Hope in Newly Diagnosed Cancer Patients

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Abstract

Context. Hope is important to cancer patients as it helps them deal with their diagnosis. Little is known about hope in newly diagnosed cancer patients.

Objectives. Based on the Transcending Possibilities conceptual model of hope, the purpose of this study was to examine the relationship of hope with pain, energy, and psychological and demographic characteristics in newly diagnosed adult oncology outpatients.

Methods. Data from 310 New Patient Assessment Forms from cancer outpatients’ health records were collected. Health records from the first six months of 2009 were reviewed and data were collected on hope, energy, pain, depression, anxiety, feeling overwhelmed, and demographic variables. A generalized linear modeling approach was used to study the relationship of hope scores with these variables. Hypothesized variables and variables that were significant at the $P = 0.01$ level from the univariate analysis were entered into the multivariate model, with hope scores as the dependent variable.

Results. Hope scores were significantly negatively related to age ($P = 0.02$). More specifically, oncology patients who were 65 years of age or older had significantly less hope than those under the age of 65 years ($P = 0.01$). Gender ($P = 0.009$) also was a significant factor, with men having higher hope scores than women. No other variables were significant.

Conclusion. Older adults comprise the majority of persons in Canada with cancer. The lower hope scores found in this age group compared with their younger counterparts underscore the importance of further research. This study provides a foundation for future research in this important area for oncology patients. J Pain Symptom Manage 2013;46:661–670. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Hope, newly diagnosed, cancer, outpatient, age

Introduction
In a recent literature review, Chi identified hope as one of the single most important elements in the lives of patients struggling with a cancer diagnosis. Hope helped them deal with the distress and uncertainty of their
The hope of oncology patients appears to be related to a variety of factors, both physical (e.g., pain and energy levels) and psychological (e.g., anxiety and depression). However, a limited number of studies have examined the relationships among hope and physical, psychological, and demographic factors in oncology patients and very often did not include those with low hope scores. Moreover, very few studies have been conducted with persons newly diagnosed with cancer.

Hope, as a multidimensional and dynamic construct, is influenced by multiple factors and is defined as the possibility of a better future from an uncertain and difficult present. Identifying factors that influence the hope of newly diagnosed cancer patients is of great importance as hopelessness is a risk factor for suicide, depression, and desire for hastened death in cancer patients.

Examples of physical characteristics that may influence hope include energy and pain levels. Energy is considered as an attribute of hope, and lack of energy (fatigue) has been found to be significantly related to hope. In a study of 122 women with breast cancer, Lee reported a significant negative relationship between hope and overall perceived fatigue, in which increased fatigue was associated with decreased hope. Similar findings occurred in a study of 51 patients with lung cancer and 85 patients with advanced cancer. In a recent study of 182 newly diagnosed patients with various solid tumors, fatigue duration and interference with mood and relations with others were found to be significantly associated with hope. Thus, energy levels may influence levels of hope in cancer patients.

Pain in lung cancer patients was found to be related to hope, with more pain associated with less hope. Moreover, more pain interference with daily life is inversely correlated with levels of hope in cancer patients. In a study of 226 cancer patients, Chen reported a relationship between the levels of bearable pain intensity and hope; the higher the tolerance (bearable pain), the higher levels of hope. The cognitive dimension of pain (meaning ascribed to pain) also was significantly associated with hope, in which higher hope scores were related to positive meanings ascribed to pain. Pain intensity levels were not significantly correlated. In a study of 225 cancer patients with differing types of cancer, however, Ume et al. reported no statistically significant relationships between pain intensity and hope. Thus, the influence of pain on hope is not clear, and more research is required to define this relationship.

Psychological factors such as anxiety and depression also have been found to be related to hope. Oncology patients who are depressed and have higher levels of anxiety report less hope. In a study of 225 oncology inpatients, subjects who did not report depression and anxiety had higher levels of hope than those who reported having both. This is similar to the findings of a study of 80 oncology inpatients, in which anxiety and depression were found to be significantly and negatively correlated with hope scores. Therefore, anxiety and depression also may be significant factors in the hope of newly diagnosed cancer outpatients.

Demographic characteristics of patients diagnosed with cancer have been found to be related to hope. In two studies of newly diagnosed cancer patients, men were found to have higher levels of hope than women, and younger people and those who lived alone had lower levels of hope than their older counterparts. In contrast, in a study of 85 patients with advanced cancer and their caregivers, younger subjects had more hope than their older counterparts. In a study of newly diagnosed cancer patients, Ballard et al. found those who were married had higher levels of hope; this again indicates that social support may be an important factor for hope. However, several other studies with cancer patients have found no relationships among demographic variables and hope.

Every year approximately 1000–1500 new patients are admitted to the Saskatoon Cancer Centre, one of two centers of the Saskatchewan Cancer Agency. A New Patient Assessment Form was developed in 2000 at the agency, and every new patient admitted to the outpatient cancer center was asked to complete this form. All newly diagnosed patients in Saskatchewan are admitted to the agency as outpatients. As such, those who are newly admitted are newly diagnosed. The New Patient Assessment Form has 27 questions, which include the Herth Hope Index (HHI), a pain intensity scale and an energy level scale. A variety of
clinical, psychosocial, and demographic variables that may influence hope also are included. It appears that the types of questions asked on this form are unique to the Saskatchewan Cancer Agency and are not part of other Canadian cancer agencies' assessment forms. A retrospective health record study using this information provided a unique opportunity to study hope with a large sample of a variety of oncology patients.

Conceptual Framework

The framework guiding this study was a conceptual model of hope entitled Transcending Possibilities. This model was developed using a metasynthesis approach of 22 qualitative studies of persons with chronic illnesses (one of which was cancer). In this model, hope is conceptualized as situational and dynamic based on multiple factors, such as symptoms and physical and mental health. It also suggests that, as a situation changes (i.e., newly diagnosed with cancer), hope objects and pathways change.

Study Aims

The purpose of this study was to examine the relationship of hope with pain, energy, and psychological and demographic characteristics in newly diagnosed Saskatchewan Cancer Agency adult oncology outpatients.

The specific study aims were to:

1. Examine the relationship between hope (HHI) and pain intensity and energy level in newly diagnosed adult oncology patients,
2. Examine the relationship between hope (HHI) and anxiety, depression, and feeling overwhelmed in newly diagnosed adult oncology outpatients, and
3. Examine the relationship between hope (HHI) and demographic variables (age and gender) in newly diagnosed adult oncology outpatients.

Methods

The study used a cross-sectional, retrospective, descriptive, correlational design based on newly diagnosed oncology outpatients' health records. This study received ethical approval from the Alberta Cancer Research Ethics Board and the University of Saskatchewan Research Ethics Committee. Operational approval was obtained from the Saskatchewan Cancer Agency.

Sample

Data from the health records of cancer patients (18 years of age and older) newly admitted to the Saskatoon Cancer Centre in the first six months of 2009 (407) were collected. The New Patient Assessment Form was revised in 2010 and did not thereafter include the questions from the HHI. Health record data from the beginning of the year 2009 were collected as they were the most recent and most complete health records with HHI data. A sample size of 150 was needed to test the individual predictors with a medium effect size on the dependent variable (HHI total score) with seven independent variables (pain, energy, anxiety, depression, overwhelmed, age, and gender), with a power of 0.80.

Measures

Table 1 lists the variables and measures collected from the health records. The main variables are described in the following:

Modified HHI. The HHI is a 12-item, four-point Likert scale that addresses three factors of hope: temporality and future, positive readiness and expectancy, and interconnectedness. The HHI has been found to be reliable (test-retest, \( r = 0.091 \)) and valid (convergent validity, \( r = -0.84 \); criterion, \( r = 0.092 \); and divergent, \( r = -0.73 \)). The New Patient Assessment Form contained 12 questions from the HHI, but the responses were in a binary format (yes or no) rather than the four-point Likert scale. Before beginning the study, data from the principal investigator's other studies on hope were used to determine the reliability of a binary HHI vs. a four-point Likert scale, using Pearson correlation coefficients. The binary scale had a reliability coefficient of \( r = 0.73, P < 0.01 \), compared with the four-point Likert scale. This is similar to the range of construct validity for the HHI. The modified HHI had a summative score, with the highest possible score being 24, as it consisted of 12 questions with a yes (scored as 2) or no response (scored
<table>
<thead>
<tr>
<th>Variable Categories</th>
<th>Variables</th>
<th>Measures</th>
<th>Where</th>
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</thead>
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<tr>
<td>Main</td>
<td>Hope</td>
<td>HHI Binary Scale (12 questions): yes = 2 and no = 1</td>
<td>New Patient Assessment Form Question 19</td>
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<tr>
<td></td>
<td>Pain</td>
<td>Numeric Pain Intensity Scale: 1 (no pain) to 5 (lots of pain)</td>
<td>New Patient Assessment Form Question 10</td>
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<td>Energy</td>
<td>Numeric Energy Level Scale: 1 (lots of energy) to 5 (no energy)</td>
<td>New Patient Assessment Form Question 4</td>
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<td>Type of cancer</td>
<td>Diagnosis</td>
<td>Oncologist notes in patient health record and New Patient Assessment Form Question 1</td>
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<td></td>
<td>Stage of disease</td>
<td>Stages I–IV</td>
<td>Oncologists notes in patient health record</td>
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<td></td>
<td>Comorbidity</td>
<td>Any other health problems? List of problems to be checked (diabetes, stroke, high blood pressure, headaches, heart disease, seizures, and others): will be checked if yes. If not, checked no (binary)</td>
<td>New Patient Assessment Form Question 3</td>
</tr>
<tr>
<td>Other symptoms</td>
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<td>List of 20 symptoms to be checked if present. Binary response: yes if checked and if not, checked no</td>
<td>New Patient Assessment Form Question 5</td>
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<tr>
<td>Problems with nutrition</td>
<td></td>
<td>List of five to be checked if they are a problem (poor appetite, food tastes bad or lack of taste, weight gain, difficulty swallowing, and recent weight loss). Binary response: yes if checked and no if not</td>
<td>New Patient Assessment Form Question 12</td>
</tr>
<tr>
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<td></td>
<td>Is there anyone you are concerned about as a result of your illness? yes or no and who</td>
<td>New Patient Assessment Form Question 16</td>
</tr>
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<td>Since your illness, have you felt any of the following? anxious, depressed, overwhelmed by emotions, or feelings about your illness. Yes if checked and no if not checked (binary)</td>
<td>New Patient Assessment Form Question 17</td>
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<td>Age</td>
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<td>Gender</td>
<td>Male or female</td>
<td>Patient health record</td>
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<td>Occupation</td>
<td>Employed (yes or no) and type of work</td>
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<td>Live alone</td>
<td>Do you live alone? yes or no</td>
<td>New Patient Assessment Form Question 13</td>
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<tr>
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<td>Caring for themselves</td>
<td>Do you have difficulty caring for yourself? yes or no</td>
<td>New Patient Assessment Form Question 14</td>
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<td>Medications</td>
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<td>Complementary and/or herbal</td>
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<td>Is there a history of cancer in your family? yes or no</td>
<td>New Patient Assessment Form Question 25</td>
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<td>Rural or urban</td>
<td>Postal code</td>
<td>Patient health record</td>
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as 1). In regard to scoring, questions in the HHI that were to be negatively scored also were negatively scored in the modified HHI. The Cronbach alpha for the modified HHI in this study was $\alpha = 0.69$.

**Energy Level.** Newly diagnosed cancer patients were asked to rate their energy level using a numerical rating scale (NRS) from 1 (lots of energy) to 5 (no energy); the higher the score on the scale, the less energy reported by participants. NRSs for measuring intensity of fatigue/energy have established reliability and validity and are used in cancer care.\(^{24}\)

**Pain Intensity.** Pain rating scores were measured on an NRS from 1 (no pain) to 5 (lots of pain); the higher the score on the scale, the more pain was being experienced. NRSs have been used extensively in measuring pain intensity in cancer patients. They have established reliability and validity and have better compliance than other pain intensity rating scales.\(^{25}\)

**Psychological Variables.** The New Patient Admission Form asks newly admitted cancer patients to identify if they are feeling anxious, depressed, or overwhelmed, with a yes or no answer.

**Data Collection**

Two registered nurses who were employees of the Saskatchewan Cancer Agency were trained in an orientation session to review the health records of oncology patients. During data collection (May to September 2010), meetings were held with the principal investigator and data collectors to discuss any issues with data collection. Using a data collection form developed by the research team and data collectors, data were entered into an Excel spreadsheet. The first five entries were cross-checked by each of the registered nurses for accuracy and interrater reliability. Revisions were made to the data collection form based on the first five entries, and the interrater reliability was 99%. The data on the Excel spreadsheet were deidentified and sent to the principal investigator on a monthly basis.

**Statistical Analysis**

Data were entered, cleaned, and analyzed using SPSS version 19.0 for Windows software (SPSS Inc., Chicago, IL). The stage of disease was categorized using the Tumor, Node, and Metastasis staging system, which is one of the most widely used cancer staging systems.\(^{26}\) Descriptive statistics were used to describe demographic, physical, and psychosocial factors and levels of hope in newly diagnosed oncology outpatients. Means and SDs are reported for the continuous variables, and frequency and percentage are reported for the categorical data.

The descriptive analysis of the data showed that 26% of the data were missing for age, gender, difficulty caring for self, modified HHI total, cancer stage, energy level, pain rating, and depression variables. There was no particular pattern of missing data. For example, the patients who did not respond to the depression question ranged in age from 18 to 92 years; also, most of the missing information for depression was from patients who were not living alone. The HHI total score for the patients with missing information on depression was minimum score of 1 and maximum of 22, a mean score of 19.82; for those with complete data, the mean score was 19.65 (minimum = 1 and maximum = 22). As there did not appear to be any particular pattern of missing data, for the purpose of analysis, we assumed missing data were completely at random. To account for the missing data, a multiple imputation method developed by Rubin\(^{27}\) was used. Multiple imputation is a Monte Carlo technique in which the missing values are replaced by $m > 1$ simulated versions, where $m$ is typically less than 10; for the current analysis, $m = 5$ was selected. Each of the simulated complete data sets was analyzed by standard methods, and the results were combined to produce estimates and CIs that incorporate missing data uncertainty.

To determine the predictors of modified HHI total score, variables were treated as continuous (i.e., age, pain rating, and energy level) or categorical (i.e., difficulty caring for self, gender, depression, and cancer stage). The variables chosen as predictors to be entered into the univariate analysis were based on a review of the literature. At the univariate level, each of the variables described previously was analyzed using a generalized linear model (GLM) method, with modified HHI total as the dependent variable.
GLM is an extension of the linear regression method and provides the flexibility to handle categorical, count, and continuous data as the response variables. The GLM analysis was performed on the original data set with no imputation and on the five imputed data sets. The results from the pooled parameter analysis were used for reporting purposes. Variables significant at \( P < 0.10 \) at the univariate level, and the variables chosen from the literature review, were entered in the multivariate model. Variables entered into the multivariate analysis were age, gender, pain and energy, depression, difficulty caring for self, and stage of cancer. Variables that were significant in the multivariate GLM at the \( P < 0.05 \) level were considered factors that were associated with the outcome variable of hope.

Results

Demographic Characteristics

A total of 407 health records were reviewed, of which 98 (24%) were missing the New Patient Assessment Form. The demographic characteristics of the remaining 311 outpatient oncology patients are summarized in Table 2. The mean age of the participants was 64.4 years (SD = 14.2); 58.5% were male, 62.7% were married, and 76.5% did not live alone. The most common type of employment was tradesperson (11.3%).

The most frequent types of reported cancer were gastrointestinal/head and neck/pancreatic cancer (27.7%) and Stage 4 cancers (23.8%). The most common comorbidity of participants who reported other health problems was high blood pressure (94.8%).

Hope and Demographic Variables

A significant inverse relationship was found between total hope scores and age \( (P = 0.02) \) (Table 3). As the patients’ mean age was 64.4 (SD = 14.2) years, data were then categorized into two groups: patients 65 years of age and older and patients 64 years of age and younger. Using Mann-Whitney \( U \) analysis to determine differences between two groups, there was a significant difference in total modified HHI scores between the two age groups \( (P = 0.017) \). Those between 18 and 64 years

### Table 2

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### Table 3

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<td>Diabetes</td>
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<td>6</td>
<td>47</td>
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<tr>
<td>Stroke</td>
<td>15</td>
<td>6</td>
<td>21</td>
<td>71.4</td>
</tr>
<tr>
<td>High blood pressure</td>
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<td>6</td>
<td>116</td>
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<tr>
<td>Headaches</td>
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<tr>
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<td>Seizures</td>
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</table>

GI/H + N = Gastrointestinal, Head and Neck.
of age reported significantly higher hope scores (mean = 20.18; SD = 2.7) than those who were 65 years of age and older (mean = 18.95; SD = 4.28).

Gender also was found to be significant at the multivariate analysis level, with men having higher hope scores than women (P = 0.01). Total modified HHI scores for men were on average 19.69 (SD = 3.74), and for women, the mean modified HHI score was 18.59 (SD = 3.26). No other demographic variables were statistically significant.

**Hope, Pain Rating, and Energy Level**

Modified HHI mean scores were 18.6 (SD = 3.7). In this study, the lowest modified HHI binary score was 1.0 and the highest was 22.0. The mean energy level score was 3.1 (SD = 0.9) (range 1–5). The mean pain rating score was 2.8 (SD = 1.1) (range 1–5).

No significant relationships were found between total hope scores and pain ratings when analyzed by univariate analysis (P = 0.86) or multivariate analysis (P = 0.56) or between total hope and energy scores when analyzed by univariate analysis (P = 0.07) and multivariate analysis (P = 0.62) (Table 3).

**Hope and Psychological Variables**

Most of the newly diagnosed cancer patients reported feeling anxious (n = 107; 96.4%), depressed (n = 64; 91.4%), and overwhelmed (n = 83; 93.3%). Feeling depressed was significantly related to hope at the univariate analysis level (P = 0.03). However, at the multivariate analysis level, it was not significant (P = 0.73). Feeling anxious and overwhelmed were not significantly related to hope.

**Discussion**

Age was a significant factor influencing hope in our population of newly diagnosed cancer outpatients. Our findings suggest that hope decreases with age, with those aged 65 years and older reporting the least hope. Hope is an important psychosocial resource that older adults use to cope with life’s adversities. It has been found to be significantly correlated with quality of life in cancer patients, with hopelessness associated with feelings of despair and desire for hastened...
Thus, it is important to understand why older adults have lower hope scores than their younger counterparts.

In a meta-synthesis study on hope and older persons with chronic illness, the authors concluded that hope in older adults changes in its interaction with suffering from a life-threatening illness. In our study, the finding of lower hope scores in older adults newly diagnosed with cancer compared with younger adults might be a function of the interaction of hope and suffering in this population. The diagnosis of cancer for older adults initiates a time of great uncertainty and confrontation of their mortality. Their life experience and being closer to mortality may affect their initial appraisal of their disease status. In older adults, processes of hope include a cognitive reappraisal and transcendence from their situation. As newly diagnosed cancer patients, the transcendence process, which involves reflection, may not yet have had time to occur. More research is needed to further explore the reason why older adults have lower levels of hope on admission to an outpatient cancer facility.

Similar to the findings of two previous studies on hope, men were found to have significantly higher levels of hope than women. Based on these studies, although we initially did not find a significant difference, we entered gender into the multivariate analysis. The significant results suggest that hope in newly admitted cancer outpatients is significantly different for women than men. In a qualitative study of cancer and aging, the authors concluded that there is a gendered discourse on how people interpret cancer and aging. Women were often portrayed as having gone through an exploratory journey and men maintained a continuous sense of identity. More research is needed to explore whether there is a gendered discourse of hope in older adults.

The stage of cancer was not a significant factor influencing hope in newly diagnosed cancer outpatients. This is similar to other studies of hope and cancer. In a systematic literature review, concluded that disease stage did not appear to have an impact on hope. In a study with 226 patients with varying types of cancer, also concluded that stage of disease did not affect levels of hope.

A study by Sanatani et al. found that those receiving curative chemotherapy had little difference in hope scores compared with those receiving palliative treatment.

The relationship between hope and pain was not significant. This was similar to the finding in the study by Utne et al. of hospitalized oncology patients. A simple descriptive scale to measure pain was used, which does not reflect its multidimensional nature. Other studies have found significant relationships between hope and pain interference and attribution of the meaning of pain, suggesting that multidimensional measures of pain may have different results. Moreover, as suggested by the Transcending Possibilities conceptual framework of hope, it may not be pain intensity alone that influences hope but rather the possibility of pain interfering with a person’s achievement of their hope objects or goals. Thus, pain interference measures may be a better measure than pain intensity in studying pain's influence on hope. This also may be the reason why energy levels and hope were not significantly related. In a study of newly diagnosed outpatients with cancer, Shun et al. suggested that fatigue duration and interference caused by fatigue are inversely related to hope. These measures are different than the energy level scale that was used in our study and may account for the differences in findings.

Although significant at the univariate level, depression was not a significant factor influencing hope, when other variables were controlled for. In two studies that reported a relationship between hope and anxiety and depression in cancer patients, the analyses were conducted at a univariate level without controlling for other variables such as age. Furthermore, the scales used to measure anxiety and depression either combined both concepts or the authors combined the anxiety and depression group scores. However, other studies have reported a significant relationship among hopelessness, depression, and distress. Thus, more research is needed at the multivariate level to understand the relationships between hope and psychological variables.

**Limitations**

There were several limitations to this study such as the study design, measures, and
missing data. The study was focused on newly diagnosed oncology outpatients and was cross-sectional in nature. A longitudinal study of factors influencing hope may have different findings at different times in the cancer journey. As this was a retrospective study, potentially significant variables influencing hope suggested in the literature, such as relationships and spirituality, were not measured. Retrospective health record reviews use data that are collected for a different purpose than the study. However, measures of pain and energy that have well-established reliability and validity were used in the New Patient Assessment Form. Although the modified measure of hope did have similar construct validity with the original HHI and internal consistency, the original measure of the HHI with a four-response choice rather than the modified one would have added to the generalizability of the study findings.

Health records data commonly have large amounts of missing data, although missing data are an issue in most clinical research. The most accurate data are actual data; however, as in the case of our study, it was important to impute missing data using a robust method rather than eliminating them.

In spite of its limitations, a retrospective health records review allows access to data that may not be accessible to prospective studies. For example, in our study, the data included a wide range of hope scores compared with other studies. Retrospective health record review data can serve as useful preliminary findings that assist researchers in planning more complex prospective studies. Future prospective studies should examine the relationships of hope in newly diagnosed cancer patients over time and also incorporate measures of spirituality and relationships. Older adults comprise the majority of persons with cancer in Canada, and given the complex construct of hope and the essential nature of hope to older persons with cancer, the findings of this study underscore the importance of further research to develop knowledge in this area.

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