

# Long-Term Care Residents with Cancer and their Health Care Providers Reflect on Hope\*

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## RÉSUMÉ

Cette étude a examiné l'espoir parmi les résidents avec le cancer en soins de longue durée et a évalué les points de vue des résidents et aussi des prestataires de soins de santé (PSS). Les données cliniques ont établi que la prévalence d'un diagnostic de cancer dans l'établissement d'étude (15%) était semblable à d'autres estimations dans la littérature. On a fait passer une entrevue parmi huit PSS expérimentés. Dix résidents avec un diagnostic de cancer ont été interrogés, et ils ont complété l'index d'espoir Herth (IEH). Les dimensions de l'espoir et les facteurs contextuels qui forment l'espoir sont manifestés comme des thèmes, et pour les PSS et pour les résidents, mais reflétaient leurs points de vue différents. En tant que partie intégrante des soins, l'espoir était un thème pour PSS. Les scores d'IEH étaient élevés, ce qui indique que les résidents étaient généralement optimistes. Les résultats de l'étude suggèrent que, pour le sous-groupe petit mais complexe de résidents en soins de longue durée qui a un diagnostic de cancer, l'espoir n'est pas perdu, mais plutôt il est pertinent, nuancé et possible d'atteindre.

## ABSTRACT

This study examined hope in long-term care residents with cancer from the perspectives of both residents and health care providers (HCPs). Clinical data established that the prevalence of a cancer diagnosis in the study facility (15%) was similar to other estimates in the literature. Eight experienced HCPs were interviewed. Ten residents with a cancer diagnosis were interviewed, and they completed the Herth Hope Index (HHI). Dimensions of hope and contextual factors that shape hope emerged as themes for both HCPs and residents, but reflected their different perspectives. HCPs identified hope as integral to care. HHI scores were high, indicating residents were generally hopeful. The study findings suggest that for the small but complex subgroup of long-term care (LTC) residents who have a diagnosis of cancer, hope is not lost, but rather it is relevant, nuanced, and possible to attain.

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## Introduction

Hope is a familiar word that has been variously defined in the clinical and scientific literature. Reviewers have concluded that hope is multidimensional, dynamic, and empowering; that it is central to life, related to caring,

oriented to the future, and highly personalized to each individual (Cutcliffe & Grant, 2001). A recent meta-synthesis of research to describe hope – representing different countries, populations, and medical diagnoses – identified five characteristics. Hope was found (a) to be

dynamic or situational in nature; (b) to consist of multiple co-existing types; (c) to target desirable, realistic possibilities; (d) to be future-focused; and (e) to involve choice or free will (Duggleby et al., 2012). Duggleby et al. have developed the theory that in older people with chronic illness, hope is associated with transcendence (i.e., reaching both inwardly and outwardly to find meaning and purpose) and positive re-appraisal (i.e., reevaluating hope in light of illness and finding positive experience).

Research has demonstrated that hope is a life-affirming construct that is related to connections with others and to personal values for patients with cancer (Elliott & Olver, 2009). Qualitative interviews conducted with community-dwelling older adults with terminal cancer supported the centrality of hope, transformed to fit present reality, for positive mental health (Duggleby & Wright, 2005). A psychosocial supportive intervention to foster hope was implemented and evaluated with 60 terminally ill cancer patients over age 60 (Duggleby et al., 2007). Results showed that the intervention (which was to have patients view a video on hope and work on an activity designed to foster hope over a one-week period) increased patients' hope scores relative to controls.

There is a growing body of research on hope in the context of long-term care (LTC) homes. Hope, together with the ability to use laughter and humour to cope with life's stressors and losses, has been identified as a psychosocial resource for older adults facing chronic illness in an assisted-living care facility (Westburg, 2003). Herth (1993), for example, compared self-reported perceptions of the factors associated with hope among older adults residing in private homes, senior citizen housing, and a LTC facility. Hope levels were significantly lower among LTC residents with high fatigue levels. Among LTC residents, hopes were found to be predominantly focused on friends and health care providers (HCPs) in the immediate future, while hope for self was often focused on life after death. Touhy (2001), on the other hand, compared levels of hope among residents of skilled nursing facilities and found no association with age, physical or mental health, or functional ability, but did find a significant association with spirituality.

In another study, three themes emerged from interviews conducted with people living in a residential care facility: (a) the meaning of hope for the residents, (b) factors that promoted hope, and (c) issues around adjustment to living in an institutional setting (Hatcher, MacDonald, Bauer, & Wilson, 1999). These researchers found that hope as a concept was less central to the well-being of the residents than expected, reflecting, at least in part, definitional challenges. In yet another

study, Cutcliffe & Grant (2001) examined the principles and processes that nurses in a continuing care environment used to inspire hope in cognitively impaired older adults. Four interrelated attributes were identified in the nurses: (a) having a humanistic mindset or approach, (b) making effective pragmatic use of their knowledge base, (c) possessing the ability to develop and maintain interpersonal relationships, and (d) organizing care delivery and the environment in ways that are conducive to hopefulness.

Evidence suggests that symptom presentations and disease trajectories distinguish LTC residents with cancer from their cancer-free peers. Research on older adults with cancer who reside in LTC homes has focused on characterizing their care needs and how they differ from needs of cancer-free residents. A chart audit conducted in five LTC facilities in a Canadian city found that cancer was the final diagnosis for 14 per cent of 185 patients who had died in the facility following a palliation period (rather than suddenly) in a 12-month period (Hall, Schroder, & Weaver, 2002). A study that used all (548,330) nursing home admission assessments in the Resident Assessment Instrument Minimum Data Set (MDS) (Morris, Murphy, & Nonemaker, 1995) recorded throughout the United States during 2002 identified that 11.3 per cent of residents had cancer on admission (Buchanan, Barkley, Wang, & Kim, 2005). Residents with cancer were significantly older and more likely to be male than were other newly admitted residents. Large proportions of these residents were totally dependent or required extensive assistance in activities of daily living (ADLs). Approximately two thirds experienced pain, and one quarter had a diagnosis of depression on admission. Residents with cancer were more likely to be cognitively intact than other residents at admission but also significantly more likely to have unstable health patterns.

Similarly, of the 544 terminal-phase patients followed in a study of 16 nursing homes in the Netherlands, 12 per cent were dying from cancer (Brandt et al., 2005). Patients who died with cancer had a different pattern of symptoms (e.g., more generalized weakness, more extreme tiredness, less fluid intake reduction, fewer pressure ulcers) than those who died with non-cancer conditions. In a U.S. study MDS data for 747 residents of a LTC facility who died between 1994 and 2004 was used to create three groups, representing primary diagnoses of advanced dementia, terminal cancer, and organ failure (congestive heart failure and chronic obstructive pulmonary disease) (Chen, Chan, Kiely, Morris, & Mitchell, 2007). The researchers compared ADLs during the last year of life, as recorded in the MDS, among the three groups. The magnitude of functional decline was greatest in the terminal cancer group, followed by the organ failure group, reflecting in part a

poorer level of ADL functioning in the dementia group to begin with. The abilities to eat independently and transfer were relatively preserved for the terminal cancer and organ failure groups until death was imminent. Functional decline was steepest in the final three months of life for all groups, with the terminal cancer and organ failure groups showing a more precipitous decline than the advanced dementia group.

Despite generally positive findings about the importance of hope for people with chronic illness, there are questions about the application of strategies to foster hope in the formal health care context. A narrative literature review of qualitative research on hope in physically ill people noted a lack of clarity in relation to hope as a want or expectation (Wiles, Cott, & Gibson, 2008). The role of HCPs in encouraging hope, the temporality of hope, and the impact of hope-sustaining activities were identified by these reviewers as understudied issues.

The concept of hope has been explored in older adults who live in LTC homes, but little is known about the experience of hope in the subset of LTC residents who have cancer. This represents a significant gap as residents with cancer form a small (11–14%) but distinct subgroup that should be considered in efforts to improve the quality of end-of-life care in LTC homes. To address this gap, we examined the factors that impede and foster hope in this subset of the facility-based LTC population from the perspectives of both HCPs and residents with cancer. We focused on residents who were cognitively able to participate in an interview and on experienced HCPs.

## Method

### *Setting and Participants*

This exploratory, descriptive, qualitative study was conducted in a large health care organization that provides residential LTC beds for eligible Canadian war veterans (veterans of World War II and the Korean War). Individual care plans are updated regularly, and integrate rehabilitation, maintenance, and/or palliative care services as needed. Over 200 staff members (all disciplines, services, and categories – full time, part time, casual) work in the Veterans Care Program that serves these residents.

HCPs from the Veterans Care Program were invited to participate in the study through posted announcements within the facility. Potential interviewees were asked to self-select on the basis of having at least two years' experience working with LTC residents, and having some experience working with residents with a diagnosis of cancer. Eight experienced HCPs from the disciplines of nursing, social work, and spiritual care volunteered to be interviewed for the study.

Ten residents from the veterans' facility with a diagnosis of cancer were also interviewed. A list of potential resident interviewees was constructed through the MDS 2.0 (Morris et al., 1995) clinical database. The MDS 2.0 is mandated by the Ministry of Health and Long-term Care for use in all complex continuing care beds in Ontario and is also used for Veterans Care Program beds in this organization. An MDS 2.0 assessment is completed for each resident 14 days after admission and quarterly thereafter. Additionally, assessments are conducted whenever there is an acute change in status.

Social work members of the interdisciplinary care team used the list of potential interviewees to select and approach residents who were thought to be capable of providing informed consent for study participation and tolerating the interview process. The majority of those approached agreed to participate, and their names were passed on to the study investigators. One person initially agreed and then withdrew consent citing concerns about fatigue given current health status; a substitute interviewee was subsequently recruited.

### *Procedure*

Approval for this study was obtained from the ethics review board of the affiliated university and the organization's clinical research approval committee.

### *Population Characteristics*

To establish whether the proportion and characteristics of the resident population with, versus without, cancer in this setting were comparable to estimates in the literature, electronically stored data from the MDS 2.0 were analysed. A data audit was conducted for all residents who were admitted to any of the eight units in the Veterans Care Program and had a full assessment completed between April 1, 2007, and March 30, 2008. Data from the most recent assessment completed in the time frame were used. Data were summarized at the population level.

Residents were grouped into two populations: those with a cancer diagnosis on the most recent full assessment, and those without. Characteristics of each population were derived from multiple aspects of the MDS 2.0 assessment including age; sex; Cognitive Performance Scale (CPS); Depression Rating Scale (DRS); Changes in Health, End-stage disease and Signs and Symptoms (CHESS) scale; pain scale; ADL – Long Form Scale and Short Form Scale (ADL-LF and ADL-SF respectively); and weight loss (loss of 5% or more in the past 30 days or 10% in the past 180 days). Associated indices – Resource Utilization Groups (RUGs) and Case Mix Index (CMI) – of clinical complexity were calculated.

The RUG-III classification system is based on data collected on the MDS assessment. Residents are categorized into one of seven RUG groups which reflect expected resource use. Each RUG has an associated weighting or CMI with the average resource user in Ontario having a CMI value of 1.0. Higher CMI values represent higher resource use.

#### *HCPs Interviews*

Seven interviews with HCPs were conducted by a research assistant trained in qualitative interviewing by study investigator EG, and one by EG directly. The interviews lasted approximately one hour and were audiotaped. The interviewer guided the interview with a series of open-ended questions, as follows: "How would you define hope? How important do you think hope is? Can you give some examples of hope that you have experienced or seen in your work here? Are there instances when you thought hope was missing in a situation? What impact did this lack of hope have on you? Are there ways that you feel you influence hope in your work? Are there challenges to hope in your work?" Prompts were provided to HCPs as needed, to encourage interviewees to think about patients, families, and staff in their responses.

The interviews were transcribed verbatim and analysed for themes. The investigators reviewed the transcripts independently and articulated a descriptive thematic framework. Resultant frameworks were compared, revealing a high degree of overlap. Modifications were made collaboratively to create a map of themes, associated keywords, and representative quotes. Member checking was achieved by providing each interviewee with a summary document including common themes, keywords associated with each theme, and two representative quotes from each theme. All comments returned were positive, with no revisions suggested.

#### *Resident Interviews*

Interviews were conducted by EG during normal visiting hours for residents. The interviews lasted approximately one hour and were audiotaped. The interview included a clinical interview (Herth, 1993), followed by administration of the Herth Hope Index (HHI; Herth, 1992). Two of the nine interviews included the presence of the resident's wife in a supportive role. Analysis was based only on the comments made by the resident and included only nine of the 10 clinical interviews due to error with one tape.

The Herth (1993) clinical interview includes these questions: "What does hope mean to you? Tell me about your hope. What kinds of things do you hope for? If you could identify a source of hope for yourself, what

would it be? What things/situations cause you to lose hope? When your hope has been low, what kinds of things do you do to help yourself regain your hope? What helps you to maintain your hope or makes you feel hopeful?" The HHI is a 12-item Likert scale (1–4 point) that has been developed and validated to assess hope in adults in clinical settings. The HHI identifies three factors of hope: (a) temporality and future, (b) positive readiness and expectancy, and (c) interconnectedness. Summative scores in the HHI range from 12 to 48 with higher scores denoting greater hope. Initial validity and reliability of the HHI have been established (Herth, 1990, 1992).

Each clinical interview we conducted was transcribed verbatim and analysed for themes using a similar collaborative process as for the HCPs data. The interviewer confirmed her understanding of each interview with the resident individually, but to avoid response burden, member checking of overall themes was not conducted with the residents.

## **Results**

### *Population Characteristics*

On the basis of 331 assessment files completed over a one-year period, we observed that 15 per cent of residents had a diagnosis of cancer, and the two indicators of clinical complexity (RUGs and CMI) were greater among residents with cancer than among those without. Seventy-four per cent of residents with a cancer diagnosis fell into the Special/Clinically Complex RUG, as opposed to 41 per cent for residents without cancer. Average CMI was 0.7538 for those with cancer and 0.6795 for those without. Thus, the local prevalence was similar to that found in other studies, and the tendency for LTC residents with cancer to have a more complex and challenging clinical profile was replicated as well.

Characteristics of the population based on MDS assessment data are summarized in Table 1. This sample is predominantly male, reflecting the fact that the patient population consists of war veterans, which in this age cohort is largely male.

### *Interview Data*

Three major themes emerged from the interviews: dimensions of hope, contextual factors, and HCPs unique perspectives. HCPs were expansive in their comments, whereas residents had less to say, restricting their responses to relatively short statements in response to questions. Representative quotes from both groups are presented together to illustrate the thoughts that were expressed within the dimensions of hope and contextual factors themes.

**Table 1: Characteristics of residents with and without a cancer diagnosis over a one-year period**

Characteristic	Residents with cancer	Residents without cancer
Percent of census	15%	85%
Average age	88 years	87 years
Sex (M = male; F = female)	M = 98% F = 2%	M = 92.2% F = 7.8%
Average Cognitive Performance Scale (CPS)	3	3
Average Depression Rating Scale (DRS)	2	2
Average Activities of Daily Living – Long Form (ADL-LF) Scale	14	12
Average Activities of Daily Living – Short Form (ADL-SF) Scale	8	7
Average pain score	1	1
Average Changes in Health, End-stage disease, and Signs and Symptoms (CHESS) Scale	2	1
Weight loss (Percent of residents)	14%	7.5%
Resource Utilization Groups (RUGs):		
Rehab/Extensive	4%	10%
Cognition/Behaviour/Physical	22%	49%
Special/Clinically Complex	74%	41%
Average Case Mix Index (CMI)	0.7538	0.6795

**Notes: ADL-LF: Each item scored 0 to 4, creating a scale with a range of 0–28; higher scores indicate increased impairment**

**ADL-SF: Scored 0–16; higher values indicate greater difficulty in performing activities**

**CHESS: Scored 0–5; higher scores indicate higher levels of instability**

**CMI: Higher values represent higher resource use**

**CPS: Scored 0–6; higher score indicates more severe cognitive impairment**

**DRS: Scored 0–14; scores of 3 or greater suggest possible depressive disorders**

**Pain scale: Scored 0–3; higher scores indicate greater frequency and intensity of pain**

**RUGs: Reflect the expected resource use of the patient based on Minimum Data Set assessment data**

**Weight loss: Percentage of residents who lost 5% or more in the past 30 days or 10% in the past 180 days**

### *Dimensions of Hope*

For residents, the prevailing dimension of hope was the centrality in their lives of other people. Family were mentioned most often. One resident commented, “Fortunately my two sons are doing very well in the States and my daughter is very happy. They’re all happily married and that gives me a lot of hope.” Friends, both within and external to the facility were also mentioned. One resident said, “I’m very fortunate that I have such wonderful people who come to see me regularly.” HCPs were included in this concern for relationships. For example, “I have hope for these nurses here that we continue to get along as good as we do.” Possibly unique to this cohort (war veterans), this hope for others included a broader world focus, as reflected in the comment: “I hope they don’t have to go through the wars.”

Concepts discussed by HCPs within the dimensions-of-hope theme included definitions, individuality, the temporal nature of hope, practical manifestations, and the power of hope. HCPs described hope as an attitude, a coping mechanism, a reason, a belief, a feeling, and a value. The definitions were quite consistent in having a future orientation. A typical comment was: “It’s a reason for being. It’s a reason for carrying on.” HCPs perceived that for many residents, hopes are pinned on surviving long enough to participate in anticipated

events, often family oriented, while for others, hope is also oriented to the future, but the context is a wish for a peaceful death. As one health care provider put it, “Many of them just hope to pass away quietly in their sleep.” Residents shared this perspective, as reflected in this comment: “I hope to join my wife who died a year ago, and I hope to go nice and quiet in my sleep.” Others spoke of acceptance, and of not actively hoping for things: for example, “I don’t have too much hope of having another long life so I think I’m prepared for that”; and “Is there more I would wish for? I don’t think so. I have everything.”

HCPs saw hope as quite individual in its manifestations, as reflected in this statement: “Hope resides in being able to find meaning in our personal experience.” In a related vein, they commented with a sense of wonder on the temporal nature of hope in relation to the residents with whom they work. For example, “There’s a couple of them [residents] that every once in a while, they’ll get so discouraged and they’ll say, I just want to die, I don’t like living like this. But the next day you’ll get that smile out of them, and they go to physio or they’ll go and do their veterans arts.” Many small comforts, activities, and rituals were seen as sources of hope as reflected in this comment, “If you hope to get up for only one hour a day, if that is your goal and you can do that, that’s like a big accomplishment.”

Residents echoed this sentiment. They associated hope with personal health, routines, and activities. Comments included: "I hope to get rid of some of this neuropathy pain I have"; "Still like to do things for myself like get up in the morning and shave"; and "[Activities like bingo] pass the time away and we have a few laughs".

Most HCPs commented on the power of hope, providing examples from their experience that illustrated this power. For example, "That fellow isn't going to live for two more days and then he lives until the summer because he has always enjoyed summer, and you think, how is that possible with all the many, many medical problems he has?" Hope as a powerful life force was also represented in comments about the situations in which lack of hope is sometimes observed. Lack of hope was often seen as giving up, as reflected in this comment: "There are some people who are just very fragile, very weak, very tired ... they don't see any point in fighting what seems to be the inevitable."

In summary, both residents and HCPs described hope as multidimensional, encompassing both the routine, fluctuating interests and needs that prevail on a day-to-day basis, as well as the ubiquitous undercurrent, in this population, of impending death. HCPs and residents also talked about different dimensions of hope, reflecting their unique vantage points. As observers, HCPs emphasized outcomes, highlighting the power of hope as a force that could even influence mortality for residents. Residents, speaking from their own experience, emphasized interpersonal aspects, highlighting the centrality of relationships as the wellspring for hope.

#### *Contextual Factors*

HCPs identified cancer as a contextual factor that could focus end-of-life decisions: "At least people are more aware of cancer being a terminal illness ... sometimes the fact that someone has dementia or the fact that someone has Parkinson's is not as readily seen as a terminal illness." The combination of advanced age and serious illness did not conclusively direct the form that hope might take. HCPs thought that some residents focused on the terminal aspects of their health status: "With our population, if they have something like cancer, sometimes they're hoping for – they're wishing for – death, rather than a cure", while others resisted their prognosis: "Many patients hope for recovery: they might be [in their] late eighties or nineties, and yet they're still hoping for recovery." Residents did not talk about the specifics of their health status (e.g., having cancer or other diagnoses) as a contextual factor that shaped hope.

Both residents and HCPs identified the LTC facility itself as a contextual factor which shaped hope. One

health care provider described this factor as follows: "People don't just come here to die. People come here to live their end stages of life." For residents, hope was related to the LTC context, but this could be viewed positively or negatively. Some residents hoped to go home despite their health status. One resident said, "I hope I'm able to get out of here and live a normal life for the next 10–15 years." Others were reconciled, but not resigned, to residency within the facility. As one resident said, "I hope my stay here will be good."

In summary, both groups referenced the LTC facility as an influence on hope, but from different perspectives. HCPs spoke from the perspective of their professional knowledge and service mandate, while residents reflected on their personal desires. HCPs spoke of cancer as a variable, comparing this disease to others they commonly encounter in the facility, while residents, with cancer as their reality, did not discuss hypothetical alternatives.

#### *HCPs Unique Perspectives*

HCPs expressed their hopes for residents and their families; boundaries to hope; challenges and ethical dilemmas; and hopes for themselves as carers.

HCPs hope that residents achieve good symptom control, especially pain management, and that the emotional needs of family members are met. A pervasive sentiment expressed was the desire that no one should die alone. As one health care provider put it, as death nears, "[HCPs] hope that they have the time to spend with the veteran, and that doesn't always happen. We hope that the family can get to the bedside if they wish, and we hope that the patient is not alone."

Among the tools HCPs use to foster hope in residents and families are humour, communication, relationships, social interaction, understanding, practical assistance, affection, language, touch, talk, and presence. HCPs try to foster hope in the way they provide their routine care and through personal touches, saying, for example, "I can't think of a big, wonderful thing that I might have done that would inject hope. It's more that [the] caring person that gets the cup of tea, it's the phone call just to give a little; it's just being there, being open. I would say probably it's no [one] big thing; it's a whole lot of little things."

Within this framework of routine, genuine caring and human emotion were espoused as means of fostering hope. For example, a representative health care provider comment was: "Sometimes all they need is that human touch, that affection, that little hug that says 'you know what, you're okay, we're going to get through it, tomorrow's another day, tonight's another night'." At the same time, boundaries are acknowledged.

Limitations to fostering hope were noted, as in this comment: "I cannot provide you with hope. I can only create the space for you to find hope within your own story, within your own life experience." Another comment was: "Sometimes people aren't hopeful, and we're not going to change that, so at the end of the day, what is the best possible outcome is not to irritate them with your hopefulness."

Professional, organizational, and interpersonal issues can create challenges to hope for HCPs. HCPs hope that their work is meaningful and valued. One health care provider explained, "We don't like to see people not having their needs met; we just want to be able to meet their needs to the best of our ability, knowing we can't possibly do it all." Workload issues, especially lack of time to build relationships with residents and families and to support them as one would like through the dying process, can contribute to burnout and loss of hope in HCPs. Conflict about appropriate treatment especially around the end of life can dampen hope, as can situations that fail to meet expectations for a good death. HCPs acknowledged these feelings, saying, for example: "Where a person's pain control has not been good, or there've been messy circumstances around the person's family ... there are conflicted feelings sometimes." These challenging situations often have ethical overtones, as reflected in this rhetorical question: "When do you decide that enough is too much, or do you kind of say this isn't in the best interest of an elderly person?" Another health care provider commented: "Instead of fighting death as if it's the enemy, now we're more looking at how we can make this a dignified end and a more peaceful kind of process."

In summary, HCPs spoke of hope in terms of being able to meet the needs of the residents in their care, within reason. They accepted limitations to their capacity to foster and support hopes that were congruent with respect for the autonomy of the resident and with the reality of their health status, but were resistant to limitations that were viewed as reflecting organizational or systemic shortcomings.

#### *Questionnaire Data*

Overall scores on the HHI were at the high end of the scale (mean: 39.34; *SD* : 4.6; range: 34–48) for all 10 residents, indicating they were generally hopeful. Three of the five items with the greatest variability were from the factor that measures inner sense of temporality and sense of future (e.g., "have short and long-term goals", "scared about the future"). There was slightly greater consistency on the factors of positive readiness and expectancy (e.g., "see possibilities", "life has value and worth") and interconnectedness (e.g., "have faith", "able to give and receive love").

## **Discussion**

We explored, from the perspectives of both HCPs and residents, the factors that impede and foster hope in LTC residents with a diagnosis of cancer. Our findings are generally consistent with the literature on hope. The findings replicate the emphasis on the importance of relationships and a supportive environment as factors that facilitate hope (Cutcliffe & Grant, 2001; Elliott & Olver, 2009). LTC residents confirmed the association between hope and their feelings towards significant others (Herth, 1993). Touhy (2001) had found that health status was not significantly associated with hope, and in a similar vein, residents in this study said little about their health status, even though they were aware that having a diagnosis of cancer was an inclusion criterion for the study. Residents demonstrated transcendence (reaching out to others and finding meaning) and positive reappraisal of their current circumstances, as theorized by Duggleby et al. (2012).

Spirituality did not emerge as a dominant factor in this study, contrary to the findings by Touhy (2001). This may reflect a difference between samples. In Touhy's study, 77 per cent of study participants were female, and HHI scores indicated less hope (mean: 35.76; range: 29–43). Residents in the present study were almost all male, reflecting their war veteran status, and were more hopeful (mean: 39.34; range: 34–48). The other notable difference is that our study included a clinical interview about hope, which allowed for spirituality to be mentioned (or not) at the discretion of the respondents, whereas Touhy administered the Spiritual Perspective Scale to directly assess this variable. Other research on end-of-life care in this setting has also indicated that population characteristics are important contextual factors that shape qualitative research results (Gibson & Gorman, 2010).

#### *Limitations*

Limitations of this study include the fact that the resident sample may not be generally representative of LTC residents with cancer. The residents in our study had consistently high HHI scores, indicating more uniformity in outlook than might be expected in a randomly selected sample. The HCPs sample was self-selected, and may have been biased towards those who have thought about, or at least were interested in and comfortable with, the topic. Again, a random sample of HCPs might have yielded a different set of themes.

#### *Implications*

Questions have been raised in previous research about the role of HCPs in sustaining hope in adults with physically ill health (Wiles et al., 2008). Research on

older adults with cancer who reside in LTC homes has tended to focus on physical rather than on psychological aspects of care, and has not addressed HCPs' perspectives on how to foster hope. Our findings address this gap, with the added benefit that the perspectives of both HCPs and residents are considered.

When given the opportunity to talk about hope, study participants shared insights focused on relationships and other quality-of-life issues such as the environment and the processes of caring. As has been found for community-dwelling populations (Duggleby & Wright, 2005), *hope transformed to fit present reality* was significant. Our results suggest that HCPs can foster hope through their support of the interpersonal relationships that are cherished by individual residents, through attention to the details of everyday life that bring meaning and joy to residents, through their own acts of generosity, consideration, and caring above and beyond the tasks of service delivery, and by accepting a resident's hopes as legitimate expressions of their personality and agency rather than judging those hopes from a different frame of reference. A balanced perspective, reflecting both commitment to life and acceptance of death is crucial, and HCPs can reflect on the wisdom of their elders to internalize this balance. Experienced HCPs are readily able to articulate, even if not always able to address, the factors that foster and impede hope in the LTC environment. They distinguish between impediments to hope that reflect the existential human condition, and impediments to hope that arise from circumstantial and pragmatic factors like workload and organizational structure.

These recommendations are consistent with the push by major advocacy organizations for culture change with LTC facilities. As a core element within this movement, care approaches based on "centredness" have been emerging for the past few decades (e.g., person-centred care, patient-centred care, family-centred care, relationship-centred care) (Hughes, Bamford, & May, 2008). All of these approaches share the same basic themes of respect for individual values and subjective meaning, the importance of the therapeutic alliance and communication, an inclusive model of well-being and client context, honouring expert lay knowledge, striving for autonomy and shared responsibility, and recognizing the professional as a person. According to the Alzheimer Society of Canada (2011), a culture based in equality, understanding, sharing, participation, collaboration, dignity, trust, and respect is essential for enhancing the quality of life experienced by LTC residents. In the United States, the National Citizens' Coalition for Nursing Home Reform (2006) has suggested that culture change will be brought about by deinstitutionalizing LTC practices and engaging the participation of staff, management, residents, and families.

## Conclusions

This study makes a unique contribution to the facility-based LTC and cancer care literatures, in that it marries these two contexts in an exploration of an understudied but critical quality-of-life issue: hope. Juxtaposition of the perceptions of HCPs and residents adds richness to our understanding of how these perspectives jointly impact both quality of care and quality of life (Beach & Inui, 2006). The use of both qualitative (interview) and quantitative (questionnaire) methods to assess residents' thoughts on hope adds validity to the findings.

Our findings support the conclusion that, for the small but complex subgroup of LTC residents who have a diagnosis of cancer, hope is not lost, but rather relevant, nuanced, and possible to achieve. Recent research on the role of hope in the lives of older cancer patients found that ageism and an overemphasis on hope for a cure in mainstream discourse served to marginalize the meanings of hope shared by these older individuals, their significant others, and their primary nurse (Duggleby, Holtslander, Steeves, Duggleby-Wenzel, & Cunningham, 2010). This study provides additional evidence to support the presence of an alternative discourse, attuned to the life circumstances of older people with cancer and their HCPs, and extends the reach of this alternative discourse into facility-based long-term care, a distinct and often maligned sector of the health care continuum, but one in which the will for change is growing.

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