

L'incertitude et l'autre niveau de soins : une étude narrative de l'expérience des personnes âgées malades et de leurs aidants naturels

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Les personnes âgées au Canada qui souffrent de multiples maladies et sont en attente d'un placement dans une unité de soins de longue durée sont très touchées par l'autre niveau de soins (ANS). La présente étude narrative vise à consigner les expériences des personnes âgées hospitalisées et de leurs aidants naturels après l'établissement de la nécessité d'un ANS. Les chercheurs ont effectué 21 entrevues avec 5 personnes âgées hospitalisées et 4 aidants naturels. Les entrevues ont été transformées en récits résumant les expériences de ces personnes et analysées pour en cerner les thèmes communs. Une des principales constatations de l'étude est que l'incertitude fait partie intégrante de l'expérience d'un ANS, comme l'expriment ces trois thèmes : *je n'ai jamais pensé que je me retrouverais dans cette situation, je ne sais pas* et *l'attente*. Pour améliorer l'expérience d'un ANS, il faudrait établir des stratégies globales à l'échelle humaine, organisationnelle et structurelle pour mieux gérer l'incertitude tout en cherchant à réduire la fréquence d'un ANS chez les patientes et les patients âgés.

Termes clés : personnes âgées, autre niveau de soins (ANS), soins de longue durée

Uncertainty and Alternate Level of Care: A Narrative Study of the Older Patient and Family Caregiver Experience

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Older adults in Canada who have multiple illnesses and are awaiting placement in long-term care are greatly impacted by alternate level of care (ALC). The purpose of this narrative study was to record the experiences of hospitalized older adults and their family caregivers after the patient is designated as requiring ALC. The researchers conducted 21 interviews with 5 older patients and 4 of their family caregivers. The interviews were transformed into stories summarizing the participants' experiences and analyzed for common themes. An overall finding was that uncertainty is integral to the experience of ALC as expressed under 3 themes: *I never thought I'd end up like this*, *I don't know*, and *waiting*. To improve the ALC experience, comprehensive strategies should be developed at the individual, organizational, and structural level to better manage uncertainty while seeking to reduce the occurrence of ALC among older patients.

Keywords: aging, clinical nursing research, geriatric, mobility, nursing interventions, transitional care

Introduction

Alternate level of care, or ALC, is a designation assigned to a patient in Canada (Canadian Institute for Health Information [CIHI], 2009) who is occupying a hospital bed but no longer requires the intensity of services provided in the hospital setting (Cancer Care Ontario, 2009). Different terms are used for the designation in other jurisdictions; in the United Kingdom it is "delayed discharge" (Glasby, Littlechild, & Pryce, 2006). There is concern in Canada that ALC is having an increasingly negative impact on an already overburdened hospital system (CIHI, 2009). The patient population most affected is older adults, especially those with multiple illnesses, including dementia (CIHI, 2009). The patient and family perspective is minimally reflected in the research literature on ALC. The main purpose of this study was to explore the experiences of hospitalized older adults and their family caregivers after the patient is designated ALC.

Literature Review

In the Canadian province of Ontario, between March 2012 and March 2013 the monthly proportion of acute-care hospital beds occupied by ALC patients ranged from 15% to 17% (Ontario Hospital Association, 2013). Older patients awaiting placement to a long-term-care home (LTCH) often spend an extended period in hospital before placement occurs (Walker, 2011). In 2008–09 older ALC patients awaiting LTCH placement in Ontario had a median wait time of 55 days (Bronskill et al., 2010).

In their review of the literature on delayed discharge in the United Kingdom, Glasby and colleagues (2006) conclude that effective responses to the problems of ALC must be guided by evidence that includes a patient and family caregiver perspective. Such evidence (of which there is very little) is needed to guide targeted strategies for improving the patient and family experience, given that many aspects of that experience have been shown to be unsatisfactory (Doleweerd & Berezny, 2009; Kydd, 2008; Swinkels & Mitchell, 2008). Glasby and colleagues (2006) propose that the patient and family perspective be used to guide comprehensive, informed solutions at the level of the health-care and social-care systems, with the goal of reducing the occurrence of ALC.

Three qualitative studies have explored the experiences of patients or family caregivers following ALC designation. In an ethnographic study of delayed discharge with three older patients, Kydd (2008) found that patients were anxious about their future; the author includes little about the assumptions underlying the study design, provides limited description of methods, and presents a list of issues rather than a cogent summary of themes and ideas emerging from the data. In a phenomenological study using interviews with 23 patients at three hospitals in England, Swinkels and Mitchell (2008) found that patients with a delayed discharge willingly or unwillingly relinquished involvement in the discharge planning process. Doleweerd and Berezny (2009) found that family caregivers lacked accurate and timely information throughout the ALC experience and were upset about the ALC co-payment. (In Ontario, most patients awaiting LTCH placement are required to start making payments to the hospital once the patient is designated ALC. This is known as the ALC co-payment.) However, Doleweerd and Berezny's report is based on interviews that took place long after the ALC experience had ended, and neither Doleweerd and Berezny nor Swinkels and Mitchell followed their participants over time. Hence, the present study sought to better understand the experience of patients and family caregivers, including their information needs, aspects of care that were positive or negative, feelings that were part of the experience, effects of the experience, and hopes, fears, and worries concerning the future.

Method

Narrative Design

The research question was as follows: *What are the experiences of hospitalized older patients and their family caregivers after the patient is designated ALC?* The narrative design was based on Clandinin and Connelly's (2000) Three Dimensional Narrative Inquiry Space approach. The three dimensions address key aspects of the ALC phenomenon: *interactions* between the *personal environment* and the *social environment*; *temporality* (*past, present, future*); and *place*. The dimension of personal and social interactions guided inquiry into participants' feelings and values and exploration of their interactions with others, including health-care providers. The dimension of temporality helped shape understanding of the continuousness of present experiences with past and future ones. The significance of place as noted in the ALC literature guided inquiry into how place shaped participants' experiences at home and in hospital and their perception of the place they would be moving to following hospitalization.

Setting and Participants

In the fall of 2010 five patients and four family caregivers were recruited on a sequential basis over a 3-month period from the internal medicine service of a large urban teaching hospital in south-central Ontario. Patients were eligible for inclusion if they were 75 years or older, designated ALC within the last 30 days, able to speak and understand English, admitted from a private home, and likely to apply for placement to an LTCH, retirement home, or complex continuing care facility. The age criterion was chosen because the median age for ALC patients in Canada is 80 years (CIHI, 2009) and most ALC patients are over the age of 75 (Walker, 2011). LTCH was chosen as a placement destination because it is highly represented in the ALC population, at 43% of possible discharge destinations across Canada (CIHI, 2009). Retirement home and complex continuing care were included in case these possible placement destinations resulted in experiences that were different from those of LTCH. Patients were excluded if they were designated as requiring palliative care, had advanced dementia or a current delirium, or were under the order of a public guardian. Eligible patients were asked to identify a family caregiver who could be approached to participate.

Recruiters for the study were members of the professional staff involved in the patients' care. At the time of ALC assignment, all patients were divided into two groups: those who could return home (ALC-Home), and those who required placement to a setting that was yet "to be determined" (ALC-TBD). The ALC-TBD designation was retained until discussion among the patient, family, and professional caregivers in

the circle of care had identified one of eight possible discharge destinations. Participants were therefore recruited from the list of patients who were designated ALC-TBD, ALC-LTCH, ALC-Retirement Home, or ALC-Complex Continuing Care. For those designated ALC-TBD, the recruiters were asked for their opinion on which patients were likely to seek one of the three destinations of interest for this study (LTCH, retirement home, or complex continuing care). In the end, a total of 13 patients qualified for the study, five of whom were eventually enrolled. Four of five possible family caregivers agreed to participate. Of the eight patients who were not enrolled, five declined to participate and three were discharged from hospital before they could be approached to participate. All those enrolled completed the entire study.

Interviews

Semi-structured interviews were conducted by the first author using an interview guide (available from the first author) based on evidence from the literature on ALC experiences and structured using the Three-Dimensional Narrative Inquiry Space approach. Given the emphasis on time as a central dimension of experience (Clandinin & Connelly, 2000), at least two interviews separated in time were obtained for most participants.

Data Analysis

The interviews were audiorecorded and transcribed. Re-storying involved a complex set of steps whereby the transcripts were analyzed using *holistic content* procedures (Lieblich, Tuval-Mashiach, & Zilber, 1998) to create one storied account incorporating the perspective of both the patient and the family caregiver for each pairing (Clandinin & Connelly, 2000). *Categorical content* analysis (Lieblich et al., 1998) was then used to identify themes that were common across participant stories. The study was guided by Kirkpatrick's (2005) suggestions for ensuring rigour in narrative inquiry.

Ethical Considerations

The study was approved by the research ethics board of the participating hospital. Given concerns about the level of physical and cognitive functioning in the vulnerable population of hospitalized older persons, the *process consent* method was employed (Dewing, 2007). This approach views consent as an ongoing process grounded in the relationship between researcher and participant. It includes efforts at each encounter to monitor the well-being of the participant to determine whether it is in any way eroded by the research process.

Findings

In total, 21 interviews were conducted, with two or more interviews taking place for seven of the nine participants. Patients ranged in age from 82 to 89 years and included three men and two women — three married, one single, and one widowed. Family caregivers ranged in age from 48 to 59 years and included three women and one man — two single, one married, and one in a common-law relationship. Patients were enrolled in the study between 3 and 30 days after being designated ALC and were interviewed approximately every 2 weeks until discharge; the longest follow-up was 8 weeks. Patients were located on five different medical wards of the hospital (ALC, Chest, Flex, Clinical Teaching, and Cardiology).

Uncertainty was found to be integral to the experience of ALC as captured under three broad themes: *I never thought I'd end up like this*, *I don't know*, and *waiting*. The three themes and 12 subthemes are described below. All names are pseudonyms.

I Never Thought I'd End Up Like This

The past: I was on the go all the time. In speaking about their lives before being admitted to hospital, patients viewed themselves as moving freely and engaging in meaningful activities. Reflecting on his life, Bob said,

I've travelled the world. I've been a lot of places a lot of people never get [to]. . . . I've done a lot, I've seen a lot. I had a good life till they took my wife [to an LTCH].

The present: I never thought I'd end up like this. Patients and family caregivers had different perspectives on the circumstances that had led to the hospital admission. In each case, the older adult's functional status gradually deteriorated over the course of weeks or months, resulting in rising concern by the family caregiver about the person's ability to manage at home. Sudden deterioration (e.g., inability to transfer out of bed, eat, or communicate) led to the hospital admission, at times against the wishes of the older adult. This deterioration was sometimes precipitated by problems related to a chronic health condition.

Most patients described their present situation — hospitalized while designated ALC — as discontinuous with their past experience and their previous notions about their future. They expressed an uncertain, almost bewildered, concept of self, struggling to come to terms with their recent decline in functional ability and to imagine themselves living in the new place. On the morning of his transfer to an LTCH, Dan's resigned tone stood in marked contrast to his usual assertive and direct manner: "I never

thought I'd end up like this." Teresa's second interview, filled with a litany of complaints about her situation, included the following reflection:

When you think of people throughout the world starving . . . I think, "What must God think of you?" He put me on this earth for a purpose. This is the way He wants things to be. [So] why don't I say, "Thank you, God, I accept it," instead of carrying on like an idiot . . . I don't like that part of me, because I never thought in my life I would be one to complain.

The future: At my age, what is there to hope for? Patients had a mostly negative view of their future. When they were asked what they hoped for, their responses ranged from tentative hopefulness (Dan and Frank), to trust in the face of uncertainty (Teresa), to resignation — "At my age, what is there to hope for?" (Nancy), to a conviction that there was no future (Bob). Because of their age and recent health decline, most patients were pragmatic and frank in speaking about their own mortality and the possibility that the end of their life was near. However, this view of the future did not preclude their expressing modest hopes for a better future. About the uncertainty she was feeling regarding her future and the challenges she was facing, Teresa said, "I think you get accustomed to things and you adjust or you go crazy." Bob had a pragmatic view of his future: "I don't have a future . . . I've been [in bed] for 2 months. That's no good." Given Bob's past experience with chronic illness and cycles of exacerbation and recovery, his inability to rebound from this acute phase caused him grave concern.

I Don't Know

I don't know the right questions to ask. Several family caregivers identified concerns related to poor communication. Barb, for example, was uncertain about how to obtain the information she needed to guide planning and decision-making for her mother's care:

I think the information could have been explained a little more clearly, because I don't . . . understand the system . . . maybe I just didn't know the right questions to ask.

Similarly, Alan said,

The degree of communication is terrible . . . It's rare that someone will come to me and say, 'This is what's going on.' . . . It seems unprofessional and it makes me wonder — I mean, not the abilities but . . . the coordination.

I don't know about hospital processes. Participants described not knowing about important processes of care. This included not knowing the meaning of "alternate level of care," the roles of different staff members, processes related to patient isolation, the availability of day

passes, or why the patient was being moved. For example, patients and family caregivers tried to read meaning into unexplained moves that occurred in the hospital. After the unexpected move of her father to the ALC ward, Sarah declared, "They didn't even explain to us . . . I thought they were going to start those musical beds again like they generally do."

I don't know about the placement process. In the midst of the experience, participants had many unanswered questions about the placement process. This uncertainty lingered right up to the moment of discharge. Participants reported not knowing about crucial aspects of the plan for placement, not being included in the planning and decision-making processes, not knowing about financial aspects of the placement process, not having basic information about the features and services of retirement homes and LTCHs, and not understanding the overall process for arranging placement. Bob was extremely upset about not being present at a crucial discharge planning meeting: "How they can hold a meeting like that and not have the person you're talking about and discussing have an opinion!" Teresa was just 3 hours from discharge:

Teresa: I'm being moved to [the Assess and Restore Program] for therapy . . . I don't know what it involves . . . and I don't think they told my niece any more than they told me.

Interviewer: Do you have any idea what the plan is?

Teresa: Not a whit.

I don't know about medical assessment, diagnosis, and prognosis. Patients and family caregivers felt they were not provided important medical information related to assessment, diagnosis, and prognosis. On the morning of her transfer to a retirement home, Nancy was so angry about not receiving adequate medical information that she held a protest, refusing to get dressed until a doctor came to assess her. Her daughter, Barb, commented,

I don't know if assessments were ever done. Well, I do know one was done but you don't know when, where, what are the results? What do they say? What does that mean?

Waiting

Waiting to be more mobile. Patients expressed a desire to be more mobile and to receive more physiotherapy and assistance with exercise. Several were waiting for assistance so they could start walking and lamented the unavailability of physiotherapy on weekends. Teresa complained to the physiotherapists about the uncertain weekday scheduling: "There's really no purpose you coming if you don't come on a regular basis." Sarah was very disappointed because of the lack of attention paid to her father's

walking. Having seen remarkable improvement in her mother's mobility after 3 months in an LTCH, she said, "The nursing home will probably have my dad up more . . . than the hospital."

Longing for meaningful activity. Patients described the challenges they faced waiting for time to pass. They attributed the lack of meaningful activity to this waiting. Nancy described herself as "whining" because of the inactivity: "It's boring . . . I mean, I'm lying there all the time . . . they get mad at me because I'm whining . . . but there's nothing else." Teresa poignantly conveyed her longing for meaningful activity using the image of a clock:

The days are long, the nights are longer, and of course in every room they have a great big clock that tells you exactly to the minute. So your life is passing . . . by and you're not going anywhere.

Waiting for care. Patients were pleased with many aspects of the physical care they received while designated ALC. However, they reported having to wait, often for long periods, for assistance with activities of daily living, such as eating, toileting, and personal care. In observing other patients on the ALC ward who were physically and cognitively more impaired than she was, Teresa commented,

I was wishing people could be more helpful to them, because . . . if you're [among] the more disabled, to me you always have to wait till everybody [else] is looked after.

Waiting for placement. Family caregivers and patients were frustrated by the protracted and uncertain wait for placement, which led to firm action in some cases and resignation in others. A particularly contentious aspect of waiting for placement was the ALC co-payment. Alan stated that it caused his parents great financial difficulty since they were simultaneously paying for their house and its expenses and his mother's LTCH placement:

Somebody who worked 50 to 70 years and, you know, accumulate this and have it depleted while in the hospital . . . I want it to go for life, not for existence . . . He's existing — he's not living.

Waiting for couple reunification. Three of the five patients were separated from a spouse with dementia and the placement they were waiting for would reunite them. Bob had been waiting 15 months, ever since his application to be placed in the same LTCH as his wife had been accepted: "Especially in these years, not that much time left, they could be a little more careful about splitting couples up." His son, Alan, exclaimed, "If someone tells me one more time that that is the way the system works — the system is broken; it needs to be fixed!"

Discussion

Uncertainty and the Experience of ALC

The main finding of this study is that *uncertainty* is integral to the experience of ALC for patients and family caregivers. Uncertainty was apparent across the three dimensions of experience described by Clandinin and Connelly (2000), including *uncertain self-concept* in the personal dimension as reflected in the theme *I never thought I'd end up like this*, *uncertain knowing* in the dimension of interactions in the social environment, and *uncertain waiting* in the dimensions of temporality and place. Other studies of patient experience of ALC have reported themes that resonate with the findings of this study, such as lack of information and anxiety about the future (Doleweerd & Berezny, 2009; Kydd, 2008; Swinkels & Mitchell, 2008). No other studies, however, have reported the combination of findings that result in the view that uncertainty is a central part of the ALC experience.

The findings of this study are consistent with Clandinin and Connelly's (2000) perspective that the dimension of place has a significant impact on experience. For example, three of the five patients were waiting for LTCH placement. The uncertainty and distress shown by these participants support Sussman and Dupuis's (2012) finding that transition from hospital to LTCH is a more difficult experience than transition from, for example, home or retirement home to LTCH. In the hospital setting, the transition to LTCH is intertwined with the process of ALC designation and is therefore shaped in significantly different ways compared to the transition to LTCH from, for example, home or retirement home.

Several aspects of this study may have contributed to the novel findings. First, the temporal design, with multiple interviews for each participant, allowed both a stronger relationship to evolve between participant and interviewer and time for participants to reflect and expand on themes that re-emerged in subsequent interviews. This generated deeper and richer insight, which included negative aspects of the experience. Second, the pairing of patient and family caregiver perspectives elicited a rich narrative of the shared experience of ALC designation. Finally, participants noted that reflecting in the midst of the experience allowed them to comment on details they might otherwise have forgotten.

Uncertain Self-Concept

The theme *I never thought I'd end up like this* conveyed patients' uncertainty about their self-concept. The research literature on the ALC experience does not report on uncertain patient self-concept. The literature on self-concept related to chronic illness, however, does discuss uncer-

tainty — for example, in relation to Alzheimer’s disease (Parsons-Suhl, Johnson, McCann, & Solberg, 2008; Pearce, Clare, & Pistrang, 2002). Charmaz (1995) points out that chronic illness disrupts the unity between a person’s concept of their body and their sense of self. She describes a process whereby some people with chronic illness go through stages of adapting to impairment. The present study identifies relocation as an added challenge in learning to live with chronic illness.

Uncertain Knowing

The findings under the theme *I don’t know* are congruent with those reported by previous studies of ALC experiences (Doleweerd & Berezny, 2009; Swinkels & Mitchell, 2008). Concerns about not knowing also reflect problems documented in the larger research literature on hospitalization of older adults (Flacker, Park, & Sims, 2007; Huber & McClelland, 2003) and family caregivers (Higgins, Joyce, Parker, Fitzgerald, & McMillan, 2007).

Participants expressed frustration at not knowing about the discharge plan, which is consistent with the ALC literature in that disempowerment related to poor communication is a barrier to full participation (Swinkels & Mitchell, 2008) and patients had little say in their discharge plan (Kydd, 2008). This study provides evidence of more active exclusion from the discharge planning process. For example, Bob was extremely upset at being excluded from a crucial discharge planning meeting. Hence, the word “disenfranchisement” might better characterize the experience of ALC patients in relation to the discharge planning process than “relinquishment,” as proposed by (Swinkels & Mitchell, 2008).

Uncertain Waiting

The theme of *waiting* illustrates how uncertainty in the dimensions of time and place contributed to participants’ global experience of uncertainty. The length of the wait for placement proved to be very uncertain. The ALC stay for the patients in the study ranged from 11 to 85 days. In all cases, discharge occurred suddenly, with little notice — less than 24 hours in two cases. Doleweerd and Berezny (2009) also report uncertain waiting for discharge and note that lack of accurate information about wait times contributed to the uncertainty.

Participants were concerned about the lack of mobilization assistance, especially on weekends, and the uncertain scheduling of physiotherapy. Swinkels and Mitchell (2008) also report *immobility* as a theme. In the larger body of research with hospitalized older adults, Callen, Mahoney, Grieves, Wells, and Enloe (2004) report that few older patients on the medical units of a teaching hospital who were evaluated as capable of walking actually did walk. The detrimental effects of lack of mobility

among older hospital patients are well documented (Brown, Friedkin, & Inouye, 2004; Fisher et al., 2011; Inouye, 2006; Zisberg et al., 2011).

Participants spoke eloquently about the lack of meaningful activity. In the ALC literature, the lack of meaningful activity is associated with mood changes, frustration (Swinkels & Mitchell, 2008), and boredom (Kydd, 2008). Other literature on hospitalized older adults reflects this same concern (McKee, Harrison, & Lee, 1999; Nolan, Grant, & Nolan, 1995).

Some of the participants' narratives display evolution of the themes over time. For example, at the first interview Teresa (who had the longest ALC stay: 85 days) was quite brief in her responses and spoke in mostly positive terms about her experience. Subsequent interviews yielded much more content, including many complaints about her situation, which centred on the theme of uncertainty as expressed across all three themes (uncertain self-concept, uncertain knowing, and uncertain waiting) and even led her to apologize for being "a complainer." The fourth and final interview continued to yield this richness but included positive reflections on initiatives she had taken to address her concerns, such as becoming more mobile and pursuing meaningful activity. Uncertainty about the plans for her discharge emerged most intensely during this last interview, just hours before her discharge. Overall, it is difficult to characterize the factors that might have influenced the evolution of the narratives. As well, the nature of the relationship between the themes and the passage of time is variable, with some aspects amplified and others diminished, depending on the particular experience being described by the participant.

Uncertainty and the Challenge of ALC Research

A number of challenges were encountered doing research related to ALC, which were impacted by the uncertainty associated with the phenomenon. For example, uncertainty about the timing of discharge meant that the researchers were given little time to arrange final interviews (less than 24 hours in two cases). As well, the physical and/or emotional vulnerability of participants coupled with the complexity of the acute-care environment made it difficult to initiate timely engagement with participants (the first interviews with patients ranged from 8 to 32 days following ALC designation), to sensitively and flexibly negotiate appropriate interview times (e.g., many family caregiver interviews were dovetailed with scheduled visits to the patient), and to find private, accessible interview locations.

Implications for Practice and Policy

Glasby (2004) proposes a framework for understanding and responding to problems associated with ALC. Problems fall into three concentric and

expanding circles or levels of concern: individual, organizational, and structural. The individual level refers to the way in which health-care providers interact with patients and families and to issues such as effective communication. The organizational level encompasses the effectiveness of care practices and policies within and between organizations. The structural level highlights the need for government action in order to address financial, legal, and administrative obstacles to inter-organizational collaboration. The implications of the findings of uncertain self-concept, uncertain knowing, and uncertain waiting are examined using the lens of Glasby's framework.

Individual level. The finding of uncertain self-concept suggests the need to provide support to patients in the midst of the ALC experience. Penrod (2007) argues that when the mode of uncertainty is existential in nature and related to learning to live with prolonged uncertainty, intervention strategies should focus on helping patients to be introspective and to seek personal growth. In her examination of older adults' perceptions and experience of time when institutionalized (specifically, in LTCHs), Wiersma (2012) observes that institutional living tends to create a culture of time that is focused solely on the present. She argues that institutional staff would do well to resist this cultural tendency and seek ways to recognize the rich and varied past of residents along with the challenging future they face. This prescription might apply equally to staff caring for older patients designated ALC.

Organizational level. The finding of uncertain knowing implies that hospitals should provide timely and accurate information to patients and families in order to manage uncertainty during the ALC experience. Although the care processes related to information provision were not examined in this study, patients and family caregivers were clear about their experience on the matter. The literature on managing uncertainty in chronic illness (Bailey, Wallace, & Mishel, 2005; Penrod, 2007) includes work based on Mishel's (1988) Uncertainty in Illness Theory. A key insight of this theory, as applied to chronic illness, is that patient uncertainty can be mitigated by education and social support offered by health-care providers (Mishel & Clayton, 2003). However, this alone is not sufficient to address information needs during discharge planning (Flacker et al., 2007). Best practices suggest that a comprehensive approach is needed to ensure the full participation of patients and families in the discharge planning process and that it should include better, earlier, and more frequent education and communication (Bauman et al., 2007). A multidisciplinary team member designated as discharge advocate might be one means of improving the discharge planning process (Jack et al., 2009; Naylor et al., 1999).

The findings on uncertain waiting suggest that hospitals should encourage meaningful activity for older adults, including the promotion of mobility. In Ontario, the Senior Friendly Hospital strategy (Wong, Ryan, & Liu, 2011), building on the work of Parke and Stevenson (1999), includes care processes that preserve the independence of older adults by optimizing physical, cognitive, and psychosocial function. Hospitals need to implement goal-directed plans for physiotherapy and recreation, ensure reliable scheduling of such services, especially on weekends, and educate all staff members in the value of meaningful activities for older adults, including nursing assistance with mobilization (Callen et al., 2004; Kalisch, 2006).

Structural level. Uncertain waiting could be reduced by revising regional, provincial, and national policies in order to address problems related to LTCH wait-list management, couple reunification, and the ALC co-payment. Doleweerd and Berezny (2009) raise similar concerns about LTCH wait-list management in Ontario. Policies should focus on developing comprehensive strategies for reducing the occurrence of ALC among older patients by providing options for care in more appropriate settings (Costa, Poss, Peirce, & Hirdes, 2012). In general, hospitalization can compromise the health of older patients and every effort must be made to reduce hospital stays when they become unnecessary (Callahan, Thomas, Goldhirsch, & Leipzig, 2002). Glasby and colleagues (2006) report that evidence on solutions is limited but that comprehensive strategies simultaneously addressing all three levels of the Glasby framework hold some potential.

Limitations

Narrative inquiry acknowledges the tentative nature of any findings concerning the human experience. “The attitude in a narrative perspective is one of doing ‘one’s best’ under the circumstance, knowing all the while that other possibilities, other interpretations, other ways of explaining things are possible” (Clandinin & Connelly, 2000, p. 31).

Although the number of patients would be quite small, the findings of the present study could likely be generalized to patients awaiting placement but not designated ALC (e.g., those for whom the ALC designation is suspended while a new acute medical issue is being treated). In addition, the transferability or generalizability of the findings is limited by the study design. For example, given the narrative approach of exploring through in-depth interviews the experiences of participants over time, the number of participants in the study was small and only one acute-care setting was used. As well, the perspective of patients with advanced dementia was not included, and since this population is signifi-

cantly impacted by the phenomenon of ALC the absence of such a perspective precludes a full understanding of the range of ALC experiences. In addition to the problem of generalizability, the study's design made it difficult to differentiate the multiple factors that might have contributed to the patients' uncertainty. These factors could include the following: the implications of the process of ALC designation for type, quantity, quality, and location of care in the hospital; implications of the life crisis precipitated by the need to seek placement in an LTCH or retirement home; factors specific to the setting to which the patients were being transferred (e.g., LTCH vs. retirement home); and the total length of time the patients spent in hospital before and after ALC designation. Finally, given that the overall tone of the findings is negative, especially in relation to experiences with the discharge planning process, it is important to note that the study did not include the perspectives of health-care providers, whose views on the processes of care and discharge planning might have differed from those of patients and family caregivers.

Conclusion

The main contribution of this study is the finding that uncertainty is an integral part of the ALC experience. This finding implies two basic approaches to improving the patient and family caregiver experience. The first is to identify strategies for better managing uncertainty in this situation. Given the findings with respect to uncertain self-concept, health-care providers should be better prepared to offer support to patients during difficult life transitions. At the organizational level, the findings regarding uncertain knowing and waiting should prompt hospitals to develop comprehensive approaches to discharge planning while better aligning processes of care to promote physical, cognitive, and psychosocial function among older patients (Wong et al., 2011). At the structural level, the findings with regard to uncertain waiting suggest the need for regional, provincial, and national policies addressing LTCH wait-list management, couple reunification, and the ALC co-payment. The second approach is to develop regional, provincial, and national policies that result in comprehensive strategies (Glasby, 2004) for reducing the occurrence of ALC among older patients in order to minimize exposure to the uncertainty and distress associated with this experience.

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