning pressure ulcer or an internal sensation that indicated medical problems. The type and location of the sensation differed among individuals. For example, Judy explained that when her hand turns 'icy cold' she knows there is impending danger. In fact, through this means, while in the hospital she was able to detect a problem with her urine bag that other health care professionals could not identify. Likewise Chris, who sustained a C5 SCI, stated that he could feel pain in his buttock that signaled a need for a pressure relief or readjustment in his body. Helen noted this phenomenon in her statement, 'You know, after so many years being a quad, I'm pretty well familiar with my body. So when something is bothering me, I usually know where it's at, cause I feel it, I can feel pressure'.

Principle 6: simultaneous presence of awareness and motivation

The sixth principle stresses that avoiding pressure ulcers depends upon the concurrent existence of prevention awareness and a motivational commitment to put acknowledged prevention practices into action. Within the framework of this principle, prevention awareness is composed of both long-term prevention knowledge and short-term attentional considerations. The long-term component reflects the awareness of basic prevention practices, such as the need to regularly perform pressure reliefs. The more immediate, attentional aspect of awareness applies to a given episodic situation. Although the two aspects of awareness are conceptually distinct (e.g. an individual with excellent prevention knowledge may, due to intoxication, be inattentive to ulcer prevention), they must both be present along with an adequate degree of motivation if successful prevention is to occur.

Awareness and motivational commitment can be viewed as deeper driving forces that set into play many of the crucial adaptive processes that characterize successful prevention. For example, having the proper knowledge provides the content that

underlies effective routines and prevention measures, proper planning, awareness of risk situations that unfold during everyday life episodes, and knowledge of what to advocate for. Without a motivational commitment to avoid pressure ulcers, sound decision making, necessary to avoid risky circumstances, will be absent.

For the most part, persons with SCI acquire initial generalized knowledge about pressure ulcers and prevention techniques in hospital settings during rehabilitation. For some participants, such instruction led to a lasting motivational commitment to apply the recommended practices on a sustained basis. Others, however, became motivated to apply prevention techniques only after they personally experienced a pressure ulcer. For example, Chris, who had lived 23 years with a SCI, stated that although he received and integrated information about the seriousness of pressure ulcers, this knowledge alone did not lead to a sufficient degree of motivation to adhere to recommended prevention techniques. For Chris and other participants in the study, the need to see the ugly aspect of a developing ulcer abruptly appear, smell its wretched odor, and experience the confusion and fear that accompanies knowing that an-out-of-control ulcer was invading *his body* was required for the 'words' he learned in the hospital to generate motivational impact.

Illustrating this notion, Chris became strongly committed to prevention after a severe pressure ulcer forced multiple hospitalizations. Following the last hospitalization, he found an advocacy job with the government, paid off his credit card (a debt he incurred while he was in the hospital), and began two separate romantic relationships. As Chris stated, 'I don't think I have ever been happier'. Chris was re-engaged in a wonderful life and had all intentions on keeping it that way. His imagined future of engagement in life contrasted sharply with his past experience of lying in a hospital bed. He was now committed to staying home from work to alleviate pressure on his buttocks when he noticed the beginnings of a red spot. At this point in his life Chris had a strong level of experienced-based motivational commitment to enact prevention practices which, combined with his awareness of specific avoidance techniques, enabled his system of prevention to work.

Principle 7: lifestyle trade-off

This seventh principle, Lifestyle Trade-off, was highly ubiquitous within the lives of the participants. In a fundamental sense, each individual faced conflicts between the desire to engage in personally meaningful activities and the need to utilize rest and

caution as a means of pressure ulcer prevention. The manner of resolving such dilemmas played a profound role in determining the participants' pressure ulcer histories. The choice to continue their activities often resulted not only in a pressure ulcer but also in subsequent extended bed rest, which ultimately disrupted their precious activities. Participants anguished over these choices.

The most prevalent source of tension revolved around the desire to continue working. For example, Judy insisted on remaining at her accounting job despite her physician's warnings that she would require surgery if she did not 'stay in bed' to heal the red area on her skin. She stated, 'No, no I mean, I just, I cannot see my lying around. I mean, it's just not in my vocabulary. I'm a workaholic. I love my job...I've been there [over 30 years] and the thought of being gone and not being productive when I'm gone for 3 to 4 months just did not please me'. Judy's need to remain at work was not simply a result of her stubbornness. Rather, Judy's outstanding success as an accountant and her extensive work-related social network fuelled her life with energy and purpose. She envisioned her life only in relation to work and thus could not reconcile an image of herself 'lying around at home.' Giving up her preferred lifestyle was incomprehensible. Yet the choice to continue working during the critical time of tax season was in conflict with the goal to avoid pressure ulcers. As a result of her choice to continue working, Judy subsequently suffered three serious pressure ulcers before she started to reinterpret her attachment to work. Only then did Judy begin to understand the necessity of physical health in order to maintain meaningful participation in life. The tension between work and health remains a difficult choice for Judy. However, she ultimately chose to put a higher degree of priority on her health, resting at home and delegating tasks when necessary. This enabled her to remain free of pressure ulcers for the final 2 years of the research study.

Dave, who sustained a T10 SCI at the age of 11, also grappled with the issue of engagement in work verses maintaining his health. Years following his SCI Dave finally dug himself out of depression and, with the help of his father, joined a consulting team at a resort and travel cooperation. The 'discipline' to be productive had been instilled in him at a young age and this quality served him well. He strove hard at work and was soon arranging multi-million dollar contracts. Dave constantly found himself making deals over drinks and dinner. He lived a fast paced life both at and outside work. As he stated, 'I went out on my own and loved it'. Unfortunately, one result of Dave's dedication to work was the development of a pressure ulcer on his buttocks which required surgery. Dave was confronted with

choosing either an extended period of rest or a surgical procedure to heal the wound. Dave chose the later because it would reduce the overall amount of down time and allow him a speedier return to life. He explained, 'I had a great life. I was there. I had a great life. I worked; I did all kinds of stuff. And I would get an ulcer and instead of doing the bed rest I would have surgery so I could get back to what I was doing'. In fact, this behavior became a pattern. Dave would overwork long hours, become lax in practicing pressure ulcer prevention techniques, develop a significant pressure ulcer, eventually opt for a surgical repair rather than allowing for the slower-paced healing found in extended bed rest, and then return to work to begin the cycle again. Dave presents an interesting situation. Unlike Judy, he was not faced with an ultimatum from a doctor, so a strict decision between health and work was not required. It appeared that Dave's choices allowed him to 'have it all.' Over the years, however, the cumulative effect of multiple surgeries was frail skin, multiple pressure ulcers, and prolonged bed rest. Thus, without making a deliberate choice Dave compromised his health as a result of living a fast paced and productive life.

Work was not the only type of activity that forced difficult choices about living a full, meaningful life. For example, Alley, who acquired a T5 SCI at the age of 44, experienced tension between caring for a friend, Lucy, and avoiding the escalation of a pressure ulcer. Alley and Lucy's relationship was exceptionally strong; they were tightly bonded as Christians. Shortly after Alley was hospitalized to heal a dangerous pressure ulcer, her friend Lucy was hospitalized for a respiratory ailment. Lucy's health took a turn for the worse when she aspirated food, leading to an infection and forcing her to rely on an uncomfortable feeding tube. Distraught over Lucy's suffering, Alley discussed her own situation with her doctor who told her that remaining in the hospital to heal the existing ulcer was his best medical advice, but that she could leave for a short time if she returned. Alley left the hospital to sit with her dying friend. As she stated, 'I could not leave [Lucy to die alone.] I just couldn't'. Indeed, Alley was at Lucy's bedside when she died. Alley's tradeoff was between her deeply engrained friendship enacted through 'being there' for Lucy and her own physical health.

Principle 8: access to needed care, services and supports

Principle 8 reflects the notion that for a variety of reasons (e.g. a delay in the arrival of equipment, overworked health care professionals, language barriers, institutions unequipped or inexperienced in providing services for people with SCI) pressure

ulcers can occur in connection with the inability to obtain timely and appropriate services from either medical or non-medical institutions. Barriers to full participation for people with disabilities exist in every pocket of the social world [32,33]. Often, our participants found themselves grappling with complex rules and mechanisms of social systems to maintain their health. This last principle focuses on the relationship between the individual and the social structures and policies that impacted pressure ulcer development.

People with SCI rely on social structures (such as clinics, hospitals, and product vendors) to manage their medical needs. In the process, they must interact with an array of service providers, including office managers, receptionists, health care professionals, sales personnel, and government bureaucrats. In some instances, these individuals, we found, serve as the 'gatekeepers' to the provision of care and exert significant influence on how services will be allocated. Furthermore, institutional, state and federal policies determine access to medical care. For example, not infrequently, our informants implicated the Medicare service system as a culprit in the development of their pressure ulcers. For example, Frank unsuccessfully tried to 'make do' with a foam cushion while he waited 3 months for the appropriate gel-filled cushion to arrive. As a result of this delay, the pressure ulcer he had hoped to cure worsened and he required surgery. Frank states, 'It was because those cushions I busted, and I was sitting on those foam cushions . . . when my gel one busted I caught a sore. Yeah that's a problem that needs to be corrected. You need to let them know. Medicare needs to let us have them right away'. Participants often noted that dealing with the Medicare bureaucracy was a daunting task. As individuals they felt overwhelmed and incapable of managing what appeared to be insurmountable barriers.

Policies that limited access to medical appointments could interfere with the need to access timely treatment. For example, Alley, when visiting a local community health centre, had been advised by her urologist to return immediately to the clinic if a small red spot that was observed on her skin worsened. However, when this occurred the receptionist clerk at the admissions desk informed her that an appointment was absolutely required to see a doctor. Despite Alley's protests, she was required to make an appointment for the following week. When she returned, she was immediately admitted to a specialty hospital for intense antibiotic treatment for her ulcer, which had worsened over the prior week. It is possible that more timely access to care would have prevented the need for hospitalization. Throughout this episode, Alley experienced a great deal of frustration, and the 'policy' as interpreted by the

clerk was not consistent with the physician's understanding of clinic operations.

Medical systems are designed to provide services for those with a disability including people with SCI, and for that reason are able to effectively accommodate most medical concerns. However, other social structures with different missions or functions are limited in their ability to do so. One such institution, jail, was especially deficient in meeting the needs of study participants who had been incarcerated. Four of our participants were sentenced to jail on at least one occasion. Aaron, who lived with an incomplete SCI at the L3 level, was one such participant. As he recounted, his wife called the police while they were arguing quite loudly. He was taken to an overcrowded jail. No bed was available and Aaron was forced to sleep on the concrete floor beneath the benches. He was not accustomed to sleeping on hard surfaces on his back and believes that a seam in his jeans embedded itself into his skin. After a few nights, he developed a pressure ulcer. Eventually he was transferred to a bed, but remained in jail without medical care because the guards did not believe the 'sore' was serious enough to warrant attention. Ultimately, the ulcer required surgery to heal.

In general the physical architecture and procedural protocols of jails are not designed to accommodate the needs of people with SCI. For this reason, Aaron was subjected to conditions that placed him at extremely high risk for an ulcer. Additionally, guards are trained to keep order in the jail, and are not exposed to specialized knowledge about pressure ulcers; although expert consultation is available to them should they notice a problem that warrants it. Nevertheless, when analyzing Aaron's case it was apparent that the physical design of the jail, its procedures and policies, and the lack of specialized training of the guards were not in sync with Aaron's needs as a person with a disability.

Discussion

To some extent, the results of this qualitative investigation overlap with the findings of prior studies. Principles that confirm some aspect of previous quantitative findings include perpetual danger, lifestyle risk ratio, and simultaneous presence of awareness and motivation. The principle of perpetual danger is consistent with the notion that individuals with SCI are at significant risk for pressure ulcers, as evidenced by statistics that underscore the high incidence rate [8]. The lifestyle risk ratio and simultaneous presence of awareness and motivation principles underscore the presence of

multiple liabilities and buffers, including educational and motivational considerations that additively predict pressure ulcer outcomes [2,34–36]. In contrast, the principles of change/disruption of routine, decay of prevention behaviors, individualization, lifestyle trade-off, and access to needed care, services and supports extend previous research outcomes by highlighting fluid, personally meaningful, or contextual issues that are salient to persons with SCI within the everyday stream of life. Thus, the subjective perspectives of the research participants led to novel insights about personally relevant, but often overlooked, issues surrounding risk and prevention.

One of the advantages of the use of narrative in this study is that it enabled a complex, intuitively generated understanding of the most personally salient themes that pertain to pressure ulcer risk in everyday situations. As such, our findings provide a useful lens for practitioners or theoreticians who are seeking to understand recurrent patterns of liabilities and buffers that affect ulcer outcomes. For example, the issue of how much activity to pursue and how to balance such activity with health risk (lifestyle trade-off) is a crucial concern to almost all individuals with SCI because meaningful activity is at the core of a satisfying and healthy life [37–39]. Consequently, it is important for clinicians to have a realistic understanding of the tension surrounding this trade-off within the lives of their clients. If this issue is ignored, then clients' quest for activity may often pre-empt the need for prevention measures such as caution or rest. By carefully addressing this concern, the clinician can help the client develop a feasible plan for achieving an adequate compromise between activity and prevention practice. Similarly, the commonly observed tendency for prevention behaviors to decay (decay of prevention behaviors) seems to support the need for periodic reminders or checks concerning the actual prevention practices that a person enacts over extended time periods. Preventive education, even if well received at the time of acute rehabilitation, is likely to disintegrate, possibly beneath an individual's conscious awareness, over a several-year time period. Thus, during follow-up visits, clinicians may consider incorporating interventions that address individualized pressure ulcer prevention within the context of promoting home and community participation. Furthermore, the decay of preventative behavior underscores the need for public policies that support the opportunity for continuous care. Existing literature suggests that extended rehabilitation is required to address the long-term psychosocial and physical needs of people with SCI. Our findings support the existing literature and suggest that intervention throughout an individual's life course may be an effective approach in

eradicating pressure ulcers and the financial burden of resulting health care costs [40–42].

In interpreting the results of this study, it is worthwhile to note a couple of limitations. First, the sample of adults with SCI was intentionally tilted to include persons at very high risk for pressure ulcers, with many of the participants evidencing frequent ulcers and hospital visits on a revolving door basis. Although such a high risk sample is in many ways ideal for exploring the salient issues surrounding the emergence of pressure ulcers in daily life contexts, it is nonetheless likely that certain principles would arise less frequently among populations of adults with SCI who are more ulcer-free. A second limitation concerns the possibility that the results were to some degree influenced by forgetfulness or selective memory on the part of the informants. Generally, in qualitative research this possibility is not a significant concern because the goal is to identify the participants' perceptions, *per se*, of fluid processes that occur within a social setting. However, to some degree the current research application goes beyond this goal by attempting to understand the genesis of serious pressure ulcers (an objective outcome) in individual lives. Therefore, any misperceptions or otherwise inaccurate statements could potentially produce incorrect conclusions about operative principles that actually lead to ulcers. In response to this possibility, it should be stressed that our results were based on themes identified repeatedly across diverse members of the study sample, thereby increasing the trustworthiness of the findings.

Future research should focus on examining the extent to which similar principles arise in the lives of adults with SCI who are more middling in terms of their ulcer risk. In addition, for individuals at high risk, there is a need to develop and test lifestyle-based interventions that utilize the eight principles as a means of preventing pressure ulcers on a long-term basis. Toward this end, our research group has recently manualized a lifestyle intervention for which the principles described in this article provide the theoretical framework. We anticipate that others in the field of rehabilitation will be able to utilize these principles for the purpose of framing future studies on pressure ulcer risk or as a means of refining and broadening intervention approaches.

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