

Perceptions of Bed Days for Individuals With Chronic Illness in Extended Care Facilities

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Abstract: We explored perceptions of bed days (defined as staying in bed for 1 or more days per week) in 46 patients receiving extended in-patient services for chronic illness management. Illness onset or exacerbation (35%), limited mobility (22%), and tiredness (15%) were the most prevalent reasons for initiating bed days. Tiredness (44%), limited mobility (26%), pain (24%), bowel treatment (22), and conserving energy for future activities (20%) were the most prevalent current reasons. Most participants (74%) noted having been involved in decisions concerning bed days and preferred to continue bed days. The results suggest patients schedule bed days to manage several health related symptoms. Based on our findings, nurses could help patients to alternate daily upright activity with rest to mitigate the known consequences of bed days. © 2009 Wiley Periodicals, Inc. *Res Nurs Health* 32:335–344, 2009

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Since the late 1950s, getting out of bed, as a minimum mobility practice, has been part of recommended basic daily nursing care (Harmer & Henderson, 1955). Complications of bed rest such as blood clots, pneumonia, joint structural changes,

contractures, loss of bone and muscle mass, orthostatic hypotension, upright activity intolerance, constipation, impaired sleep, skin breakdown (Browse, 1965; Fortney, Schneider, & Greenleaf, 1996), and pain management problems (Hagen,

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Jamtvedt, Hilde, & Winnem, 2005) have spurred the nursing community's focus onto ambulation and physical activity.

In Ontario, Canada, this focus on ambulation and physical activity is reflected in the goals established for Complex Continuing Care facilities. Similar to American skilled nursing facilities (Wodchis et al., 2006), Complex Continuing Care emphasizes maximization of functional and health status in preparation for discharge to the community or a long-term care facility (Ontario Hospital Association, 2006). These facilities admit individuals who are, on average, 76 years old (Canadian Institute for Health Information, 2004) and who have unstable chronic illnesses requiring skilled technology-based nursing, medical, and allied health care services unavailable in community or nursing home settings (Teare et al., 2004). Most (80%) admissions directly follow an acute care hospitalization (Canadian Institute for Health Information, 2004). Circulatory, neurological, and musculoskeletal problems represent the most common diagnoses upon admission (Canadian Institute for Health Information, 2006).

Although there are no published data on Complex Continuing Care patients' activity levels, recent reports suggest that remaining in bed during the daytime is relatively common in populations that are comparable in age and level of chronicity (Bates-Jensen, Schnelle, Alessi, Al-Samarrai, & Levy-Storms, 2004; Bernhardt, Dewey, Thrift, & Donnan, 2004; Brown, Friedkin, & Inouye, 2004). This is an important consideration as older and chronically ill persons are more vulnerable to the complications of bed days because of diminished physiological reserves (Covinsky et al., 2003). The healthcare literature contains calls to avoid excessive time in bed: for this population in general (King, 2006); for the conditions with which they present, including heart disease (Allen, Glasziou, & Del Mar, 1999), stroke (Bernhardt et al., 2004), pulmonary disease (Bailey et al., 2007) and spinal cord injuries (Haisma et al., 2007); and, for the surgical procedures they undergo (Killewich, 2006).

Notwithstanding the importance of helping this population avoid excessive time in bed, their perceptions of remaining in bed during the day, particularly patients' understanding of the reasons why they do so, their involvement in related decisions, and their preferences, are unexplored. Yet, such understanding is critical given our current era of practice in which nurses strive to incorporate patients' perceptions into decisions around daily care (Sidani, Epstein, & Miranda, 2006), including decisions around activity and rest. Moreover, as

perceptions are associated with health behaviors, having a clear understanding of them is needed in order to respond appropriately (Hale, Treharne, & Kitas, 2007).

The purpose of this study was to explore Complex Continuing Care patients' perceptions of remaining in bed during the day. Participants were asked whether they had been involved in and were currently making the decision to remain in bed, their understanding of the reason(s) why they had begun and were currently staying in bed, and their preferences to continue staying in bed during the day.

METHODS

This study was part of a larger cohort study testing several hypotheses on the direct and mediating relationships between the number of bed days, defined as staying in bed for 24 hours continuously, and orthostatic hypotension, sleep quality, and fatigue (Fox, 2007). This study was conducted in five university-affiliated free-standing Complex Continuing Care facilities in a large metropolitan city in Canada.

Quota sampling was used in the larger study to ensure equal representation of individuals who had different levels of bed days, defined by the total number of bed days during a 1 week period. The cohorts representing the different levels of bed days were naturally occurring rather than allocated by the researchers. Data on the level of bed days were collected prospectively by a registered nurse research assistant who conducted daily checks for 1 week. One bed day was equivalent to remaining in bed continuously for 24 hours without getting up into a chair or commode for any reason, including personal care. The levels included 0 ($n = 21$), 2–4 ($n = 23$), and 5–7 ($n = 23$) bed days/week. The 0 level consisted of individuals who did not spend any days in bed, and it served as the comparison group.

To target the sample for the larger study, entry was restricted to patients whose days of staying in bed and getting up were documented in the care plan and/or known by the nurses. Entry was restricted also to individuals who had resided in the facility for at least 1 month, were not expected to be discharged within the following month, were able to communicate in English, and had the cognitive ability to give written consent and respond to questions. To control for extraneous variables, individuals who were able to ambulate out of bed without assistance from another person, experiencing an acute illness, receiving

hemodialysis, and/or hospitalized for palliative care or short-term rehabilitation were excluded.

The current study was conducted to gather supplementary information on perceptions of bed days not provided by the larger study. We used a qualitative descriptive design involving semi-structured interviews with the 46 participants enrolled in the larger study who had stayed in bed at least 2 days during the week-long monitoring period. This restriction was imposed in order to obtain a sample that could provide information on the questions eliciting perceptions of bed days.

Data Collection and Procedure

The study was approved by the research ethics boards at the university and participating facilities, and written consent was obtained from participants. Data on the participants' sex, age, length of stay, types of chronic illnesses, current medical order for bed days, and functional status were obtained from their medical records. Functional status was derived from the seven activities of daily living (ADL) items (hygiene, dressing, toilet use, transfer, locomotion, bed mobility, and eating) comprising the Minimum Data Set (MDS; Morris, Fries, & Morris, 1999).

Using a semi-structured interview guide, one of us (MF) personally interviewed each participant. The interviews were conducted at a location within the facility of the participants' choosing after data collection for the larger study was completed. Participants were asked to indicate when they had started staying in bed during days of the week after the interviewer clarified: "By days of the week, I mean staying in bed for the entire day, 24 hours, without getting up at all to go into a chair or to the toilet." The interviewer then inquired about the participants' understanding of the original reason(s) for staying in bed, their involvement in the original decision to start staying in bed, whether it was their decision to currently remain in bed, their reasons now for staying in bed during the day, and their preference to continue to do so.

Data Analysis

The participants' responses to the questions regarding perceptions of bed days were analyzed using the conventional content analysis method Hsieh and Shannon (2005) described. The transcripts were first read in order to gain an overall impression of the responses to the questions. In a second reading, words and phrases were

highlighted and comments written in the margins that captured this impression. Preliminary categories, based on the text, and which were as exhaustive and mutually exclusive as possible, were then developed. Most categories were chosen from the exact words and phrases used by the participants. The participants' responses corresponding to each category were organized accordingly. A codebook was created that defined the properties of each code and the rules for classification. The interview questions were used as the organizing framework for classifying the data. The rules for classification were further based on the properties of the codes, derived from the participants' responses. The data were then reexamined and coded according to the classification rules.

Descriptive statistics were used to identify the number and percentage of participants reporting the coded responses related to their involvement in the decision to begin staying in bed during days of the week, making the current decision to have bed days, reasons for bed days, and preferences to continue bed days. In addition, descriptive statistics were used to characterize the sample in terms of demographics, relevant clinical characteristics, and the days of the week that the participants stayed in bed during the 1 week monitoring period.

Lastly, we plotted the data on decision making and preferences in relation to bed days, and the demographic and clinical characteristics for each respondent. This facilitated examining trends both within and across cases that may not have necessarily been confined to a specific interview question and/or a specific reason for bed days. Trends that were identified are reported.

RESULTS

Demographic and Clinical Characteristics of the Participants

The sample of 46 participants consisted of 24 (52%) women and 22 (48%) men. The median age was 74 years (range 32–96 years). The median length of stay at the facility was 961 days (range 26–17,749 days), which is about 2.5 years. The average Cognitive Performance Score was 1 (range 0–3) out of a potential maximum disability score of 6 (Morris et al., 1994), indicating that the participants had the cognitive ability to participate in an interview (Simmons & Schnelle, 2001), express their preferences and make their own decisions regarding daily care (Mezey, Teresi, Ramsey, Mitty, & Bobrowitz, 2000). All participants had

a diagnosis of at least one chronic illness including stroke ($n = 15$, 33%), multiple sclerosis ($n = 14$, 30%), diabetes ($n = 9$, 20%), spinal cord injury ($n = 7$, 15%), cerebral palsy ($n = 3$, 7%), and end-stage cardiac disease ($n = 2$, 4%). The mean MDS ADL self-performance score was 24 ($SD = 4.6$) out of a potential maximum of 28. This represented a high level of physical disability and indicated that the average participant required total assistance in almost all activities of daily living (Morris et al., 1999).

Days Spent in Bed

The average participant spent 4.5 (range 2–7) days in bed during the week of monitoring. Almost 20% ($n = 9$) of the sample spent the entire week in bed. Twenty percent ($n = 9$) spent 5 days, and 11% ($n = 5$) spent 6 days in bed during the week. About a third ($n = 16$, 35%) of the participants spent consecutive days in bed whereas others ($n = 11$, 24%) spent alternating days in bed. Most ($n = 19$, 41%) participants spent some consecutive and alternating days in bed during the week. Only two participants had a medical order to remain in bed during the day. Although both orders were based on pressure ulcer treatment, one order stipulated consecutive days in bed whereas the other stipulated alternating days.

Decisions Around Bed Days

Seven participants (15%) were either unsure or could not remember if they had been involved in the original decision to remain in bed during the day. Twenty-eight (61%) participants stated that they had been involved in the original decision, and only 11 (24%) stated that they had not. The majority ($n = 33$, 72%) of participants stated that they were currently making the decision to stay in bed either on their own or in collaboration with their nurse or physician. One participant explained that she decided the days she would spend in bed and routinely emailed an updated weekly schedule to the nursing staff for inclusion in her care plan.

Six (13%) participants said that they were not currently making the decision, and 7 (15%) did not indicate either way. Regardless of their responses, the notion that it should be the patients' decision to stay in bed and that this decision should be respected was typical. One woman explained: "It's my choice (to stay in bed), and, like I said, I'm 66 years old and nobody, nobody but me is going to tell me what to do."

Preferences for Bed Days

Most participants expressed a preference to either continue ($n = 32$, 70%) or to vary the days they spend in bed according to how they were feeling ($n = 2$, 4%). Twelve (26%) stated that they preferred to get up every day and not stay in bed on any days of the week. This preference, however, was not necessarily associated with being uninformed in decisions regarding staying in bed during the day. Five participants (11%) stated that although they had been involved in and agreed with the original decision, they would prefer to get up every day. One participant explained:

They (the nurses) asked me, and I said, "Yes, I'll stay in bed." It was for my own good because they were trying to make my behind better . . . I just hate staying in bed, period. I'd rather get up out of bed every day.

Similarly, two participants, who expressed a preference to get up every day, said they had been involved in the original decision and were currently making the decision to stay in bed. Their decisions reflected attempts to manage situations over which they perceived having no control, such as getting up for only short periods at a time. One participant explained:

I guess you could say that I put myself on a schedule . . . I don't necessarily like it. It's the only decision I could make . . . I can't get to be up for an hour . . . You're up and you have to stay up til they're (the nurses) willing to put you back to bed and that's it.

Lastly, observation of the data revealed a trend whereby participants who had expressed a preference to continue bed days had higher disability scores on the MDS ADL self-performance scale than those who had expressed a preference not to continue bed days.

Reasons for Initiating and Continuing Bed Days

Participants identified more than one reason for initiating and currently continuing bed days (Table 1). About a third of the participants acknowledged illness onset or exacerbation as the reason for initiating bed days. They explained that staying in bed during the day was common during acute care hospitalization for their illnesses, such as stroke, congestive heart failure, falls, and for related surgical procedures. Limited mobility, tiredness, and bowel care were other commonly mentioned reasons for staying in bed.

Table 1. Frequencies of Reasons for Bed Days Identified by Participants (*n* = 46)

	Reason Initiated (%)	Reason Now (%)
Illness onset/exacerbation	16 (35)	2 (4)
Limited mobility	10 (22)	12 (26)
Tired	7 (15)	20 (44)
Cannot remember	7 (15)	2 (4)
Bowel care/treatment	6 (13)	10 (22)
Pain	4 (9)	11 (24)
Nurse cannot or will not get me up	4 (9)	6 (13)
Ulcer treatment	4 (9)	4 (9)
Fear	3 (7)	1 (2)
Not sure/do not know	2 (4)	0
To rest up/relax	1 (2)	9 (20)
Hassle	1 (2)	4 (9)
Ulcer prevention	1 (2)	1 (2)
Poor sleep	0	6 (13)
No activities/appointments scheduled	0	6 (13)
Dizzy when up	0	2 (4)
Lost interest in getting up	0	1 (2)

Tiredness was the most frequent reason given for currently staying in bed during the day followed by limited mobility, pain, bowel care, and the need to rest or relax. Participants described "tiredness" as actual "fatigue" that prevented them from getting and staying up. Getting up would require too much energy and it would tire them out. Comments such as, "I have no energy to do anything," and "I'm too tired to get up" were common. Moreover, participants explained that they experienced fatigue while sitting. Most expressed not being able to tolerate sitting up for "too long," often defined as periods of 1 hour or more. Furthermore, common everyday events, such as taking a shower, were regarded as a form of activity that depleted energy. One man explained: "Because the shower day is a form of activity and by the time it's over I'm pooped."

Participants described strategies to try to prevent and manage fatigue experienced with being out of bed; however, the strategies usually involved more bed days. One participant recalled her experience with fatigue after transfer from an acute care hospital:

When I came here (the Complex Continuing Care facility), I got up every day and then it tired me out. I was back in bed for 2 weeks . . . I made a mistake when I came here. I thought, "Oh, boy!" I got up every day for a week, but I got totally wiped out. I did it too much, too fast. I was being free . . . I stayed in bed 2 weeks after that. Then I figured out

a system that would work for me, of staying in bed. I get up Mondays and Tuesdays. I stay in bed Wednesdays. I get up Thursdays and Fridays, and I stay in bed Saturday and Sundays. And that works well.

The use of bed days as a management strategy was not restricted to fatigue. Several (*n* = 9, 20%) participants explained that they planned bed days in order "to rest up" or "relax." "Sunday is my day of rest. It's a lazy day . . . You take time out, let the body relax." Yet, when asked to explain, participants denied that they were resting or relaxing because they felt tired. Rather, they defined resting or relaxing as a specific strategy to conserve energy that they would need for a future day's activity that required them to be out of bed. One participant clarified:

I would have stayed in bed today just so I would have rested up for tomorrow. I don't need to be in bed today. I'm not tired . . . It [staying in bed] lets me get by the next day.

Moreover, participants perceived that their nurses supported this decision. "My nurse said: 'You're up every day. You need a day off.'"

Whereas some participants perceived staying in bed a few days a week to be effective in conserving and restoring their energy ("I feel rejuvenated after a day in bed") others were unsure. Still other participants noted that staying in bed made them feel restless. "When I'm up, I don't feel as tired . . . You can get restless (while staying in bed for the day)."

Another prevalent reason for bed days was limited mobility, such as not being able to physically get around when out of bed and having lost their electronic wheelchair privileges because they could no longer drive safely. Limited mobility was characterized by a sense of futility in getting up: "There's not much sense in getting up when you can't walk." Moreover, the perception of being independent while in bed but dependent when out of bed was typical. One participant explained: "Now I've created an environment that's independent of bed. So why should I get up? I have created an environment in which I can be totally independent in bed." Another recalled:

My mind is telling me, "(states her name) you're in a wheelchair again. I don't like this." In bed, I feel like I'm resting a bit, like I'm going to get up and maybe cook, clean up . . . I don't want to be in a wheelchair. I want to be walking. In physiotherapy I walk with two men and I use a bike . . . When (name of unit) was closed for 8 days because of the outbreak, (the nurses) tried to get me up and said they would wheel me around, but I didn't want to.

If I didn't have physiotherapy, I would stay in bed all the time.

"Bowel care," also referred to as "bowel treatment" by some participants, was identified as a frequent reason for bed days. Bowel care involved receiving a laxative during the prior night or an enema on the morning of a bed day. Participants' perceptions of bowel care as a valid reason for a bed day and their preference to continue bed days for this reason seemed to be dependent upon their experience of fecal oozing after defecating. Participants who expressed a preference to stay in bed on the day of bowel care explained that fecal oozing continued throughout the day; this was a source of embarrassment for them and it interfered with their upright activities. Participants who preferred to be up after having received bowel care said that they could not understand why they were required to stay in bed because they were not oozing stool.

I don't have to stay in bed because I go [defecate] and that's it. It's [a bed day] not necessary because I go in the morning and that's it . . . It's bowel care. You stay in bed. That's it.

We further examined whether the reasons for bed days differed according to patient preference. The reasons for bed days were similar for participants who had expressed a preference to continue bed days and those who had expressed a preference not to continue, except for the finding that none of the participants who had indicated a preference to continue bed days stated that the nurse could not get them up. Six of the 12 participants, however, who preferred not to continue bed days observed that the nurse "could not" or "would not" get them up. When asked to elaborate, the participants said that the nurses were "too busy" or that it was "not the nurses' responsibility" to get them up, it was the job of the "physical people" [rehab assistants].

DISCUSSION

The principal findings of this study were that: (a) illness onset or exacerbation was the most frequently identified reason for starting bed days; (b) most participants perceived having been involved in the original decision and were currently making the decision concerning bed days, and expressed a preference to continue bed days; and (c) most of the reasons for this preference centered on symptom management strategies, particularly those related to fatigue.

The identification of illness onset or exacerbation as the dominant reason for starting bed days

suggests that a tendency toward bed days may begin during the acute illness phase. This is similar to Zegelin's (2008) categorization of an incident as fundamental in the trajectory towards becoming bedridden. In Zelegin's study, German community-dwelling elders and nursing home residents defined the incident predominantly as illness onset accompanied by an acute care hospital stay. Findings from other studies conducted in various regions of the world suggest that remaining in bed during the day is relatively common during the acute care illness phase. Bernhardt et al. (2004) found that 16% of patients admitted to specialized stroke units in Australian teaching hospitals had a medical order to remain in bed. Yet, most reasons for bed days during an acute care hospital stay remain unknown. Brown's team (Brown et al., 2004) found that 33% of Americans aged 70 years and older had a medical order to remain completely in bed for at least 24 hours at some point during hospitalization on medical units; yet, almost 60% of their participants who had remained in bed for 24 hours continuously had no medical order nor any documented reason for remaining in bed. This suggests that there are likely other factors contributing to staying in bed during acute care hospitalization that require further investigation.

Although it was not possible in our study to collect data on the participants' original acute care medical orders, almost no participant had a current medical order to stay in bed. Rather, most participants observed that they were making the current decision and preferred to continue bed days. Although the reasons for this decision and preference varied, they seemed to have predominantly emerged from attempts at self-management of symptoms. Management strategies that individuals living with chronic illness employ are often directed at bringing about order and control in their lives (Kralik, Koch, Price, & Howard, 2004). This notion of bringing about order and control was evidenced mainly in fatigue, but also in other reasons such as mobility and bowel care that the participants gave as reasons for bed days.

Participants' decisions to have bed days both to prevent and manage fatigue are not surprising because individuals with chronic illness are known to have less energy and often attempt to increase it through rest (Saylor, 2006). In fact, the participants' identified use of bed days to conserve energy, particularly alternating days in bed in order to "rest up," "get by," and prevent "tiredness" is similar to pacing, a component of rest, that is frequently employed by chronically

ill community dwellers (Kralik et al., 2004). Pacing involves paying attention to one's bodily responses (Kralik et al.) and modulating activity with rest in order to restore energy and "keep going" (Allison, 2007, p. 72). Pacing requires organization, including "preplanning," "setting limits," and "scheduling" (Allison, p. 72). This requirement may explain the process of "figuring out a system that would work" and the "scheduling" aspect of bed days to which some participants referred. Yet, unlike the participants' use of bed days, pacing is more refined as it involves alternating activity with rest periods throughout 1 day, not 1 week. Although the participants noted that they should be making their own decisions regarding staying in bed, they were, nonetheless, dependent on staff to get out of and back into bed. Consequently, the participants may have had little control over their level of pacing. Scheduling entire days of staying in bed, or forgoing getting up altogether, may have been the only way in which they could exercise control over their need for restoration.

Participants' explanation of employing bed days as a strategy to "rest up" and conserve energy for an upcoming day out of bed seems to imply that they anticipated being active at a future time. Although rest is usually regarded as an effective strategy to conserve and restore energy (Allison, 2007), excessive rest can be detrimental if it leads to reduced activity (Piper, 1993). Regular daily physical activity, including getting out of bed daily at a minimum, is a critical component for health promotion and illness prevention for all individuals, including those with disabling chronic illnesses (Durstine et al., 2000). Given the adverse consequences known to be associated with bed days, the participants may have experienced a worsening of their health situation, and they may have unwittingly chosen to stay in bed more often. This experience could function to reinforce a cycle of bed rest dependency, and ultimately decrease a person's overall ability to tolerate upright activity.

Limited mobility, characterized by perceptions of dependence when out of bed and independence when in bed, was also a predominant reason for initially and currently staying in bed during the day. On average, the study participants had a high level of disability, requiring assistance in almost all activities of daily living, yet they objected to being wheeled around and even to just sitting in a wheelchair. Doing so was perceived as futile and it made them feel dependent. This is similar to the findings of other studies in which perceptions of dependence were associated with both wheelchair

use (Barker, Reid, & Cott, 2004) and level of assistance required (Falter, Gignac, & Cott, 2003; Gignac, Cott, & Badley, 2004). Yet, these two factors do not necessarily, on their own, explain perceptions of dependence; the nature of the activity has also been found to be critical (Falter et al.). Several participants spoke of having lost use of their electronic wheelchair as the starting point of their bed days. In the facilities, it was common to see patients with high levels of physical impairment using electronic wheelchairs that they propelled by breathing into an apparatus or moving their head. In this context, being unable to move on one's own may represent one of the last frontiers of losing one's independence. Being wheeled around may be particularly objectionable because, unlike receiving assistance with other activities, such as washing and dressing, it conveys dependence in the public realm. This may force individuals to confront their disability, reinforcing their perceptions of dependence.

To our knowledge, this is the first study in which participants conveyed that staying in bed actually enhanced perceptions of independence. Getting up may no longer be viewed as necessary because, as one participant indicated he had "created an environment" in which he could "be totally independent in bed." Participants' ability to make decisions regarding when to stay in bed, rather than staying in bed per se, also may have enhanced their perceptions of independence. Gignac and Cott (1998) proposed that the ability to exercise control over a situation and the belief that the decision facilitates managing a disability may enhance perceptions of independence. Such decisions also carry risks and tradeoffs (Gignac & Cott), such as the physical health consequences known to be associated with bed days.

Lastly, a quarter of the study sample indicated that they had not been involved in the original decision and preferred not to continue bed days. Their reasons for current bed days suggest that they perceived external factors such as organizational issues, including staff business and lack of clearly defined roles regarding ambulating out of bed, to have played a role in their bed days. Although we found no studies examining organizational issues at a comprehensive level, staffing levels have been associated with the amount of time that older nursing home residents spend in bed during the daytime (Bates-Jensen et al., 2004). Similarly, nurses have identified lack of time as a reason for low mobility in older adults hospitalized on acute care medical units (Brown, Williams, Woodby, Davis, & Allman, 2007). The average participant in this study had a higher level

of disability than the general Complex Continuing Care population (Canadian Institute for Health Information, 2006). Changing demographics, particularly an increasingly older and chronically ill population requiring more assistance to get out of bed, may be a contributing factor. Bed days also may facilitate work load issues associated with pressure ulcer and bowel management in individuals who are physically disabled and dependent upon others.

Limitations

The results of this study should be viewed in the context of its limitations. We did not probe for reasons for bed days that may be reflective of psychosocial factors such as depression, social withdrawal, or ineffective coping. We did not examine participants' knowledge about the consequences of bed days, which may provide information on the risks that the target population is willing to take in order to derive the benefits they perceived bed days to have afforded. We did not inquire about physical activities that the participants performed while in bed and perceptions of the benefits of such activities. Bed days have been found to have a major and profound effect on the cardiovascular system, limiting a person's overall tolerance for upright activity (Convertino, Bloomfield, & Greenleaf, 1997). As repeated exposure to upright sitting and standing has been identified as the single most important activity to prevent and rehabilitate these detrimental effects (Convertino, 1983), such inquiries may have provided important information indicating related educational needs of the participants.

The study participants had been residing in the facility for an average of 2.5 years. Although the open-ended questions were phrased in the context of the original reason(s) for staying in bed on certain days of the week, it is possible that changes occurred in the participants' situations over this time period that may have contributed to their current decisions and reasons for bed days.

Lastly, the generalizability of the results should be interpreted in light of the limited geographical region from which the sample was drawn. The results may not be generalizable to all chronically ill patients experiencing high levels of physical disability admitted to extended care facilities.

Implications for Practice

The study results suggest that patients make decisions about staying in bed as a self-management

strategy, predominantly to prevent and reduce fatigue, and have a preference to continue to do so. The results also suggest that patients plan bed days in order to have sufficient energy for future activities that are performed out of bed. In light of the research findings presented from other studies, nurses may inform patients of the potential for bed days to mitigate goals of preventing and managing upright fatigue, and to lead to other detrimental health consequences. As nurses tend to be responsible for getting patients up (Arias & Smith, 2007), they are in an ideal position to facilitate and refine patients' attempts at pacing. This could involve helping patients to alternate shorter periods of upright activity with rest throughout the day, in order to mitigate the known consequences of staying in bed. Additionally, this may help patients manage other health related problems, such as poor sleep, as well as prevent skin breakdown and facilitate bowel evacuation, which were identified as reasons for bed days. Most importantly, future interventions would need to foster patients' goals of having a sense of order and control in their lives. This may involve negotiating strategies to facilitate these goals that take into consideration organizational resources.

Implications for Research

The study provides preliminary evidence suggesting that a tendency to use bed days as a self-management strategy to address symptoms may begin with its initial exposure during the acute illness episode, and could be related to individual preferences. Understanding the initial contributing factors from a broad perspective, which may include personal and caregiver behaviors, and organizational structures and care processes, is critical. This knowledge could be used to target interventions aimed at reducing patients' initial exposure to bed days and viewing it as a potential management strategy. The process for decision making around continuing bed days into the extended care environment after discharge from acute care also needs to be examined.

Research on the effectiveness and patient acceptability of more refined pacing strategies is also needed. Several participants explained that being up out of bed for 1 hour was excessive. Other studies have suggested that individuals with poor sitting tolerance would be willing to spend more time out of bed if they were confident of being returned to bed in a timely fashion (Schnelle, Alessi, Ludlow, Al-Samarrai, & Ouslander,

1998). The amount of time that these individuals would be willing to spend out of bed at any one time and their definition of a timely fashion are unknown, and remain potential areas for future study. This information could be used to design and test pacing interventions for the population.

We also uncovered potential areas for future research in expanding understanding of perceptions of dependence and independence in chronic illness and disability that may influence preferences for bed days. Although much research has been conducted on the limitations and losses that persons with chronic illness experience, little research has been done examining the factors associated with perceptions of independence and the strategies that individuals use to maximize independence (Gignac et al., 2004). Given that the participants observed that being in bed enhanced their perceptions of independence, future research examining this phenomenon in greater depth is needed.

Knowledge of nurses' views of bed days as an energy conserving and restoring strategy is urgently needed as they will be increasingly caring for an older chronically ill population (Kane, 1998), known to have limited tolerance for activity. The participants of this study suggested that their nurses viewed bed days as effective in this regard. Although we found no recent studies examining nurses' views on this topic, in 1989, long after its detrimental health effects were established, references to both continuous and alternating bed days as useful strategies to conserve energy, particularly for older persons, was still being made in the nursing literature (Juras, 1989).

Lastly, we learned that patients preferred bed days and believed that they were and should be making their own decisions concerning them. Consequently, future researchers should examine patients' knowledge levels about the hazards of staying in bed and its association with expressed preferences.

REFERENCES

- Allen, C., Glasziou, P., & Del Mar, C. (1999). Bed rest: A potentially harmful treatment needing more careful evaluation. *Lancet*, 354(9186), 1229–1233.
- Allison, S.E. (2007). Self-care requirements for activity and rest: An Orem nursing focus. *Nursing Science Quarterly*, 20(1), 68–76.
- Arias, M., & Smith, L.N. (2007). Early mobilization of acute stroke patients. *Journal of Clinical Nursing*, 16(2), 282–288.
- Bailey, P., Thomsen, G.E., Spuhler, V.J., Blair, R., Jewkes, J., Bezdjian, L., et al. (2007). Early activity is feasible and safe in respiratory failure patients. *Critical Care Medicine*, 35(1), 139–145.
- Barker, D.J., Reid, D., & Cott, C. (2004). Acceptance and meanings of wheelchair use in senior stroke survivors. *American Journal of Occupational Therapy*, 58(2), 221–230.
- Bates-Jensen, B.M., Schnelle, J.F., Alessi, C.A., Al-Samarrai, N.R., & Levy-Storms, L. (2004). The effects of staffing on in-bed times of nursing home residents. *Journal of the American Geriatric Society*, 52(6), 931–938.
- Bernhardt, J., Dewey, H., Thrift, A., & Donnan, G. (2004). Inactive and alone: Physical activity within the first 14 days of acute stroke unit care. *Stroke*, 35(4), 1005–1009.
- Brown, C.J., Friedkin, R.J., & Inouye, S.K. (2004). Prevalence and outcomes of low mobility in hospitalized older patients. *Journal of the American Geriatrics Society*, 52(8), 1263–1277.
- Brown, C.J., Williams, B.R., Woodby, L.L., Davis, L.L., & Allman, R.M. (2007). Barriers to mobility during hospitalization from the perspectives of older patients and their nurses and physicians. *Journal of Hospital Medicine*, 2(5), 305–313.
- Browse, N.L. (1965). *The physiology and pathology of bed rest*. Springfield, IL: Charles C. Thomas.
- Canadian Institute for Health Information. (2004). Complex continuing care in Ontario: Resident demographics and system characteristics, 1996–1997 to 2002–2003. Retrieved December 22, 2008, from http://secure.cihi.ca/cihiweb/products/OCCPS_Patient_Demographics_and_System_Characteristics_e.pdf.
- Canadian Institute for Health Information. (2006). Facility-based continuing care in Canada, 2004–2005. Retrieved December 29, 2008, from http://secure.cihi.ca/cihiweb/products/ccrs_annualreport06_e.pdf.
- Convertino, V.A. (1983). Effect of orthostatic stress on exercise performance after bed rest: Relation to in-hospital rehabilitation. *Journal of Cardiac Rehabilitation*, 3(9), 660–663.
- Convertino, V.A., Bloomfield, S.A., & Greenleaf, J.E. (1997). An overview of the issues: Physiological effects of bed rest and restricted physical activity. *Medicine & Science in Sports & Exercise*, 29(2), 187–190.
- Covinsky, K.E., Palmer, R.M., Fortinsky, R.H., Counsell, S.R., Stewart, A.L., Kresevic, D., et al. (2003). Loss of independence in activities of daily living in older adults hospitalized with medical illnesses: Increased vulnerability with age. *Journal of the American Geriatrics Society*, 51(4), 451–458.
- Durstine, J.L., Painter, P., Franklin, B.A., Morgan, D., Pitetti, K.H., & Roberts, S.O. (2000). Physical activity for the chronically ill and disabled. *Sports Medicine*, 30(3), 207–219.
- Falter, L.B., Gignac, M.A., & Cott, C. (2003). Adaptation to disability in chronic obstructive pulmonary disease: Neglected relationships to older adults' perceptions of independence. *Disability & Rehabilitation*, 25(14), 795–806.
- Fortney, S.M., Schneider, V.S., & Greenleaf, J.E. (1996). The physiology of bed rest. In M.J. Fregly

- & C.M. Blatteis (Eds.), *Handbook of Physiology* (pp. 889–939). New York: Oxford.
- Fox, M.T.C. (2007) The effects of scheduled bed rest in complex continuing care. (Doctoral dissertation, University of Toronto, 2007). Dissertation Abstracts International B, 69, December 2008.
- Gignac, M.A., Cott, C., & Badley, E.M. (2004). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journals of Gerontology: Psychological Sciences*, 55(6), P362–P372.
- Gignac, M.A.M., & Cott, C. (1998). A conceptual model of independence and dependence for adults with chronic physical illness and disability. *Social Science & Medicine*, 47(6), 739–753.
- Hagen, K.B., Jamtvedt, G., Hilde, G., & Winnem, M.F. (2005). The updated Cochrane Review of bed rest for low back pain and sciatica. *Spine*, 30(5), 542–546.
- Haisma, J.A., Busmann, J.B.J., Stam, H.J., Sluis, T.A.R., Bergen, M.P., Post, M.W.M., et al. (2007). Physical fitness in people with a spinal cord injury: The association with complications and duration of rehabilitation. *Clinical Rehabilitation*, 21(10), 932–940.
- Hale, E.D., Treharne, G.J., & Kitas, G.D. (2007). The Common-Sense Model of self-regulation of health and illness: How can we use it to understand and respond to our patients' needs? *Rheumatology*, 46(6), 904–906.
- Harmer, B., & Henderson, V. (1955). *Textbook of the principles and practice of nursing* (5th ed.). New York: MacMillan.
- Hsieh, H.-F., & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288.
- Juras, M.A. (1989). A quality day in bed. *Canadian Nurse*, 85(5), 17–19.
- Kane, R.L. (1998). Managed care as a vehicle for delivering more effective chronic care for older persons. *Journal of the American Geriatrics Society*, 46(8), 1034–1039.
- Killewich, L.A. (2006). Strategies to minimize postoperative deconditioning in elderly surgical patients. *Journal of the American College of Surgeons*, 203(5), 735–745.
- King, B.D. (2006). Functional decline in hospitalized elders. *MEDSURG Nursing*, 15(5), 265–271.
- Kralik, D., Koch, T., Price, K., & Howard, N. (2004). Chronic illness self-management: Taking action to create order. *Journal of Clinical Nursing*, 13(2), 259–267.
- Mezey, M., Teresi, J., Ramsey, G., Mitty, E., & Bobrowitz, T. (2000). Decision-making capacity to execute a health care proxy: Development and testing of guidelines. *Journal of the American Geriatrics Society*, 48(2), 179–187.
- Morris, J.N., Fries, B.E., Mehr, D.R., Hawes, C., Phillips, C., Mor, V., et al. (1994). MDS Cognitive Performance Scale. *Journal of Gerontology: Medical Sciences*, 49(4), M174–M182.
- Morris, J.N., Fries, B.E., & Morris, S.A. (1999). Scaling ADLs within the MDS. *Journals of Gerontology: Medical Sciences*, 54(11), M546–M553.
- Ontario Hospital Association. (2006). Optimizing the role of complex continuing care and rehabilitation in the transformation of the health care system. Retrieved December 22, 2008, from www.oha.com.
- Piper, B.F. (1993). Fatigue. In V. Carrieri-Kohlman, A.M. Lindsey, & C.M. West (Eds.), *Pathophysiological phenomena in nursing: Human response to illness* (2nd ed., pp. 279–302). Philadelphia: WB Saunders.
- Saylor, C. (2006). The circle of health. *Journal of Holistic Health*, 22(2), 98–115.
- Schnelle, J.F., Alessi, C.A., Ludlow, K., Al-Samarrai, N.R., & Ouslander, J.G. (1998). Sleep hygiene in physically dependent nursing home residents: Behavioral and environmental intervention implications. *Sleep*, 21(5), 515–523.
- Sidani, S., Epstein, D.R., & Miranda, J. (2006). Eliciting patient treatment preferences: A strategy to integrate evidence-based and patient-centered care. *Worldviews on Evidence-Based Nursing*, 3(3), 116–123.
- Simmons, S.F., & Schnelle, J.F. (2001). The identification of residents capable of accurately describing daily care: Implications for evaluating nursing home care quality. *The Gerontologist*, 41(5), 605–611.
- Teare, G.F., Daniel, I., Markel, F., McKillop, I., Pink, G.H., Rashkovan, N., et al. (2004). Hospital report 2003: complex continuing care. Retrieved December 22, 2008, from http://www.hospitalreport.ca/downloads/2003/CCC/CCC_2003_FullReport.pdf.
- Wodchis, W.P., Teare, G.F., Naglie, G., Bronskill, S.E., Gill, S.S., Hillmer, M.P., et al. (2006). Skilled nursing facility rehabilitation and discharge to home after stroke. *Archives of Physical Medicine & Rehabilitation*, 86(3), 442–448.
- Zegelin, A. (2008). 'Tied down'—The process of becoming bedridden through gradual local confinement. *Journal of Clinical Nursing*, 17(17), 2294–2301.